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Enabling Health and Healthcare through ICT

Available, Tailored and Closer

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Preface

Information and communication technologies (ICT) can enable the delivery of healthcare in ways unimaginable in a paper-bound world. Internationally, the use of ICT in healthcare is growing rapidly as the need to provide efficient and effective care becomes more urgent to patients, providers and payors alike. Research in new models of healthcare delivery is starting to examine how ICT can increase the effectiveness and efficiency of healthcare delivery.

Universal health care is still not the norm for many people in developing and developed countries alike. Socio-economic status and geography have been substantial barriers to accessible care. Leveraging the diversity and ubiquity of available ICT may be one of the keys in enabling accessible healthcare across geographic and socio-economic divides.

Improvement in the health of nations begins with the individual. Recent developments in genomics and mobile networked information technologies have re-generated interest in individualizing health care to leverage current knowledge for the greatest individual benefit. In the not-so-distant past, it seemed unachievable to collect, store, analyze and share information and advice tailored to a specific individual. At best, in the past, clinical decision support systems made recommendations to clinicians about how to apply population health probabilities based on only a few individual characteristics; usually age and gender. Now researchers are testing personal decision support systems, which provide recommendations directly to the individual based on a myriad of characteristics, symptoms, signs and personal preferences. The inclusion of personal genomic information as part of this cluster of characteristics is in the near future.

Governments, health systems and other payors are beginning to recognize not only the subjective value of individualized care provided at a location of the patient's choice, but also the potential economic benefits as well. Globally, evidence is being gathered that supports health care delivery models that embrace co-management of health behaviors between health care providers and patients and encourage "localized" health care delivery. In this context, local care might take place in a community clinic, in the home or even in the pocket, as telehealth takes healthcare mobile. The term, "house calls", may once again become familiar in 21st century healthcare, albeit with a different implementation.

We hope that the knowledge shared between ITCH 2013 participants will generate further discussions and collaborations and lead to breakthroughs in delivering effective and efficient healthcare worldwide.

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Clinician-Led Development of Electronic Health Records Systems

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Abstract. The open source cityEHR system was evaluated as a toolkit for clinician-led development of an Electronic Health Record for management of patients in the Ponseti clinic of a major London hospital. As a toolkit, it was found that the ontology-driven approach of cityEHR was too complex for clinicians to use. The toolkit was refined to use more familiar spreadsheet s to represent the ontology and was then used successfully to create an effective clinical system, generated automatically from the information model.

Keywords. Electronic Health Records, Open Standards, Open Source, Clinician-led Development

Introduction

The cityEHR electronic health records system has been developed as an integration of 'best of breed' open source software components, configured to support open standards for clinical records such as ISO-13606 [1] and HL7 CDA [2]. It provides clinical users with a toolkit that enables them to develop their own Electronic Health Records (EHR) systems and then to deploy them on an enterprise-scalable platform. The system was originally conceived to address the fundamental issues that caused the failure of the EHR systems implemented as part of the National Programme for IT in England from 2004 to 2010 [3].

The platform for the deployed EHR is shown in Figure 1. It combines major open source software components that run on an Enterprise Java platform and that are freely available on the web: Apache Tomcat (tomcat.apache.org), eXist (exist-db.org), Mirth Connect (www.mirthcorp.com), Orbeon (www.orbeon.com) and FusionCharts (www.fusioncharts.com). These components are integrated and configured using the XML-based languages XForms, XSLT and XQuery; there is no compiled code in the cityEHR. The EHR deployed on this platform is configured entirely from an information model represented as an ontology, in the Web Ontology Language (OWL) [4]. This ontology uses a core architectural model (represented in OWL/XML syntax as classes, object properties and data properties) to supply the building blocks for the information model that contains specific individuals and property assertions.

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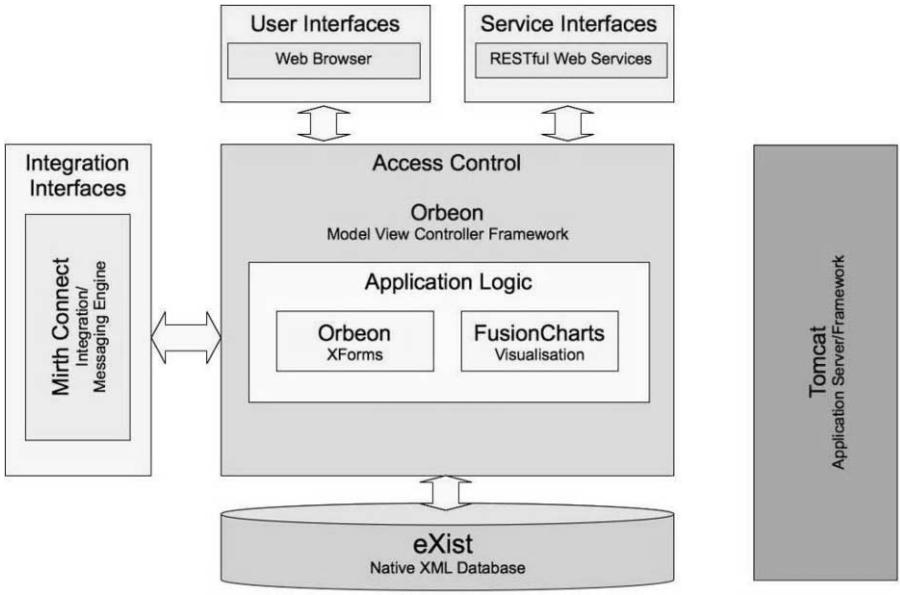

Figure 1. cityEHR Reference Platform of Open Source Software Components

This OWL information model is then transformed using XSLT into a s et of XML configuration files that define how the (automatically) generated cityEHR system functions for clinical users . The main XML representation in this configuration is the XForms language for specification of clinical data entry forms, summary views and letter templates. Behind the XML configuration of the user interface lies the model of the patient data which uses the XML-based Clinical Document Architecture (CDA) from HL7.

Thus there are four stages to the generation of patient data in the functional cityEHR system: architecture, clinical information model, runtime configuration and finally the stored data in the clinical system [5].

The purpose of this study was to evaluate the cityEHR toolkit by developing a system for recording patient encounters at the Ponseti out-patients clinic at a major hospital in London, UK. The main research question to be answered was : 'Can clinicians develop their own information model that can be used to automatically generate a functional EHR system?'

1. Requirements

The requirements for the Ponseti system were gathered without reference to the capabilities of the cityEHR system or its modeling toolkit. A clinical analyst worked with clinical staff (an orthopaedic surgeon and specialist clinic nurses) to gather requirements using structured interviews and analysis of existing paper-based data records . The products of this analysis were a set of Use Cases, a System Requirements Specification, a Data Dictionary and a set of User Interface Wireframes. The base functional requirements (Table 1) were relatively simple and in our experience are typical of the requirements for systems used in out-patient clinics and research studies .

Table 1. Main Requirement s for the Electronic Health Records System in a Ponseti Clinic

Clinical Data Collection	Other Requirements
Edit patient data systematically and store in a database	Secure authentication method to verify users
Clean, functional, form based user interface	Basic role-based access control
Pre-defined datasets in a drop-down menu	
Forms clearly sectioned into given headings	Complex queries on the patient database
Attach/upload multimedia t o t he patient record	Output result ant queries in a report
Conditional inclusion of sect ions/entries on forms	Graphical or/and tabular format for reports
Enforce mandatory fields for data entry	Display summary view(s) for existing records
Hints - short help assistance with data entry	Generate standard letters (e.g. in MS word)
Hyperlinks to external web resources	Query to assemble cohort s for research studies
Calculations and scoring on assessment forms	Automatically calculate standard data (e.g. patient age)

2. Implementation Using cityEHR

The basic functional requirements and user interface wireframes were used as the starting point for configuration of the cityEHR. The data model elicited from clinical users was coded as an ontology by the clinical analyst, using the open source Protégé tooling from Stanford University [6]. Figure 2 shows the user interface of Protégé with the basic architecture of the cityEHR represented as classes and the specific in formation model for the Ponseti clinic system represented as individuals, object property assertions and data property assertions.

The resulting OWL model was then loaded to the city EHR system and generated a working EHR prototype which was compared with the original wireframes and functional specification. It was found that the user functionality and general layout of data entry forms could be created to the general satisfaction of users , but that a number of specific functional requirements were not met by the automatically generated system, specifically:

- complex calculations and s coring on assessment forms
- calculation and representation of patient age in days , weeks , months or years depending on the age of the patient
- attach/upload multimedia to the patient record

These features were then added to the cityEHR system in a two stage process: firstly adding the semantics to the cityEHR architectural ontology so that the features could be specified in the information model and secondly adding functional support for the features when the EHR system was generated from the model. Having added these features to cityEHR it was then possible to generate a clinical EHR system that was acceptable for piloting in the Ponseti clinic, as shown in Figure 3.

3. Spreadsheets for clinical users

Although it was possible for the clinical analyst to create an information model using Protégé and use that model to generate a clinic system in the cityEHR that met the functional requirements, there were some major issues with the usability of the toolkit.

Figure 2. Information Model as an Ontology, Edited Using Protégé

As the information model increased in size the clinical analyst struggled to create a consistent model in a timely fashion; it proved impossible for clinical staff to use the Protégé tooling themselves. The three main issues encountered were:

- The atomic assertions of the OWL language mean that even simple constructs (e.g. the title of a section in a form) require two or three levels of abstraction in the model; as the model grows , it becomes very difficult for a user to work with this level of abs traction, even using a graphical tool such as Protégé
- Although reasoners can be run on the OWL model to check its consistency, the language (and the Protégé tooling) does not provide easy mechanisms for constraining user input so that cons is tent models are made in the first instance.
- For clinical users, unfamiliar with the concepts of ontology and with the Protégé tooling, the learning curve proved too steep to allow them to work effectively within an already busy clinical schedule.

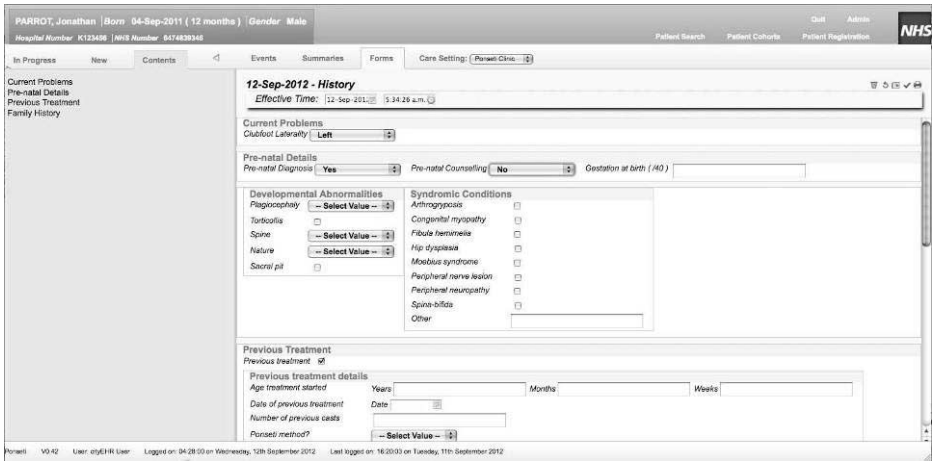

Figure 3. Electronic Health Records System Generated from Information Model

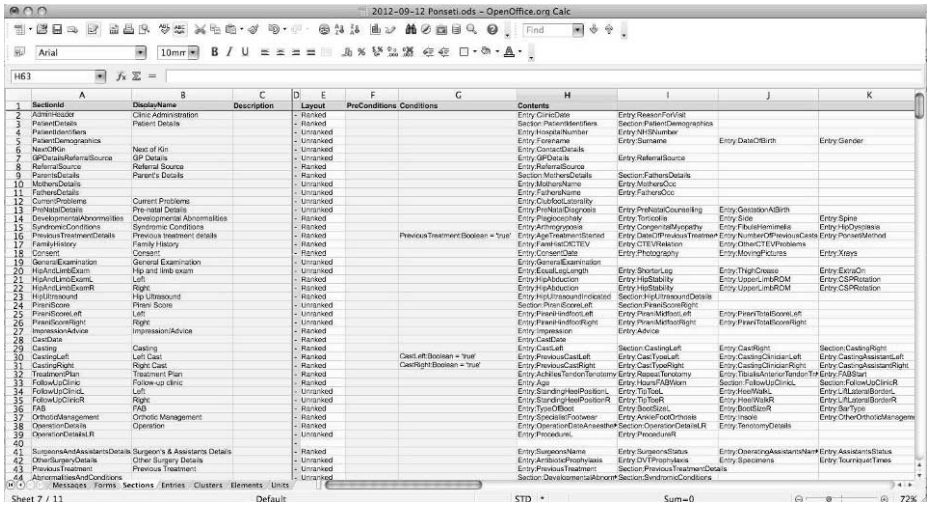

Figure 4. OpenOffice Calc Spreadsheet Mirrors the OWL/XML cityEHR Architecture

To address these three issues, the toolkit was 'refaced' to use a standard spreadsheet to specify the model. The spreadsheet follows the structure of ISO-13606 and mirrors the ontology model but allows constraints to be placed on the data entered into various fields. The spreadsheet can then be saved as XML and transformed using XSLT into the OWL representation of the model. Figure 4 shows a sample of the spreadsheet tooling that was developed using OpenOffice Calc (the open source equivalent of Microsoft Excel).

4. Conclusions

Our study in the Ponseti clinic proved that it is possible to generate a usable EHR system directly from an information model specified by clinical users. However, it also showed that the complexity of the ontology-based approach (both conceptually and in the available open source tooling) made it impossible for clinicians to develop that model themselves directly using the cityEHR tools. Once a simpler spreadsheet-based interface was introduced to specify the information model then it d id become possible for clinical users to create and modify their information models directly.

In subsequent studies we have found that a variety of tooling can be used to create the models (not just spreadsheets). This more general approach is shown in Figure 5.
The openness of the OWL/XML language, the widespread support of XML across modeling tools and the capabilities of XSLT for trans formation combine to provide a flexible approach to information modeling that can be used by clinical users to automatically generate functional EHR systems using open source platforms such as cityEHR.

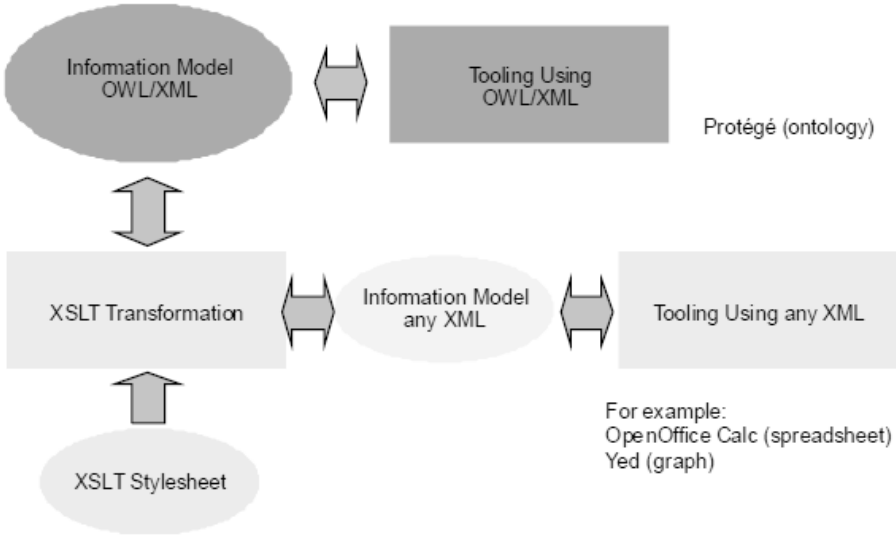

Figure 5. Information Model in OWL/XML Transformed to any XML for Editing

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Implications of the Mature Personal Health Record for the Empowered Consumer

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Abstract. The purpose of this paper is to present a future scenario projecting a fully developed, i.e., mature, personal health record (MPHR) that is instrumental in linking health care services delivery with preventive and wellness activities to provide informed and responsive consumer-driven health care. The legal-regulatory, institutional management, socio-cultural and technological challenges to implementation are discussed to guide future policy development in this area. We conclude that the potential pay-offs for enhancing the individual's health and well-being and protecting and sustaining the public's health overall is worth a considerable investment in policy analysis, technological R&D, partnership building and the expenditure of political capital by influential advocates and decision makers.

Keywords. Personal health record, mature personal health record, health information, challenges.

Introduction

The Personal Health Record (PHR) has become a point of focus for a number of the trends characterizing medical informatics, health information technology and their intersection with public (community) health in the early decades of the 21st Century. "Meaningful use" of the EHR stipulations required by the American Recovery and Reinvestment Act for reimbursement for providers under US Medicare and Medicaid programs, patient-centered care, patient-provider partnerships, accountable care organizations (ACOs) all can be seen as converging on the ultimate goals of the empowered consumer of health care and preventive services. Parallel to these factors is the priority given to translational research in medicine and public health to inform and justify evidence-based clinical practice to insure patient safety and cost-effective delivery of health care and community health interventions to eliminate health disparities and sustain the public's health and wellness at the local, regional and global levels.

The purpose of this conceptual paper is to provide a future vision of a "mature" PHR (referred to subsequently as the MPHR), identify the potential benefits of and

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challenges to MPHR implementation, and present an agenda for health policy research relevant to MPHR development. By doing so, we wish to focus attention on the MPHR as a useful focus for health system reform from the perspective of the empowered consumer.

1. Defining the Personal Health Record

Although various but similar definitions of the Personal Health Record (PHR) have been proposed, the following language is succinct and consistent with the HIPPA regulatory logic. The US Office of Civil Rights defines the PHR as "an electronic record of an individual's health information by which the individual controls access to the information and may have the ability to manage, track, and participate in his or her own health care."[1] The PHR as defined and discussed above is viewed not only as a repository for Personal Health Information but more importantly as a channel and mechanism for enhanced communication between the individual consumer of health care and related services and the provider system.

2. Future Scenario for the MPHR

To suggest the potential capacities and benefits of the "mature" PHR (MPHR), we provide the following brief scenario of the empowered health consumer using her MPHR in 2020:

> *After checking her Outlook calendar in preparation for the work week ahead, Maria realizes that she has a potential conflict with a mandatory staff meeting on Monday at 11:00 and a previously scheduled routine follow-up visit with her PCP three months after knee surgery. She accesses her PHR though her Apple MyPhone/MyLife Pad. She places an instant message to the office of her PCP, requesting a cancellation and new appointment on one of the available dates and times highlighted in her on-line calendar. Within 10 minutes the confirmation of the new appointment the following week is received along with a copy of an inquiry to her physical therapist whether the range of motion data for Maria's knee is current. If not, Maria is asked to schedule a PT appointment prior to the PCP visit. Also she is reminded to update her fitness and dietary plan with the current week's entries and to complete the six-month personal wellness survey. Once she does so she will receive a table of her responses during the past three years of key variables, e.g., weight, BM, HCL levels, blood pressure, pulse/OX reading, mood (depression) scale, as compared to statistics for the health plan of which to which she belongs and national benchmarks in the aggregate and by age, gender and Regional cohort.* If she had been interested Maria might have accessed her cumulative use and cost of services history again with bench make comparisons. *Having requested a PT appointment later in the week, the PT office Maria provides an on-line Pain Chart for her to complete on the touch screen, 24 hours prior to the confirmed appointment.*
>
> *After her meeting Maria finished her workout at her employer's fitness club. During lunch she enters her weight training and aerobic exercise data and her calorie count for the lunch she is enjoying, intending to trade off excess calories*

for the slice of fruited cheesecake with a light dinner of fish and rice. While completing her records, she receives an alert from the County Health Department about a food-borne illness associated with a salad bar at a chain of family restaurants in the Region with a request that anyone who dined at any of the locations identified within the past 48 hours should complete an on-line survey attached and if experiencing any severe gastric symptoms, contact the PCP or receive expedited treatment at the closest ER. Finally a broadcast message in her Healthy Community folder alerted subscribers of a current need for her blood type at the Blood Bank and that first time donors would receive bonus points toward a discount of their health plan premium payment .Next Maria logged into the MPHR of her aging mother who had recently been diagnosed with early onset Alzheimer's. Having obtained power of attorney for all her mother' affairs, Maria had complete access to her PHR and the tethered EHR. She duly noted the alert that her mother had missed her medication last evening, an issue that Maria intended to address with the home health aide directly. Realizing that the time was drawing near when her mother would require institutional long term care, Maria used the messaging utility linked to her MPHR to contact the local Area on Aging to access their quality ratings and prices for long term care facilities with dementia care unit.

2.1.Challenges to the vision of the Mature PHR

The scenario described presents a PHR fully embedded in the consumer's preferred communication channels and serving as the nexus for linking medical care, personal health behaviors and public health services and information potentially relevant to the consumer and family members. The supporting technology is already in place and almost certainly will become more powerful and available at lower cost within this decade. So the technological infrastructure for the applications identified is neither remote nor radical. The challenges presented by this scenario from a public health policy perspective are related to use, acceptance and satisfaction with the MPHR on the consumer side and the will and capacity for data system integration, provider system commitment and inter-institutional bridge building on the provider side.

2.2. Legal and Regulatory Challenges

One obstacle to consumer acceptance may be heightened concern about maintaining the security and privacy of the consumer's PHI from inappropriate access and use. The PHI embedded in the PHRs that are tethered to the EHRs under the control of institutional health care providers in the US are covered by the protections of HIPAA legislation. However, PHI contained in proprietary PHRs available commercially is not covered under HIPAA. The research evidence related to patient perceptions about the security and privacy of their PHI presents a mixed message about the level of consumer concern. While one national survey found that two-thirds of all respondents expressed concern about the privacy of their PHI, the majority of those who identified as PHR users did not report concerns [2]. Another study of the use of Web-based access to the patient's electronic health record showed that patients who were frequent users reported less concern than providers about privacy and security [3]. One could argue that barring any statutory changes that loosen restrictions on PHI, the US consumer is adequately assured that the privacy of her/his PHI is well-protected. Nonetheless, the

pervasive societal concern about potential assaults on privacy of information and confidentiality, identity theft and other threats to personal security –given the ease of on-line communication and economic transactions may increasingly be perceived as a threat to privacy during the decade ahead..

2.3. Institutional and Management Challenges

A mature and fully functional PHR entails an integrated health care system in which medical services, in-hospital, ambulatory, rehabilitation and home health services are coordinated with and mutually reinforce the disease prevention, environmental protection and health promotion population-based services associated with public health practice. Such system integration is inherently complex even if the political will, appropriate incentives and regulatory mechanisms are in place to support it. The daunting and ongoing challenges faced in implementing the Patient Protection and Affordable Care Act (2010) in the US, at best a partial health care system reform, are instructive and not encouraging for comprehensive health system integration and reform, at least for systems that are non-nationalized hybrids. The existence of multiple payers and conflicting reimbursement logics, e.g., fee-for-service, bundled, capitation premiums, pay for performance and other managed care incentive plans, makes total integration even more complex. The alignment of medical care provider practices and incentives with community and population-based program designs and intervention strategies while not inherently incompatible present the challenge of coordinating and accommodating two different organizational cultures and institutional frameworks.

2.4. Societal and Cultural Factors

Perhaps an even greater concern from the public health perspective is that the accelerating proliferation of information available electronically provides cover for intentional generation of misinformation whether motivated by narrowly political, financial or doctrinal purposes. In the health arena such misinformation masking as scientific evidence and/or supported by (for example) celebrity endorsements can lead to adverse health consequences for the individual or population targeted. The false attribution of a link between immunization and autism, even in spite of the repudiation of any causal link by medical researchers, can result in gullible, uniformed parents refusing vaccinations for their children resulting in increased risks to the community's health by reduction in herd immunity.

The sophisticated health consumer may be expected to weigh the evidence and reject implausible and unfounded claims and advice from unreliable sources. However, the less educated and more vulnerable consumer will likely be at greater risk of basing health behavior on bad information and fraudulent claims. Consequently, the ocean of health related information potentially available to the consumer can pose risks to the integrity of the MPHR and/or the consumer's effective use of it in sustaining her/his health and well-being. It should be noted that this situation is complicated by the rapid release and distribution of translational research which may offer contradictory or ambiguous findings which can baffle even the more well-informed consumer.

2.5. Technological Challenges

For the MPHR to be successful, various technological challenges must be addressed. First, the technological infrastructure must ensure that health-related information is being shared across organizations according to nationally recognized standards [4]. Without an adequate infrastructure, it will be difficult to develop a MPHR that combines various data sources from the multiple interactions the patient will have within the healthcare system, across venues of care. The MPHR requires a functional health information exchange to ensure that patient interactions are recorded so as to comply with nationally recognized standards to allow EHR systems to share patient information that is timely, accurate, relevant and secure.

Furthermore, with the rise of social networking, the MPHR should include social networking elements to help patients connect to various support groups. Given the widespread use of the internet and its relatively inexpensive bandwidth, social networking media are increasingly used by healthcare professionals and patients. In a commentary in the *Journal of the American Medical Association*, Shachak and Jadad argue that the use of social networks will eventually lead to a more people-centered healthcare system that will improve communication and information flow between patients, providers, and administrators [5]. Other studies have shown that users of Facebook currently seek health information online [6]. How to incorporate social networking utilities within the MPHR while maintaining the privacy and security of patient records will be a significant challenge.

3. Conclusion

In summary, the evolution of the PHR beyond its current state of adoption, use and functionality into a more mature and widely used tool for the empowered health consumer is an exciting prospect but one that presents an array of challenges, both regulatory, managerial, socio-cultural and technological. We conclude that the potential pay-offs for enhancing the individual's health and well-being and protecting and sustaining the public's health overall is worth a considerable investment in policy analysis, technological R&D, partnership building and the expenditure of political capital by influential advocates and decision makers.

Acknowledgements

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Applying the Clinical Adoption Framework to Evaluate the Impact of an Ambulatory Electronic Medical Record

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Abstract. This paper describes the application of the Clinical Adoption (CA) Framework to evaluate the impact of a recently deployed electronic medical record (EMR) in a Canadian healthcare organization. The CA Framework dimensions evaluated were EMR quality, use and net benefits at the micro level; and people, organization and implementation at the meso level. The study involved clinical and support staff from two ambulatory care clinics, and managers and technical staff from the organization. A number of issues were identified at both levels of the CA Framework that had affected EMR adoption in the two clinics. Some perceived benefits in care coordination and efficiency were reported despite challenges that arose from early deployment decisions. There were five lessons that could be applied to other ambulatory care settings. The CA Framework has proved useful in making sense of ways that EMR can add value to the organization.

Keywords. Electronic medical record, clinical adoption, benefits evaluation

Introduction

Despite increased adoption of the electronic medical record (EMR) in primary health care reported in recent years, its impact on provider performance and patient outcomes has been mixed [1,2]. For instance, a systematic review by Lau et al. [3] of 43 EMR evaluation studies has shown only 51.2% had positive impact, while 30.2% had no effect. Given the recent attention to transform primary health care in Canada and the great expectations on EMR as the enabler [4], the lack of positive evidence to date is cause for concern. That said there are successful primary health care practices that have shown improved care thru innovative use of their EMR. Examples are the use of individualized decision support and reminder tools by Holbrook et al [5] to improve diabetes care in a Canadian community, and the EMR supported quality improvement project by Nemeth et al [6] in 99 primary care practices in the United States. In this paper we describe the formative evaluation of a recently deployed EMR in two ambulatory clinics of a regional healthcare organization in Canada. We applied the Clinical Adoption (CA) Framework [7] to make sense of the impact of EMR adoption in both clinics and the lessons learned.

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1. Objective

This formative evaluation study [8] applied the Clinical Adoption Framework (CA) to examine the impact of EMR adoption in two ambulatory care clinics in a regional healthcare organization, and the lessons learned to guide future implementation effort.

2. Methods

2.1. Evaluation Design

A team of four university-based researchers conducted the evaluation over a 6-week period. The conceptual model used to make sense of the impact was based on the Clinical Adoption Framework by Lau et al [7]. This Framework provides an organizing scheme by which one can examine the quality, use and net benefits of a health information system (HIS) in specific contexts. For this evaluation the relevant micro level metrics were EMR system, information and service quality, usage and satisfaction, and care quality in terms of coordination and efficiency. For the meso level people, organization and implementation issues were examined. People included roles, expectations and experiences. Organization included infrastructure, strategy and process. Implementation included deployment process and EMR-practice fit.

2.2. Data Collection and Analysis

The research team employed a set of rapid evaluation methods [9] that consisted of EMR adoption survey [10], user assessment, usability/workflow analysis, document review, data quality review, project risk assessment, and group practice reflection. The data collection took place over four weeks including review of project documents and EMR data which took place concurrently. The EMR support staff organized sessions, assembled relevant documents, and extracted EMR data for the research team. During the study, the research team worked closely with EMR support staff to verify the information collected to ensure its accuracy. All notes taken during interview, usability/workflow, and focus group sessions were transcribed and analyzed for common themes. The evaluation report was finalized in the last two weeks.

3. Evaluation Findings

Forty-three participants were recruited in the study that included providers and support staff from both clinics, EMR support staff, and managers involved in the project. Over 4 weeks the team visited the clinics 3 times and completed 13 adoption surveys, 14 usability/workflow sessions, 13 user assessment interviews, 11 project risk assessment interviews, 3 focus group sessions, and reviewed 65 project documents and 3 months of EMR data. The findings were summarized according to the micro and meso dimensions of the CA Framework. Due to space limitation only selected findings are included.

3.1. EMR Quality

For system quality, six EMR functional areas and four types of usability issues were examined through two patient scenarios. The functional areas covered general system flow, medications, appointments, referrals, lab tests and radiology. The EMR was found to be a sophisticated product with many configurable features. The usability issues related to workflow, user interface design, system feature/performance, and user knowledge. In total 36 usability issues were identified. Most issues were in general system flows and referrals in terms of unexpected system behaviors, sub-optimal performance and inadequate default settings.

For information quality, the EMR successfully captured the patient information need to deliver care. In general the recording of encoded problem lists and medications were satisfactory. Free-text was often used especially for recording allergies where ~50% of the entries were uncoded. Some medications such as HIV drugs and frequencies were in free-text. The use of free-text impaired the ability to perform drug-allergy/interaction checks. Since implementation the EMR had accumulated some inconsistent user login configuration records and unmatched clinical documents. The master code lists for diagnosis, medications and allergies were incomplete or had incorrect entries. Several patient records had mismatched diagnosis codes and descriptions, or missing information such as being treated for diabetes but without the diagnosis present.

For service quality, while EMR support staff was highly responsive this resource was limited. On a feature by feature basis, the EMR was as sophisticated as the inpatient HIS with such core clinical functions as patient scheduling, team-based care planning, order processing, clinical documentation, specialist referral and decision support. At the user level, EMR support was expected for all aspects of patient care in the clinics. Such expectations were beyond those in the inpatient setting, where providers were not yet into full electronic charting in their hospital information system.

3.2. EMR Usage and Satisfaction

For usage and satisfaction, the EMR adoption level was 2.1/5 for Clinic A and 1.4/5 for Clinic B across 10 functional areas based on the EMR adoption surveys (0 as paper and 5 as advanced). The best sub-scores in Clinic A were for referrals at 3.4/5 and medications at 3.1/5, whereas in Clinic B they were for health information at 2.9/5, medications at 2.5/5 and lab at 2.5/5. The low scores in both clinics were in decision support and electronic communication and patient support. Clinic users ranked their overall satisfaction with the EMR at 2.4/5 with 5 being highly positive.

Participants revealed that Clinic A was a high volume short visit environment typical of primary care. Providers worked full-time and needed information to be immediately at hand and in one place. This environment provided strong incentive for providers and support staff to become proficient in using the EMR. Yet the time pressures could also drive users to find workarounds for tasks that interfere with workflow. Many providers from Clinic B had their own practices elsewhere and were only present for 1-2 days a week at the clinic. It was often easier for them to use paper than to invest time into learning the EMR. The survey revealed decision support for prescribing such as drug interactions had been disabled.

Despite frustrations, clinic users were hopeful and expectant that there would be improvement over time. For EMR functions that were already in place, there was a need to revise existing user and system configurations to improve their intended use. These included medication prescribing, lab/imaging investigations, referrals and patient

charting. For EMR functions in limited use, revisions and testing were needed to ensure they work as intended. These included care plans and chronic disease management forms. The EMR functions not yet in use that should be considered were flowsheets, database queries and clinical decision support for drug interactions and allergy checks.

3.3. Net Benefits in Coordination and Efficiency

For care coordination, clinic staff saw value in capturing encounter notes, medications, lab work, referrals and billing electronically in the EMR. The technical interface between the HIS and EMR had created a potential patient safety issue. The HIS was the source of truth for patient demographics, scheduling and allergy information. Though the EMR had the ability to schedule appointments and record allergies, clinic staff were not able to do so. For allergies, providers had to relay the information to the clerks who then had to enter it into the HIS. This information would then be downloaded to the EMR later. Clinic appointments had to be booked through the HIS, which did not allow detailed reason for visit to be recorded or timely updating of patients who showed up late at the clinic. The billing interface for physician services and labs required legal patient names which sometimes were different from what was in the EMR. As a result, clerks had to change the names for billing then matched the lab results.

For efficiency, clinic staff appreciated the EMR allowed them to find the chart and the information needed at the time of patient visit. Yet providers faced challenges working with fragmented charts. Clinical documents such as diagnostic imaging, discharge summary and consultation reports were not stored in the EMR as they were out of scope for the initial implementation. This had impeded workflow and incented staff to find workarounds. Some consultation reports were supposed to be stored in the HIS but were entered in the EMR since that was where the providers needed the information. If a provider needed an imaging report and it was not found in the EMR, they had to login to the HIS to look for it then returned to the EMR. Often they would add a free-text comment in the patient's medical history to indicate an imaging result was in the HIS.

3.4. People, Organization and Implementation Issues

For people issues, clinic staff described having the opportunity for initial training but with little follow-up afterward. These included existing users who wished to improve their proficiency with additional EMR functionality and training for new staff that joined the clinic after the system went live. Clinic staff recognized the EMR could do much more for them if they only had time and resources dedicated to training them and helping them move to the next level. For instance, the EMR had the ability to generate automatic reminders to recall patients for follow-up lab work and investigations. However this function was unavailable early on thus staff created workaround routines which then had to be undone when it became available. At a more fundamental level, some clinic staff indicated a lack of basic information management knowledge such as ICD-9 coding that could be of value for EMR users.

For organizational issues, the two clinics had unique challenges in that the EMR was deployed at the same time when the ambulatory care centre was being opened. As such, there were lack of clearly defined staff roles on such tasks as scanning documents, no clear clinical workflows on handling of scheduling, referral and billing, and no detailed planning of the business requirements of how an EMR supported clinic

would function. These had led to different expectations of what the EMR should do and how the system should be configured. For instance, the EMR had care plans, custom templates and chronic disease management flowsheets that were not exploited due to lack of defined requirements on where/how to use them.

For implementation issues, managers and EMR support staff involved with the initial implementation rated their experience at 2.4/5 on a Likert scale of 1 to 5 with 5 being strongly positive. Most felt that there were insufficient resources available and the EMR was not aligned with the clinic workflows. Interviews with staff involved with the initial EMR implementation revealed their frustration that it was viewed by others in the organization as a simple project. There was also a perception that the EMR was a shrink-wrap product ready for plug-and-play with little training required once installed. This view was reinforced by the project approach used to implement the EMR, where an aggressive timeline was established to deploy the EMR and the measure of success was that it got implemented and went live at the clinics. The review of project documents confirmed the interview findings where similar issues were reported.

4. Lessons Learned

The EMR adoption level achieved at the two ambulatory care clinics was comparable to similar clinics that we had studied in the past two years that were within 1-year after their EMR was implemented. Our experience suggested EMR users often had variable experiences with the system depending on their expectations and prior IT experiences. We should point out this evaluation represented only a point in time shortly after the EMR was implemented at the two clinics. Despite the challenges reported, we found clinic staff was resilient believing that the EMR was better than what they had before, and that the system would improve over time and add further value to their work.

The lessons from this study that could guide future EMR implementation efforts are to: (1) recognize EMRs as sophisticated clinical applications that require resource, effort and commitment over time to adopt successfully; (2) have clearly defined staff roles, clinical workflows and business requirements for the clinics involved to maximize EMR-practice fit; (3) pay early attention to EMR data quality to minimize subsequent database cleanup and realize benefits sooner; (4) provide incremental user training over time to maximize EMR value based on a comprehensive training strategy with different modalities; and (5) Redefine successful EMR adoption as being able to demonstrate tangible clinical value beyond system going live. We believe the CA Framework provided a useful organizing scheme for us to make sense of the EMR impact from the dimensions of EMR quality, use and benefits, and contextual factors involved.

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Role of Healthcare Information Technology in Handoffs

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Abstract. Handoffs—transfer of patient care from one clinician or service to another—are well known patient safety dangers. Healthcare Information Technology (HIT) as an intervening and powerful force in handoffs has received comparatively little attention. The role of HIT in concert with paper documentation has received even less attention. We analyze handoffs in relation to electronic records and hybrid systems (both paper and HIT) to identify sources of error and miscommunication. We propose a typology of handoffs and illustrate several of them..

Keywords: Handoffs, Handovers, Care Coordination, Healthcare IT

Introduction

In the inpatient setting, handoffs occur several times a day for each patient. Handoff communication failures are a known and frequent source of errors.[1-5] These errors occur in almost all medical settings, e.g., emergency departments, among units in a hospital, between hospitals and nursing homes. Yet, the role of healthcare information technology (HIT) in handoffs has received little attention, especially in light of HIT's growing role in all medical settings and its potential to enhance handoff safety. Equally important, the potential usefulness of HIT in handoffs when combining paper *and* HIT has received even less attention—even though several HIT programs print out paper handoff forms from programs within the EHRs themselves.[4]

In our observations, EHRs and other digital media are inconsistently incorporated in handoffs even when the hospital is fully wired. Moreover, clinicians' use of HIT during handoffs is frequently an afterthought or a supplement that can distract as well as illuminate—a reality affecting both departing and incoming clinicians. Oral communication and paper remain the media of choice, and even paper is not systematically employed. Integration of paper and HIT is less common and is even less well thought out when it does occur. Hospitals and other medical settings lack a coherent strategy for handoff processes that use HIT and/or HIT with paper documents.

In this paper, we examine handoffs that often incorporate HIT (usually EHRs)–or—more commonly, handoffs that fail to incorporate HIT or incorporate HIT in haphazard fashion. Until recently, HIT/EHRs were seldom a part of the handoff process. But with the growing availability of HITs, ignoring its information in the handoff is a

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potentially significant loss of patient safety and clinical efficacy. Equally disconcerting is allowing the HIT to structure the handoff process haphazardly – perhaps missing needed emphases while mechanically repeating obvious or insignificant information.

Most often, handoffs involve pieces of paper that are subsequently discarded. Even though the EHR is presumably the repository of the official and most accurate information, it is often ignored or relegated to a marginal role. This may be because of its widespread use is comparatively recent; because it is not part of the routine training process; because it is seldom designed for handoffs; or because the use of HIT has heretofore required proximity to a computer screen—a situation that has been altered with computer tablets.

Information Source and Limitation

The presentation is based on several years of observations of handoffs in many hospitals. We examine handoffs that are primarily face-to-face between two staff members. Thus, we exclude hospital discharges, transfers from ambulatory care, or transfers between hospitals and long-term care facilities unless there was an additional meeting of clinicians that we could observe. We exclude phone conversations since we could only overhear one side of the interaction.

1. A Typology of Handoff Elements

To create a context for analyzing handoffs, we explore some of the parameters within which they occur, e.g., specific locations; whether they occur *with or without* paper, structured formats, access to computers, participation of other clinicians, presence of senior clinicians, and so on. The table (Table 1) presents a typology of factors that influence handoffs' clarity and accuracy. We refer to clinicians leaving the patient, shift, or hospital as "departing" clinicians and to clinicians accepting care of the patient, starting the shift, or managing the floor as "incoming" clinicians.

While the table reflects months of observations and interviews over several years, we offer no systematic analyses of the frequency of each category or of the correlations among the categories. Some relationships are obvious: Patient involvement is more likely if handoffs are in or near patients' rooms; proximity to computers is needed for their incorporation in handoffs. Other physicians are more likely to be nearby if the handoff is conducted in a group setting or at physicians' workstations. Moreover, the parameters provide a basis for examining additional issues such as: errors if the documented information is wrong or outdated; errors of memory; staff sanitizing phrasing due to concern about a patient overhearing prognoses; time required to create a structured report versus information loss or misunderstandings with unstructured or poorly documented reports; corrections provided by third parties and by those from other disciplines; inefficiencies of 'translating' information to another discipline's argot.

In addition, other categories could be included, e.g., fragmentation of the information by other activities, role of clinician experience (head nurse, interns, senior physicians), and delays caused by efforts to collect needed additional information. This typology is elaborated in the following discussion, in which we use paintings and etchings as metaphors to illustrate vulnerabilities involving handoff communications.

TABLE 1. Sixteen Parameters of Handoff Interactions: Roles of Media (HIT, Paper), Memory, Type & Use of Structured Formats, Location, Patient Presence, Other Artifacts, Dyadic or Group Setting, Intra- or Inter-disciplinary, Face-to-Face or Mediated, & Involvement of Other Clinicians

1. Media	Generally includes Oral. If also other media, they could be: Paper only; Paper combined with HIT; HIT only. Different media might be used by incoming and departing staff, e.g., HIT information from departing recorded on paper by incoming; paper information entered in HIT and also on paper, etc. There might even be a note in lieu of face-to-face communications.
2. Documentation	Oral handoff with no recording of information in any medium. Paper, and even more, HIT provide documentation accessed by more people. Many handoffs were observed without reference to paper or HIT documentation.
3 Reliance on Memory	Extent to which information is provided based on what the departing clinician knows or remembers rather than/in addition to what is documented.
4. Incoming clinician seeks information	Recipient's questions and recipient looking up information. Reflects incoming clinician's active involvement in researching information and asking questions.
5. Degree and Type of Structure in Handoffs.	Categories by problem, medication, organ system or temporal proximity, etc – adhered to by departing clinicians. Use of structured discussion (such as SBAR) may be informally recorded.
6. Use of Available Structured Forms	Structured handoff reflected in templates or forms: HIT, paper or a combination. Templates/forms may be used, partially used or ignored.
7. Accessibility & Readability	For paper: Small print summary sheets with little room for additions and notes. For computer: large-enough screen, viewable/findable by relevant parties
8. Handoff Location	Patient Room; Nurse Station; Physician work area; Hallway; Other
9. Proximity of patient & artifacts	Role of patient's presence in the handoff process. Role of other artifacts (e.g., medications, IV bags)
10. Dyadic or Group	Two clinicians alone or as part of team, rounds or other group settings
11. Intra- v. inter-disciplinary	MD to MD; RN to RN versus interdisciplinary, e.g., MD to RN or multi-disciplinary rounds.
12. Hierarchy	Peers (resident to resident); or different levels (nurse manager tostaff nurse)
13. Face-to-Face or Mediated	Traditional face-to-face, or involving the use of tape or voice mail.
14. Consultations	Others contacted or not; participation by others by chance or actively sought.
15. Speed	Time allotted or available for handoffs.
16. Fragmentation	Degree to which staff are interrupted and face other distractions to the handoff.

2. HANDOFFS AND HIT

Hierarchy and status are always elements of handoffs (Figure 1), and their roles in patient safety are critical—whether between peers (e.g., nurse to nurse; resident to resident) or between those of different positions (e.g., resident to attending).

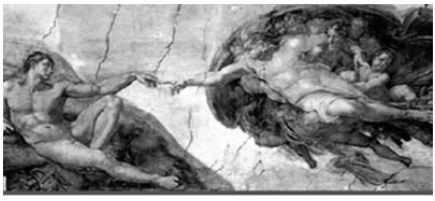

Figure 1

Figure 2

2.1. Structure and Meaning

The Kandinsky painting (Figure 2) depicts the often amorphous structure and freeform presentation in handoffs--allowing clinicians much latitude in evaluating essential vs. less important information as long as they use the two forms well and the incoming clinician sees which is which. Many of the handoffs we observe combine areas of clear and understandable information with opaque, and sometimes information that is missed entirely or assumed away. These handoffs are largely unstructured either by the departing clinician or the incoming clinician. Notes are sporadic and not organized in any clear way. For example, we often observe clinicians referring to areas of a page or screen that encompass medications, diagnoses, and laboratory reports. Some of the information is specific (e.g., laboratory values) but other parts are suggestions for new observations or tests. Of course, assumptions about the other clinician's focus or understanding may not be shared.

As suggested by the next Kandinsky (Figure 3), even when there is clear structure in the handoff process, clinicians may differ about what data are most essential and what should be covered. That is, one or both of the clinicians has a physical or mental check list or set of items that is a backdrop to the interaction. Only a few of the items, however, are discussed in the handoffs and no structured handoff record is maintained. The rest of the checklist is taken for granted as known. This is not necessarily dysfunctional: in the hands of experienced clinicians *both* of whom know what items are essential and what are sufficiently routine or well known, much information can be skipped.[6,7] (Some information might be intentionally excluded [e.g., prior drug use] to protect patients by only allowing sanitized medical records.) Moreover, there is an infinite amount of information that can be conveyed about the patient; only certain items are news. It is impossible, however, to be sure both sets of clinicians are fully aware of all patient issues, and such assumptions are risky. Even attentive and experienced people might miss or forget an essential item, or they might assume a level of understanding and familiarity that the other clinician does not possess. Patient status and lab results change, sometimes unexpectedly—and clinicians who have been treating a patient for a week or more may be believe there is little new information in the chart. In addition, because not all relevant information is always systematically recorded, some information might not be available for later review. In turn, systematic documentation, while it can be reviewed and interrogated, is subject to the same selectivity and need for assumptions about each participant.

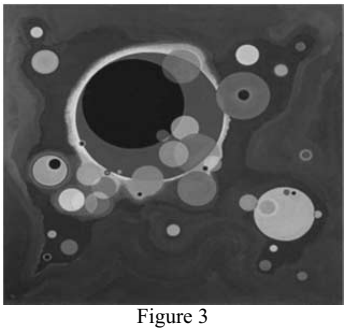

Figure 3

Figure 4

2.2. Level of involvement

The disaffected woman in the Modigliani (Figure 4) reminds us that clinicians, like all humans, vary in their level of attention to and involvement in the handoff process. Is the departing clinician/team exhausted or eager to leave? Is the incoming clinician/team a passive recipient due to overconfidence, unrealistic beliefs about the patient's condition, disciplinary presumptiveness or risky eagerness to start care? On the other hand, perhaps the incoming clinician already knows a lot about the patient, so only new information is needed. Adding more information would be wasteful or at least one presumes so. In these cases, the failure to incorporate structured handoff forms, EHRs, and/or paper records could produce unwanted consequences. Relying on memory, when the initial transfer of information was poorly attended and documented, seems unwise.

The image of two angels with Christ (Figure 5) poses the dilemma when an authority figure (e.g., attending physician) offers insights and great learning, but may also inhibit free (and needed) communication. Some handoffs are mediated by a respected authority, such as a senior physician or a nurse manager. The respected authority may help clarify ambiguous information, demand additional information, raise new issues to increase understanding and improve treatment plans. As noted above, however, the authority figure may prevent questioning and additional inquiry.

2.3. HIT Handoffs and Hierarchy

We often observed younger clinicians in the presence of older and respected authorities use available HIT as a neutral means to broaden the discussion by referring to patient information, clinical guidelines, or even recent articles on patients' conditions. Here the authority's power is moderated by the HIT in respectful but helpful ways. We also repeatedly observed settings where senior clinicians, while acknowledging the HIT-provided information, offered additional insights to impart lessons on the complexity of care and the need to balance factors missing in the standard protocols.

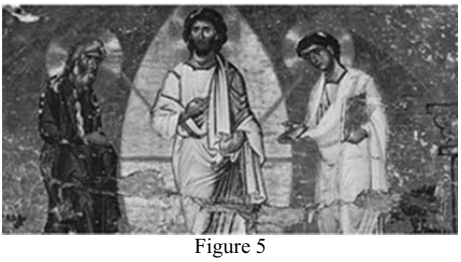

Figure 5

Figure 6

2.4. Templates and Structured Handoff Forms

Ellsworth Kelly's painting (Figure 6) highlights the role of structure. Highly structured handoff forms & processes increase the probability that all items will be included. But critical issues and consequential nuance may be lost. Highly structured forms or templates can simplify and organize handoff information—making information entry and retrieval faster and more secure than other methods. The downside of such forms is that they often encourage a disgorging of routine and redundant data, in loss of

emphasis and critical nuance. These advantages and disadvantages hold true for both HIT-based templates and paper forms. One possible advantage of paper is that the affordances of the medium allows easier annotation and comment than does the digital form. Also, independent of the medium, each of these forms and templates are met with varying levels of compliance.

2.5. Paper and HIT Integration

We insert a computer screen into Durer's Adam and Eve (Figure 7) to ask whether HIT helps to convey needed information or is a distraction. EHRs, lab reports, I-O charts, progress notes (in paper or HIT or both) are used in some handoffs. How can these media be integrated to help focus clinicians on essential elements and present their missing critical information? What are the risks these media will disperse focus and lead clinicians to incorporate irrelevant or obvious information? Do they generate more "busy work" that detracts from the clinicians' thought-flow, workflow and time for direct care? Are they used consistently or erratically? Does their use vary by unit, individual, or supervisor? Most important: how are the paper and HIT (if both) integrated? If they are hybrid systems – which most appear to be – do they maximize the advantages of each medium? Are they redundant, complementary, reinforcing, or distracting? While these are not new questions for any handoff analysis, the framework suggested in Table 1 may help structure questions and a research agenda for further and systematic investigation.

The meaning of Rembrandt's Abraham and Isaac (Figure 8) depends on knowing the biblical story. In addition to conveying information (in whatever form), a successful handoff must reflect not only the recipient's level of understanding--both of medical knowledge and the patient's condition--but also accommodate the participants' interactions and relationships. There is always a context, expertise of each participant, and a history of previous interactions in addition to the information exchange. Efficient and effective handoffs reflect both needed information and awareness of the participants' context, backgrounds, and expectations.

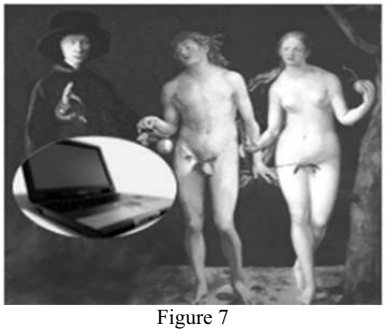

Figure 7

Figure 8

3. Summary

Handoffs are consequential for patient care, clinician learning, patient safety, clinical efficiency and liability. Improving our understanding of handoffs--especially how to integrate HIT into handoffs--can improve outcomes. We suspect the use of HIT in

handoffs will improve care and efficiency. To date, HIT use in handoffs appears inconsistent, is frequently supplemental, and may distract as well as illuminate. Paper remains the medium of choice and integration of oral, paper and HIT is not well thought out. To address this essential patient safety concern, we need a coherent strategy for handoff processes that use of HIT and/or HIT with paper documents. We hope this typology and the illustrated discussion spur further examination of HIT in handoffs, leading ultimately to efficacious use of HIT and other media to improve the quality and efficiency of patient care.

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Computerisation in General Practice: Lessons for Canada from the UK and Australia

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Abstract. In 2000 Shaw and Kidd published an article on the lessons that could be learned from the UK in general practice computerization. Over a decade later many of these lessons remain yet to be learned. Hence Shaw & Bainbridge felt that it was time to revisit these issues and review progress made against each in both the UK and Australia in an effort to help Canada learn the lessons as it follows behind both countries. Nine lessons are identified, reviewed and discussed in the hope that Canada will choose to take note and leapfrog these jurisdictions by learning from history, rather than being doomed to repeat it.

Keywords. General practice computerization; EHR; EMR; education, training & support; common data model; coding; information exchange; business case; data validation & verification; system support; security & confidentiality; research

Introduction

"Those that fail to learn from history, are doomed to repeat it." *~ Winston Churchill*

At the turn of the century Shaw (formerly Ellis) and Kidd published an article on what lessons Australia could learn from the United Kingdom (UK) in the area of general practice computersisation [1]. Just over a decade later and it seems that many of these lessons remain outstanding. Further, that other developed countries with comparable medical systems, such as Canada, seem to be ignoring what has been learned through, recent global experience of success as well as failure. We therefore thought that it was an appropriate time to revisit the original article and draw attention to the lessons that need to be learned, and acted upon, if we don't wish to simply repeat the failures that have gone before us.

Given also that the Canadian government has committed to primary care reform and to a primary care led health care system and that Canada Health Infoway has finally been allocated funding to support the adoption and implementation of Electronic Records (ERs) in general practice it seemed especially appropriate to re-target these lessons.

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1. The Good, the Bad and the Ugly

1.1. Education, Training & Support

The fundamental need for appropriate education, training and support is a lesson that Australia learned well from the UK. By establishing the General Practice Computing Group (GPCG), from 1998-2001, with a specific mandate to provide localised education, training and support independent of which vendor system was being used, Australia moved from less than 10% of general practitioners using computers to over 86% in just 3 years[2]. In the UK only, there have also been notable initiatives around 'informatics professionalism'[3] as well as ensuring informatics is 'embedded' into the clinical curriculum[4]. These national-level initiatives do not currently exist in either Australia or Canada.

Except in the UK it is still rare that clinical systems are used to document the entire clinical record in a structured and coded fashion. Many are still only used as billing tools with little use for management or audit. What is also missing is a culture of information proficiency both within the General Practices and the local agencies charged with the delivery of healthcare in an area.

Lesson for Canada – Successful implementation and sustained use of clinical information systems requires a bedrock of informatics support as well as an acceptance that informatics is a core clinical skill for the 21st century. Appropriate resource and effort needs to be urgently mobilized to achieve this wrapped around supportive policy. A piecemeal approach will be ineffective for reasons we shall discuss in this document.

1.2. Common Data Model

Being able to transfer data between different vendors clinical systems whilst maintaining semantic integrity has long been desired. Were this to be realized, multiple benefits would accrue from avoiding duplicate data entry to the removal of barriers to better research as well as the more obvious ones of safer and more coherent patient care. Over the years a number of different models have been tried to achieve data interoperability without scalable success.

The English National Program for Information Technology (NPfIT) has achieved a world first where over 57% of all GP practices are now transferring the clinical record with semantic integrity when a patient moves[5]. This work was achieved by NHS clinicians and informaticians working together taking forward the culmination of the work achieved in the European EN 13606 standard [6], the OpenEHR and GEHR projects [7] linked with HL7 [8] and SNOMED-CT [9]. The GP extraction project [10] is also set to derive a large research database based on this same 'logical data model'. Over the last decade there has been a slight reduction in the number of clinical system vendors (There are now 7 actively marketing with over 95% of the market represented by four suppliers.). A contraction in the marketplace occurred in the decade preceding the National Programme for reasons largely to do with commercial pressures and an increasingly robust mandatory accreditation process linked to the 2003 'Quality-based' GP contract [11].

Australia is in a similar position with only 6 vendors attaining membership of the 'GP vendor panel' in 2010 [12] .The position with a common data model is, however, largely unchanged. All systems use proprietary coding systems and structures and there is no transfer of data between systems apart from conversions when a practice changes their vendor [13]. Multiple agencies (both Government and Commercial) are

developing data extraction and aggregation programmes but one must question both the clinical and research value of these data without standardisation of definitions, coding, structures or semantics. The Personally Controlled Electronic Health Record [14] (PCEHR) for Australia went live in July 2012. It is based on a core 'document' set indexed by a Unique National Individual Health Identifier (IHI) (shared health summary, event summary, discharge summary, Medicare data, & consumer entered data with pathology, specialist letters, prescriptions and dispensing notices to follow). At present, the conformance criteria for some documents are low and permit free text and 'pdf' content. However, the system is built to allow structured and coded data [15] and will, over time, catalyze change and be delivered through increasing the level of conformance criteria.

Lesson for Canada -The implementation and use of the PCEHR is a program that Canada should follow closely. Minimal initial change from both vendors and clinicians is needed at first but this approach also sets a path towards strategic goals which is flexible.

1.3. Clinical Coding

Read Codes for diagnosis and symptoms were accepted as the standard for English general practice computerisation in 1988 [17]. Their initial use wasn't standardised with slightly different versions being by different vendors. The editorial process was seen as unresponsive and some vendors also authored and released their own additional proprietary codes. This practice has now died out as the twin forces of interoperability and a quality-based GP contract have emerged. As electronic records expanded beyond general practice, the need for a more comprehensive terminology was recognised. This led eventually to the international development of the SNOMED Clinical Terms (SNOMED-CT) and its current instantiation as a 'not for profit' collaborative organization between 19 Countries [18]. It has become a 'fundamental' standard for clinical coding in England [19] with other countries set to follow this lead. Since the advent of the 2003 GP contract the use of the computer at the point of care is almost ubiquitous. There is also much more delegation and sharing of information between Health Care Providers (beyond the scope of this paper). Both Canada and Australia are participating members of the International Health Terminology Standards Development Organisation (IHTSDO) and have named SNOMED-CT as their 'preferred' nomenclature nationally. However, in both countries, the proliferation of other coding schemes and the confusion between nomenclature and classification has been allowed to continue. Classifications such as ICD-10 and ICPC2 remain in use at the point of care rather than being derived from a nomenclature such as SNOMED-CT. Many vendor systems still don't encourage or support clinical coding and rely heavily on financial coding undertaken for billing purposes to derive clinical utility, audit and reporting data.

Lesson for Canada – It is vital to set a course toward a mandated SNOMED and Canadian National drug extensions as soon as possible. This effort has demonstrably moved England forward. Australia has been less demonstrative but has set the same direction of travel through conformance with CDA architecture [20]. Consideration must be given for effective Vendor and Clinical engagement as the usability of systems incorporating SNOMED will determine acceptability.

1.4. Information Exchange/Interoperability

Despite almost complete general practice computerisation since the mid 1980's it was only in 2007 that records were able to be transferred between practices using different UK vendor systems. Five years after initial success nearly all clinical systems have been deployed containing (or about to contain) accredited software [21]. To date 2,137,301 (27th June 2012) patient records have been transferred. There has been great investment of time, effort and money in establishing data transfer standards, building and then deploying a central 'spine' through which data would be transferred. Awareness and acceptance of the need for record transfer amongst the medical professional community who traditionally felt a great deal of ownership towards "their" records has also had to be achieved on top of safe and professionally acceptable and semantically correct transfer standards.

Despite the domination of the market by one single vendor there is still a complete lack of interoperability in Australian general practice although the intention is that the PCEHR will catalyse resolution in this area. The PCEHR is a document based implantation of Clinical Document Architecture [15,16-20] with an ultimate goal of fully structured and SNOMED coded content. Increasing levels of compliance will be driven through the Standards-Australia process. There is considerable overlap with this section and section 1.1 the common data model. The two are synergistic and inseparable.

Lesson for Canada – Interoperability is the best catalyst for change as it forces the re-examination and re-configuration in multiple areas from definitions to infrastructure. There is an opportunity to shape the hard-won successes in this area for local use in Canada. This, however, will only be achieved through a coordinated national approach.

1.5. Business Case

Developing a business case for electronic records has become the subject of many case studies and classroom debates. Whilst more readily accepted by larger groups of practitioners and those concerned with population level health, as opposed to individual general practitioners, a true business case for adoption and implementation of Electronic Health Records (EHR) has not yet been mad [22].

Despite this there is an increasing consumer demand for service, excellence and availability that electronic record supporters purport that such systems can support and achieve if only they were implemented. At the same time consumers are increasingly sharing their own personal information electronically, through social media. Other service industries are increasingly reliant on online consumer participation for much of their service provision.

Likewise, there is a growing emphasis on clinical safety as a driver for computerization. Whilst it makes inherent sense that computerisation could improve safety, by such measures as forcing compliance with standardization and ensuring legibility, there is little, to no, evidence that electronic records do actually improve clinical safety beyond the area of prescribing [23,24]. Some of the reasons behind this lack of evidence lie in the proprietary nature of the systems and the continued difficulties in deriving interoperable and truly comparable data at a scale to prove the hypothesis.

Lesson for Canada – Consumer demand for excellence and safety will rapidly mount if the current situation continues – It is also important to keep in mind that ubiquity of implementation of the current systems will at best mechanize current practice and this is insufficient to meet upcoming demands.

1.6. Data Validation & Verification Procedures

The quality of data within an organization has been a recognized problem for decades but clinics rarely run simple data quality checks of their own accord. In the UK the government attempted to address this issue by establishing the PRIMIS programme [25] to provide localized training and data analysis. One of the primary components of this program is to help general practitioners ensure that they have good data quality. Australia has recently published training materials for Clinicians to use in support of the PCEHR[26] and has recently funded the Royal Australian College of GPs (RACGP) to intervene on the broader e-health agenda [28] .There is, as yet, however, no national 'bottom up' support for e-health and information proficiency although the eCollaboratives [27] set up to innovate in Chronic disease care and self-management may grow to fulfill this role.

Lesson for Canada - Installing the computer into the practice with appropriate infrastructure is the easy bit. What is less easy and traditionally less well done is to help the practices to become more able with electronic clinical data. All the benefits derive from high quality data. To achieve this requires a complex and personalised mix of usability, infrastructure and culture.

1.7. System Support

Traditionally, most primary care clinical systems, their hardware, software and a maintenance contract are sourced from a single clinical system vendor. In all three countries in the past two decades this has slowly changed so that buyers can now buy these items independently. The cost, for this freedom, however, is that clinics embracing technology have had to become incredibly technically literate or have had to hire specific IT staff. For larger clinics this may be a reasonable administrative cost; not so much for those that are smaller. Often the response to this issue is for practitioners to work in groups. However, this discriminates against those practitioners choosing to work in the more isolated, rural regions where having *a* practitioner is a luxury and a group of them merely a pipe-dream.

In the UK, hosted systems are becoming the norm. Clinical System, data, infrastructure and maintenance are managed centrally. To date, this has not been possible to replicate in Australia due to the high capacity internet requirements that result. However, the Australian National Broadband Network [29] which will be installed over the next 2-3 years may make this a more feasible option reducing the cost of ownership, mean time between failures (MTBF) and also removing the need for specialized knowledge at the clinic. Since the implementation of the 2003 Contract UK GPs do not pay for their clinical systems and choose them from a 'guaranteed' choice of conformant vendors. The Primary care trust / commissioning group are centrally funded to provide these systems. Australian General Practice has not moved towards a contractual change and still works on a strict 'fee for service' model with the GP

Practice responsible for their own IT provision. A national incentive programme ePIP [30] will come into operation in January 2013 and focuses on laying sound foundations for the uptake of patient identifiers as well as coding of diagnosis and electronic prescribing.

Lesson for Canada - Australian infrastructure requirements and limitations closely resemble those of Canada given the similar geographical conditions and rural, isolated communities. Successful implementation, however, requires vendor systems to be based around current state of the art practices and design. The approach, however, also raises many privacy, security and confidentiality issues discussed below. At a more fundamental level, financial incentives have a history of accelerating change.

1.8. Security & Confidentiality

Despite the plethora of legislation, good practice guidelines, major international scandals and professional codes of conduct; security and confidentiality issues remain a major concern. Medical education facilities include little training in recording the encounter with a patient in an electronic record let alone providing training in security and confidentiality requirements. It is a common occurrence for nurses to be logging in to systems *"as the doctor"* because the doctor has delegated them with a responsibility beyond their legal scope of practice (which is enforced by the system parameters). Rather than developing an understanding that the system is designed to protect them from inappropriate working practices staff simply find ways round the perceived blocks.

To address this issue and the wider implications of security and privacy, the UK NHS implemented the national Smartcard [31] which is a physical card that must be inserted and a matching PIN entered (Just like your bank card) before you can access services available through the 'spine'. This makes user authentication much simpler while increasing security. This 'role-based' implementation required a single national security architecture with a single set of roles, a directory of all NHS personnel and the setting up of 'registration authorities' within each organization in the NHS to manage card administration, job and role changes etc.

In contrast both Australia and Canada currently rely on username and password. Australia is in the process of setting up a National Authentication Service for Health [33] although this has been significantly delayed [34].

Hosted systems allow more actors to work with a record but risk divulging unauthorized information to unauthorized people without excellence in both privacy and its enforcement at the point of care. A single unique ID per patient is vital to ensure data is linked to the appropriate person. Consumer control will be resisted but may be a way forward

Lesson for Canada – There is considerable maturity of thinking in this area and care should be taken to learn from both the successes and errors in England and Australia. The requirements are virtually identical and implementation need not be difficult if a mature and informed national approach is taken.

1.9. Research

Enormous investments in EHRs have been made over the last forty years in the belief that they will bring cash releasing financial savings to an over-burdened health care

system, address issues of continuity of care by providing continuity of information, and improve patient care. To date, remarkably little research has been conducted, or replicated, on just what is the impact that these systems are having. In the last decade we have seen an increase in the recognition that such systems may result in unintended consequences and that these may in fact be negative, but still little rigorous research is undertaken, funded or published. Work in progress in Australia is starting to addesss this area [32]

The General Practice Extraction Service [10] and PRIMIS [35] are important exceptions to this. Both programmes are being undertaken in the UK and are based on the fundamental tenet that research data should be derived from data collected at the point of care wherever possible rather than being 'something extra'. As a result these programmes are set to achieve success in demonstrating that the appropriate use of electronic records can improve patient care in terms of adherence to clinical practice guidelines and protocols.

The basic skills of data and information proficiency are still lacking in many health care providers portfolios. This is changing slowly as younger generations come into the workplace for whom the internet and similar technologies have always been a component of their working practices. Unfortunately, being able to use a technology doesn't always mean that they understand it or can self-determine which information should be shared and under what circumstances. Rather there is an increasing sense in academic circles that this new generation relies on technology to the exclusion of their own mind. This has resulted in some medical schools banning the use of hand-held devices during training, except in select circumstances, as students were becoming too reliant on a programme designed to support clinical diagnosis and were forgetting to attend to the actual patient in front of them. This is an interesting position given the opposing informatics opinion long expressed that *"Knowledge should be held in tools that are kept up to date and used routinely—not in heads, which are expensive to load and faulty in the retention and processing of knowledge"*

2. Conclusions

For over three decades now the potential benefits of computerization in health care have been touted. Despite this and despite billions of dollars of public funding being invested, the fruits of these systems have not yet been fully realized. We believe that until the nine lessons above are truly learned that this will be the status quo for another quarter century. This, for those of us that work in health informatics and truly believe in its capabilities when used appropriately is intensely disheartening. We hope that by laying out these issues and pointing users in the direction of progress in these areas, where it has been made, that internationally we can pick up the pace and put the building blocks in place that will mean that Canada will truly be providing the world class health care that we know its health care workers are striving to provide.

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Challenges in data quality assurance for electronic health records

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Abstract. Data quality is an integral part of EHR systems. Quality assurance for these systems not only identifies the current defects in the data but also aims for minimizing the risk of their future occurrence. Previous studies for secondary use of data in research projects presented several dimensions for such defects and proposed few methods for identifying them. Although those methods were successful in small scale research studies, their application to large scale day-to-day flow of information in EHR systems involves many challenges. In this paper, we highlighted those challenges for each method and each dimension and proposed a framework for using existing technologies to address those challenges..

Keywords. Data Quality Assurance, Electronic Health Records, Systems Analysis

Introduction

Electronic Health Record (EHR) is a repository of health-related data for every individual in a population. This data warehouse can provide a wide range of benefits for individuals by making their data available at the time and place of care and also from population point as secondary use of data for modeling, planning, governance and prediction. The prerequisite for providing the required value for both primary and secondary usage of EHR is having high quality data to achieve reliable conclusions.

Quality is defined as the totality of features and characteristics of an entity that bears on its ability to satisfy stated and implied needs [1]. Data quality is considered as integral part of health data warehouses [2]. There are two concepts related to quality which are Quality Control (QC) and Quality Assurance (QA). Data QC is looking into the defects in the data whereas data QA goes one step further and aim for providing methods to prevent such defects in the future. The quality of data in health data warehouses have raised many concerns [3]. Although the sources that causes problem in data quality are discussed in details in previous literature, there are many challenges in addressing them.

1. Methods

In this paper, we classified the potential issues in data quality based on the existing evidence from the literature. Then, we continued with presenting the challenges in

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current methods suggested to resolve those issues and proposed a QA framework to address those challenges.

2. Results

According to the American national dictionary for information systems, data quality concerns the correctness, timeliness, accuracy and completeness that make data appropriate for use [4]. Also, the Canadian Institute for Health Information (CIHI) has developed a comprehensive framework including 69 quality criteria in 24 quality characteristics, which was further grouped into 6 quality dimensions [5]. These dimensions include the ones proposed by American national dictionary for information systems and two additional dimensions as comparability and privacy. In a recent systematic review, Weiskopf and Weng categorized the data quality issues in five groups which were completeness, correctness, concordance, plausibility and currency [6].

For making decision about any of those factors, we need a second measure for comparison. Weiskopf and Weng identified seven general approaches for this comparison, including gold standard, data element agreement, element presence, data source agreement, distribution comparison, validity checks and log review [6].

Comparison against a gold standard reference is a common method for checking the data completeness. The gold standards used in previous studies were double-checking with patients [7] or paper-based records [8]. This method is not feasible for large scale day-to-day quality assurance. Another method used for this purpose is comparing the data with an expected list of elements [9]. There is no comprehensive set of evidence-based guideline for every problem in healthcare or in some cases existing guidelines are outdated. Also, there are cases in which healthcare professionals have to make decision with less than optimum amount of information caused by lack of equipment in rural areas or urgent cases which mandate an empiric approach such as septicemia. Identifying the parameters that can make a difference between positive and negative decisions using techniques such as clustering can be used for dynamic generation of expected list of elements. This process can reach higher level of accuracy, if it is performed on larger datasets available at central data warehouses.

The second measure of quality is the correctness of the data. Our proposal for location of this control is at the point of data collection similar to the approach used in medical labs. The challenging factor in these cases is edge of distribution cases [10]. Also, in some cases there is no previous data from the same person at the point of care. This will mandate a second tier of quality control at the warehouse site which might have previous records of that person. The other challenge for correctness of information is our abstract approach to many clinical measures. We are aware of the sensitivity and specificity of our measurements, yet in many cases we take an abstract model of the situation. For example, the test results usually present a single number which is compared against a normal range. What you will never see is the confidence interval for that test result. In some cases the confidence interval can be highly skewed, especially if the test result shifts toward the extremes. The situation is even worse in qualitative measures such as heart sounds. Doctors can have quite a wide range of interpretation about the heart condition of a single case based on their listening.

The third dimension for quality assurance of data in EHR systems is concordance. The best place for evaluating this measure is at the data warehouse where data from

different sources are available for comparison. The best approach for this case is setting up a staging repository. This staging repository can easily identify systematic biases in measurement, which should be investigated further. A main requirement for this comparison is using comparable coding and classification in different data sources [11]. This is also useful for identifying fraudulent claims. One of the challenges for this dimension in British Columbia is temporary healthcare numbers issued for new immigrants while they are waiting to get their Care Card. The data recorded under these identities needs to be merged to their future records. The other challenge is health-related events which happen to individuals outside jurisdiction of healthcare authorities and not recorded in their EHR.

The fourth dimension is plausibility. In many cases the reference for comparison in this dimension is general medical knowledge which is defined based on specific studies and the extent of comparability between the participants of those studies and the case under investigation cannot be assured. This issue is far more complex when dealing with overlapping cases such as people suffering from co-morbidities which has a high prevalence in chronic diseases [12].

The final dimension of data quality is the currency of the measures. The first factor in this dimension is up-to-date death records applied to EHR. There are evidences about claims from deceased people which raise the concern about up-to-date health records [13]. The other factor is guidelines for patient follow-up, which in many cases are either non-existent or not up-to-date. Failure to follow-up because of missed appointments is another contributing issue [14] and unfortunately the family physicians have no extra resources to follow the patients and make sure that they will come back for on-time follow-up. The problem is more complex for walk-in clinics and individuals who are not registered with family physicians. In these cases we cannot hold responsible any front-end healthcare service, so there is a need for a central organization to control the currency of their records.

3. Discussion

The quality control for EHR systems is an extensive process. This issue is more difficult when the plan is shifted from quality control to quality assurance which requires preventive methods. We believe that quality assurance should be dealt with as a distributed process including data collection, data integration and consolidation points.

The data is encryption in most of proprietary EMR systems to ensure the security and confidentiality of their content and also to prevent direct modification of them at the database tier. Also, the source code for their software is only available in open-source systems. These issues will enforce any control to be through the integration pipes where the system produces data exchange messages such as HL7-based files. Performing quality control at site of data collection will limit the amount of message exchange between the control unit and data collection site for completing the missing items. Also in secondary care, it will give the opportunity to complete the data before the patient is discharged.

The important factor about this model is that it can fit very well within existing data integration systems. Provided that existing systems can talk in standard messaging languages such as HL7 or there is a third-part solution that can facilitate this process, the QA system can fit very well as a middleware solution between them.

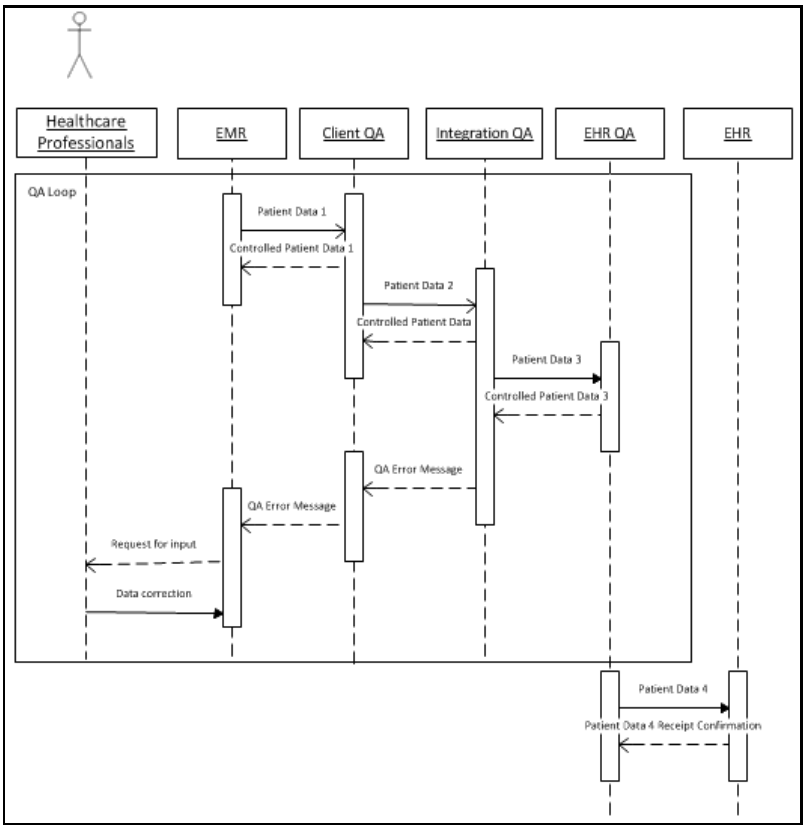

Figure 1. Sequence diagram for multi-tier data quality assurance model

Also, each layer is highly cohesive and the solution can be implemented in a staging process starting from the client QA layer. The other important aspect of this model is contribution of healthcare professionals in the quality assurance process. This approach ensures that the process is not purely machine-based and it will not interfere with decision-making authority of healthcare professionals. Also, these individual feedbacks can play an important role to improve the quality of data collection and decision-making of healthcare professionals and continuously update them about any potential systematic or random bias in their work.

The integration QA module is responsible for translating concepts in the data to their preferred terms. This will result in better concordance of the data and also can contribute to better compression of data during transfer. EHR QA module is responsible for producing knowledge from existing data in EHR and comparing the received data against that dynamic knowledge. Concordance of data can be measured better in this module as it will receive data from different sources and can draw a better picture about this data quality measure. As it is depicted in Figure 1, any identified issue will be corresponded from higher level QA module to previous modules and flag the dubious records for further investigation. The EHR QA layer can identify the variables that are differentiating clusters of patients considering success in their diagnosis or treatment. Then it will control the presence of those factors in each patient's EHR for evaluating the differential diagnosis and quality of service. The important factor about this model is that it can fit very well within existing data

integration systems. Provided that existing systems can talk in standard messaging the QA system can fit very well as a middleware solution between them. Also, each layer is highly cohesive and the solution can be implemented in a staging process starting from the client QA layer.

The other important aspect of this model is contribution of healthcare professionals in the quality assurance process. This approach ensures that the process is not purely machine-based and it will not interfere with decision-making authority of healthcare professionals. Also, these individual feedbacks can play an important role to improve the quality of data collection and decision-making of healthcare professionals and continuously update them about any potential systematic or random bias in their work.

4. Conclusion

Quality assurance should be built in a distributed proactive model which can modify the system to improve the quality. Considering the constraints in healthcare services, achieving this target requires an independent system which can be incorporated to existing data integration models and feedback the data quality issues to the source of data production. This approach can minimize the risk of repeated errors in data. It also can suggest the healthcare professionals the methods to improve their practice. This model can be considered as an individualized Continuing Medical Education (CME).

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A Systemic Approach to E.H.R. Implementation

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Abstract. E.H.R implementation is a welcome response to the increased complexity of the health care delivery. An effective implementation relies on correct systemic understanding of the challenges of diagnostic and treatment as well as the value of shared information and multi-specialist collaboration. The paper presents a systemic approach to both health and health care delivery seen through the perspective of an E.H.R. implementation.

Keywords. Electronic Health Record, Systems thinking, Organization models, Health Care Economy, specialization, integration, Autopoiesis

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A Scoping Review on Health Records for Child-in-Care

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Abstract. A scoping review was conducted to determine the current state of knowledge on child-in-care health records in academic literature. Eight studies describing five such health records were found. Different terms were found between countries. A key finding from the studies was that research needs to report on "what worked" to inform policy and practice for positive changes. Complete, accurate and consistent health records for child-in-care are needed that can support care and be aggregated to identify policy and practice gaps and interventions that were effective. Such health records enabled moving from reactive to proactive care for the child. Social work case data elements found in a child-in-care health record not included in a child personal health record include: court dates, dental, abuse, placement, and education. Including these data elements allows looking at the overall wellbeing and development of the child. With the exception of two, all studies reported positively on their implementation. Further, all studies advocated for continued development of a tailored child-in-care health record. The evidence points toward child-in-care health records as a tool toward achieving healthy outcomes and policy development.

Keywords. child, in-care, foster, looked after, out of home, health record, review

Introduction

Children-in-care are among the most vulnerable populations and at risk for inadequate health care compared to other groups of children [1]. When a child is taken into care, the province or state has a legal obligation to provide reasonable health and dental care [1-5]. Record keeping is required to provide tailored care to the child-in-care [6], to procure records for the judiciary system [5,7,8], and for research on interventions for good health outcomes [9]. The challenge is that "child care [traditionally] lacks an information-driven culture" [10]. Many health records have been developed for adult care [11]. Further, intake screening tools [12,13] and systems for child protection research [9] have been implemented. A health record for a child-in-care needs to capture additional data to meet statutory care requirements [7,9] and these data are also needed for current and future health and social care planning [6,7]. Further, in the United States, maintaining up-to-date foster care health records is legislated [4,7]. To determine the current state of knowledge on these health records, this review focuses on published academic studies on paper-based and electronic health records designed specifically for child-in-care.

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1. Methods

A scoping review was conducted to explore evidence on the current state of the child-in-care health record in academic journals. Findings would inform whether to proceed to include grey literature for other systems or to an in-depth systematic review [14]. Two concepts were searched: "child-in-care" and "health record". The records or "systems" could be either paper-based or electronic or both. Databases searched were: Social Services Abstracts, Social Work Abstracts, FAMILY (Informit), Academic Abstract Complete, and Web of Science (ISI – Web of Knowledge) from 1980 to August 2012; and Medline (EBSCO) from 2002 to August 2012. Detailed search protocols are available upon request from the authors.

One reviewer screened the title and abstract of each study for inclusion. Studies included must 1) detail an electronic or paper-based child-in-care health record used by providers at point of care, 2) describe a specific information system or record, and 3) be a primary study. Studies were excluded if they were 1) a commentary or discussion, 2) a secondary analysis, or 3) a system used for adults. Where it was not clear whether to include a study, the full article was retrieved and screened. The included studies were then reviewed.

The studies were reviewed for data elements specific to child-in-care health records and compared against the data recommended for child personal health record (PHR) [15]. Child PHR recommendations were chosen as a comparison as PHRs are longitudinal summaries of key events from all providers, distinct from electronic health records, and are held by the individual [15]. As a child-in-care moves the record should move with the child [5,7,19]. Further, close linkages are needed between research, policy and practice for positive changes [5,16]. Research findings must be presented within a "what works" framework for research to effectively inform practice and policy for positive changes [17]. "What works" were defined by the studies and reported as "results" or "findings" and were thematically aggregated [18].

2. Results

We started with 1264 citations and, after applying the inclusion/exclusion criteria, eight (8) studies met the criteria and are detailed in Table 1. One study was published in a medical journal [3], and the other seven studies were published in social work journals. No studies were published in informatics journals. The studies report on five unique child-in-care health records. Four records were paper-based; two were paper-based moving to electronic; one was electronic and generated a paper report; and one was electronic. Overall, the eight studies reported positive findings on the implementations and advocated for further research and development. The following sections summarize the findings in terms of definitions, study descriptions, data elements, and key findings on what worked for the implementations.

2.1. Definition and Terms

The *Child, Family and Community Service Act* [2] defines a "child-in-care" as a "child who is in the custody, care or guardianship of a director or a director of adoption". In this context, "child" means "a person under 19 years of age and includes a youth" and "care" means the "physical care and control of the child". Different terms were found

to represent the concept "child-in-care" depending on location. "Child-in-care" is used in Canada [5]. "Looked after" has replaced "in-care" in the United Kingdom [3,8,10,19]. The United States of America uses "out-of-home care" and "foster care" [7,20]. Last, Australia uses "in care", "out-of-home care" and "foster care" [21]. Nuances between terms were not fully stated within studies to allow for comparison.

2.2. Eight child-in-care health record studies.

Table 1 lists the eight studies by first author and publication date (pub date), study aim, setting and location, participants and records, child-in-care health record (CIC System), paper or electronic. Adoption levels ranged from not implemented [10] to poor usage [3] to fully integrated into practice [5,8,19] to able to use record data to generate reports [7,20,21]. Current levels of adoption are outside the scope of this paper.

Table 1. List of eight studies on child-in-care health records .

First Author; pub date	Study Aim	Setting; Location	Participants; Records	CIC Record; Paper or electronic
Bundle [3]; 2001	To identify information gaps using community child health records against child-in-care health record	Mixed Residential Care; UK	None; 36 records for 12-16+ age group	Looking After Children; Paper (inferred)
Champion [21]; 2009	To determine the possibility of deriving reliable data from the Looking After Children Assessment and Action Records for outcomes monitoring	32 Community service organizations; Victoria, Australia	None; 614 records for 0-15+ age group	Looking After Children Outcomes Database; LAC/A&ARs – paper Outcomes database – electronic
Hunter [19]; 2008	To investigate whether a specialist nursing service could improve health care for these children	Child care units; three areas of Scotland	NHS staff, children, nursing services; 162 children in residential care records	BAAF Health Record Booklets (carer-held health records); Paper
Kerslake [10]; 1998	Inferred: Evaluation of implementation to resolve difficulties in achieving wider implementation	12 Local Authorities; England, Wales	Information Technology, Administrative & Social Work staff; Record count not stated	Looking After Children; Computerizing paper records
Knowles [8]; 1998	To develop and evaluate use of the Joint Professional Record	Barnet Children's Services; NHS, UK	Interdisciplinary staff ; 31-39 children of concern records	Joint Professional Record (JPR); Paper

First Author; pub date	Study Aim	Setting; Location	Participants; Records	CIC Record; Paper or electronic
Kufeldt [5]; 2006	To describe experiences of one child welfare unit during Canada's first National Looking After Children and Assessment and Action Records pilot	One location in the 6 Eastern Canadian Provinces	Social Workers, Foster Parents, Youth; 37 and 42 AAR records for 10-15+ age groups	Looking After Children and Assessment and Action Records (UK and Canadian versions); Paper (inferred)
Lindsay [7]; 1993	To describe the implementation of the Health Passport Project; includes a content analysis of the health information stored	Care provider consortium; San Diego County, CA	Interdisciplinary; 431 records of children in non relative foster care	Health and Education Passport for Children in out of home care; Electronic database, paper report
Smart [20]; 1998	To describe CHS's development and features, with a brief overview of the 2,688 cases entered during first 7 months	Department of Children and Family Services; Los Angeles County	2 physician consultants, public health nurses, staff; 2,688 records of children receiving protective services	Child Health System (Social Worker system for health info and services); Electronic

2.3. Child-in-care health record data elements

Child-in-care records contain additional data elements beyond those in a child PHR. Data elements recommended for a child PHR include: demographic and insurance information; contact information for family members, other support providers and health care providers; advanced directives; and clinical information such as: problem lists, encounters, procedures, chronic conditions, medications, immunizations, and allergies, vital signs of weight, health, length, body mass index, laboratory results, family history, birth history, durable medical equipment and supplies [15]. The child-in-care health record also needs to include: placement information (e.g. at a foster home), dental, abuse, education and court dates, among other data elements. These data allow looking at the overall wellbeing and development of the child [21]. For instance, low education level and high placement changes could be seen as co-existing factor [21], multiple placements and behaviour issues may be identified concurrently [5], medical history is known when planning for child adoption [5]. Further, at an aggregate level, the data can inform policy and practice. For example, a service need for a therapeutic environment for children who have experienced trauma [21].

3. Discussion

The paucity of studies that met the inclusion criteria suggests that there has been little development specifically on child-in-care health records; however, studies were found on other child records: pediatric, school, and personal health records. These records might contribute to the further development of the child-in-care health record. Of the eight studies included, three provided few details on the record or implementation

[3,10,19] and two studies did not report positively on the implementation [3,10]. Four of the eight studies were on the *Looking After Children* records. All studies anticipated or reported benefits from using the records. One study reported that using the health records enabled moving from reactive to proactive care for the child [5]. None of the studies indicated that the records would no longer be used, except in *Smart et al* where the system was decommissioned and replaced by a state-wide system. As several studies referenced child-in-care health records not found during this review, a fuller review is needed.

A key concept in the studies was the joining of the social work case management record and child health status record [7]. Range in integration reached from one study with six source records [3] to two studies with single source records and ability for aggregate reporting [7,21] to a real time record with aggregate reporting ability [20]. There is clear direction to link research to policy and practice for evidenced-based policy and practice changes. For example, identifying factors associated with developmental progress or deterioration while in care [21]. Interagency cooperation was found to be integral to developing and effective using the record in all the studies. Further, to support individual care and research, complete, accurate and consistent records are needed. Success factors to better recordkeeping included support roles, audits, education, and results reporting.

4. Study Limitations

Review limitations include a single reviewer did the search, analysis and synthesis so there could be selection, synthesis and reporting bias. Only studies in English were included. No formal quality assessment of the eight studies was done. For terms, through searching, it was found that "child welfare" may reach beyond the connotation of "a child-in-care" to the broader connotation of overall child health and wellness. In addition, all the terms relating to "child-in-care" may not have been included in the searches.

5. Conclusion

There has been some implementation of paper-based and computerized child-in-care health records. The data elements needed in a child-in-care health record reach beyond those recommended for a child PHR to include social work case management and education data [20]. These additional data support holistic care planning for the child. Several studies highlighted the need for data to inform policy and practice. Further development of the child-in-care health record needs to integrate research and care provision data requirements. This step will require an interdisciplinary approach. This scoping review provides the first step toward determining the current knowledge on the child-in-care health record. A fuller scoping review is needed to provide more evidence to develop a tailored tool that supports both surveillance of child-in-care holistic development and enables research to inform policy and practice changes.

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Application of the Technological Pedagogical Content Knowledge Framework in Integrating an Educational EMR into Health Informatics Education

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Abstract. The discipline of health informatics is highly immersed in information technology, specifically health information systems. Students graduating from Bachelor degree programs in health informatics are expected to be familiar with a variety of systems upon entering the workforce. The adoption of systems like electronic medical records is on the rise across Canada, therefore it would be highly beneficial for students to have exposure to such systems in their coursework. While some individual instructors have done this to some extent on an ad hoc basis, formal strategies for EMR integration do not exist. A prominent framework for technology integration in learning that has been applied in many scientific disciplines is the Technological Pedagogical Content Knowledge (TPCK) framework. This paper describes how TPCK was used and applied as the guiding conceptual framework for exploring the integration of an educational EMR into undergraduate health informatics education.

Keywords. electronic medical record, electronic health record, health informatics, education, technological pedagogical content knowledge

Introduction

According to COACH, Canada's Health Informatics Association, "health informatics professionals develop and deploy information and systems solutions, drawing on expert knowledge from fields such as computer science, information management, cognitive science, communications, epidemiology, management sciences and health sciences" (p. 7)[1]. This statement demonstrates two key needs for students training to become health informatics professionals: 1) the need to be familiar with information technology (IT) and 2) the need to be able to apply it in many areas.

Several types of health information systems (HIS) are introduced in undergraduate health informatics programs. Electronic health record (EHR), computerized patient record (CPR), and electronic medical record (EMR) are all terms used to describe systems used to manage patient records. The latter, EMR, is the term used in the Canadian context to describe systems used in physician offices [2]. Adoption of EMRs is on the rise in Canada. For example in British Columbia, the Physician Information

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Technology Office (PITO) was established to support the implementation of EMRs in physician office practices [3]. In preparing health informatics students to enter the workforce upon graduation, it is important that they obtain competencies in relation to EMRs and other types of HIS. However, a key challenge is effectively integrating the technology into the classroom. As Mishra and Koehler explain, "merely introducing technology to the educational process is not enough"(p. 1018)[4]. The technological artifact is a tool but it needs to be used correctly in order to produce good outcomes. This challenge is not specific to the field of health informatics, but it does possess some unique contextual factors which need to be explored and addressed. Thus far, EMRs have been used to some extent on an ad hoc basis by individual instructors but there has not been a concentrated effort to explore integration components in depth. Research was recently undertaken to address this gap [5].

The integration of technology in education is not a new concept. Technology has become a large part of the learning environment. From the basic use of Microsoft® PowerPoint to more discipline-specific technologies, the use of technology in education is now commonplace and the majority of students entering university have grown up surrounded by IT in daily life. Looking at theoretical foundations for technology integration, a prominent concept in the literature is the Technological Pedagogical Content Knowledge (TPCK) framework. TPCK has been applied in many scientific disciplines and was used in this research as the guiding conceptual framework for exploring the integration of EMRs into undergraduate health informatics education. The result was a unique application of TPCK for this specific integration context.

1. What is TPCK?

Technological Pedagogical Content Knowledge represents a form of teacher knowledge which is an extension of Shulman's Pedagogical Content Knowledge (PCK) idea proposed in the 1980s [4]. PCK emphasized a need to understand how pedagogy fits with content for teaching. Given that technology now plays a large role in teaching as well, Mishra and Koehler added a third construct or knowledge base of technology to form TPCK[4] (also referred to as TPACK). TPCK is illustrated as a Venn diagram (see Figure 1) which shows several types of knowledge are involved. First is the knowledge of each individual construct: content, pedagogy, and technology. Next is the knowledge of each pair of constructs. In addition to the original idea of PCK, there is TPK and TCK. Technological pedagogical knowledge (TPK) requires an understanding of how pedagogy changes according to particular technologies in relation to the benefits and limitations of the technology within learning activities. This requires the teacher to consider which technology tools are best suited to specific activities, even those not specifically designed for learning. Technological content knowledge (TCK) refers to knowledge about how content is influenced and constrained by technology and vice versa. This requires consideration of which technology is best suited to specific content being taught. Finally, TPCK in the center is the knowledge that represents the interaction of all three constructs together. Surrounding this is a circle label "contexts" which plays a large role in any integration endeavor. The external factors and circumstances that influence integration will also have an impact on TPCK (e.g. the classroom environment and curriculum).

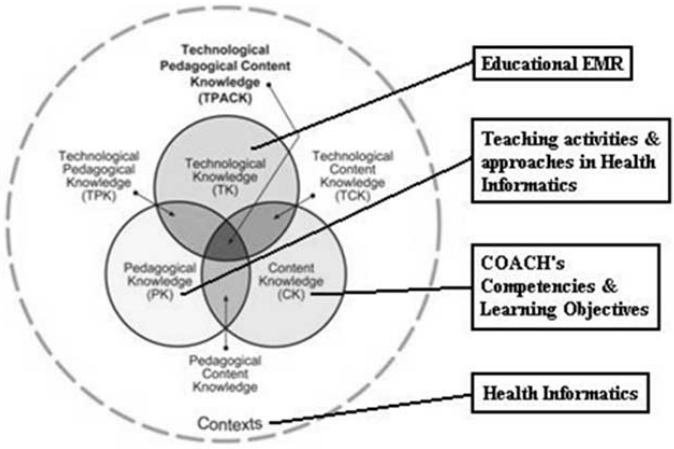

Figure 1. Original TPCK (left) (Source: http://tpack.org/) and TPCK in context of research (boxes at right).

2. TPCK in the Research Context

Each integration context is unique. In exploring EMR use for health informatics education, the three knowledge bases required were defined as follows.

2.1. Technology

In the real-world, EMRs have many functionalities to support healthcare. Common components include documentation support, decision support features such as reminders and alerts, administrative support, test and imaging ordering, results management, prescribing and medication management, and reporting [6]. From a design perspective, components include the back-end database, programming, and interface design. For this research, a modified version of an EMR called Digital Health Designs EMR® was the technological artifact being explored for use in education. In addition to being a fully functional EMR, it has added features for learning such as different users modes for instructors and students that allow instructors to control fictional patient cases within the system [7].

2.2. Pedagogy

Pedagogy refers to the practice of teaching. Instructors employ a variety of teaching activities, methods, strategies or approaches according to their chosen pedagogy. The specific teaching and learning activities can be categorized into one of the following [8]:

- Instructor-centered: instructor primarily passes on information to students
- Interactive: learning through communication between instructor and student and among students
- Individualized: student works at their own pace individually
- Experiential: learning takes place in natural or simulated settings

Assessment spans all four categories, with the assessment method reflecting the nature of the activity. For example, an instructor-centered assessment method may be a

written test whereas an interactive activity may be assessed through an oral presentation.

2.3. Content

The content piece reflects the competencies or knowledge that students are expected to possess. For health informatics, several groups have established sets of competencies for the health informatics professional that outline both the knowledge and skills graduating students should have. In Canada, COACH produced the Health Informatics Professionalism (HIP™) Competency Framework [9]. In this framework, the core body of knowledge for health informatics comes from three source practices: health sciences, information sciences, and management sciences. Within these three areas are seven subcategories: clinical and health sciences; Canadian health system; information technology; information management; project management; organizational and behavioral management; and analysis and evaluation. The specific competencies for a health informatics professional are organized under each of these subcategories.

3. Resulting Application of TPCK

This research utilized TPCK, both in study design and the resulting output. Previous authors have expressed that technology should not drive pedagogy [10,11] and in specifically referring to TPCK, Harris and Hofer[12] express that TPCK shouldn't be "technocentric", that is, focused on the technology. They have advocated for the exploration of technology to best suit learning needs. While in this research the technology was preselected, the goal was not to fit the health informatics curriculum around the educational EMR, but rather to determine where it fits best into the curriculum.

In exploring EMR integration into health informatics education, the TPCK framework was used to frame the research questions as well as instrument design i.e. interview and focus group questions. Given that each construct could be defined for the health informatics context, the next step was to look at each of the pieces in relation to each other to effectively uncover all the considerations (i.e. types of knowledge) required for effective integration in this context (see boxes at right in Figure 1). For example, what learning activities (pedagogy) could employ the educational EMR (technology) to give the instructor TPK? Or what topics (content) covered in health informatics courses are directly related to EMRs (technology) to give the instructor TCK? Instructors and students were recruited to provide answers to these questions (in interviews and focus groups) using TPCK as a guide.

The result of this research is a proposed framework for integration that builds on and extends the original TPCK framework [5]. The items identified in the research within each knowledge area (technology, pedagogy, content) are included with two additional pieces. The first added piece is a continuum for when to integrate the technology into the education. From the research, points of integration emerged which ranged from a single activity to integration across multiple programs including health informatics in a multidisciplinary approach. The second added piece is contextual considerations that emerged which "open-up" the context circle surrounding TPCK. These include course, student, instructor, technical, and system considerations as well as overall learning pedagogy.

Conclusion

In exploring the integration of educational EMRs into health informatics education, TPCK forms a useful approach to guide educators. As the creators of TPCK state, "there is no general solution to a teaching problem for every context, every subject matter, every technology, or every classroom" (p. 20)[13]. However, TPCK provided a good basis for exploration of potential solutions and in turn, the extended framework developed through this research for health informatics education now provides a mechanism for health informatics programs to explore integration of educational EMRs into their own curriculum, regardless of location and the specific system involved.

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Telecare, Telemedicine and Telelaboratory

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TeMaD System: Telecare for Managing Diabetes in Saudi Arabia

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Abstract. This paper briefly describes the main characteristics of the TeMaD system, developed for the Saudi National Guard Hospital in Riyadh. TeMaD attempts to improve current healthcare services for diabetic patients, and assists healthcare givers in disease management. It strengthens communication channels between patients and their healthcare givers, possibly leading to better health.

Keywords. Saudi Arabia, Telecare, TeMaD, Diabetes, KAMC, National Guard

Introduction

Diabetes is rapidly spreading in Saudi Arabia, affecting almost one third of the population [1]. The healthcare sector is struggling to cope with the growing numbers of diabetics and associated healthcare costs, nor is it prepared to deal with the expected rise in chronic diseases due to an aging population [2]. Reasons fuelling this problem include poor dietary habits, inactivity, an aging population and associated social factors.

The Telecare for Managing Diabetes (TeMaD) system has been developed to help improve healthcare services offered at King Abdulaziz Medical City (KAMC) in the capital Riyadh. It presents a telecare system that is tailored for patients in Saudi Arabia in order to overcome specific obstacles sometimes linked to local culture and traditions [3]. TeMaD is also a highly available system offering a number of practical communication channels between the patients and their healthcare givers.

This paper reviews the main characteristics of TeMaD, and examines the impact it has had on diabetic patients, during a three month trial period between 2009 and 2010.

1. Review of Current Healthcare Services Offered at KAMC Diabetic Clinic

The KAMC Diabetes clinic provides healthcare services through Physicians, Diabetic Educators (DEs), and Nurses. DEs are primarily responsible for educating patients about the disease, and for long-term monitoring of blood glucose levels, medications, and other associated factors such as diet and physical activity regiments.

More than 1500 diabetics were registered at the clinic during 2008/2009, with only four DEs. Since then, these numbers have risen considerably. Unfortunately the

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number of DEs remains the same, leading to a strain on hospital resources. Furthermore, blood glucose levels are recorded and monitored in an inefficient manner. Patients log their readings in a small booklet, kept with the patient at all times. During the hospital visit (may vary from once a month to once a week depending on the patient), the DE reviews all recorded readings and discusses any anomalies with the patient. Based on this information, the DE determines the next step. The DE has no access to these readings between hospital visits, which may put high risk patients in danger, delaying required medical intervention when necessary.

2. Common Obstacles in Saudi faced by Patients

In addition to existing obstacles commonly found in other countries, we find the following to play a major role:

2.1. Transportation

Saudi Arabia lacks an adequate public transportation system. In addition, Saudi law prohibits females from driving. This combination has resulted in 'Transportation' being amongst the highest obstacles in receiving healthcare services as rated by KAMC patients during a survey conducted in 2010, mostly affecting female patients.

2.2. Cultural Factors

Saudi has a unique culture which combines social, traditional, and religious factors. It is common for patients to insist on receiving care from same-sex healthcare givers. Society's strong endorsement of gender-segregation may also contribute to the problem. This may be difficult to satisfy, especially in rural centres with limited resources.

3. TeMaD Design

TeMaD targets diabetic patients at KAMC Clinic between 16-70 years. It allows patients and healthcare givers at the clinic to communicate using 3 different modes: Internet, SMS, and Dedicated Landline. These modes make TeMaD an accessible solution, allowing patients from different age groups to select the most suitable one. Let us review the TeMaD interfaces for both Patients (Users) and DEs (Administrators).

3.1. TeMaD Patient Modes

TeMaD offers patients three different modes of access. Each one targets a different age group and offers different functionality, making TeMaD more accessible.

3.1.1. TeMaD Internet mode

The online mode offers patients a user-friendly interface with clear and simple design and structure making data entry easy (see Figure 1). It offers the most functionality, allowing users to monitor their blood glucose levels over a period of time using graphical representations. It is expected to draw younger patients.

Figure 1. TeMaD Patient Web Interface

3.1.2. TeMaD SMS mode

This mode enables patients to send daily readings (up to seven) to the TeMaD system through SMS using a local number. This mode is easy to use, and accessible to any patient owning a mobile. It is expected to draw middle-aged patients.

3.1.3. TeMaD Landline mode

A DE manages a dedicated landline, responding to patient calls and directly logging their readings and any other necessary information onto TeMaD. This mode was added for two primary reasons: direct verbal communication between DE and patient may enable capture of essential information, and to also encourage older patients, not particularly interested in using technology, to use TeMaD.

3.2. TeMaD DE Mode

The DE uses the TeMaD Web Interface to manage patients' diabetes. The interface is user-friendly (see Figure 2), and enables DEs to perform various tasks, such as:

- Review existing readings uploaded by patients via Web Interface and/or SMS
- Log patient readings collected during a landline call
- Examine patient performance levels over a period of time (daily, weekly, monthly, 3-month)
- Communicate with patient (SMS sent via TeMaD)

4. TeMaD Study

TeMaD was used to manage the diabetes of 79 participating patients during the period December 2009 and June 2010. Random sampling is used, with ages between 16 to 70 years. Only 52 patients completed the trial period while 27 patients dropped out for various reasons.

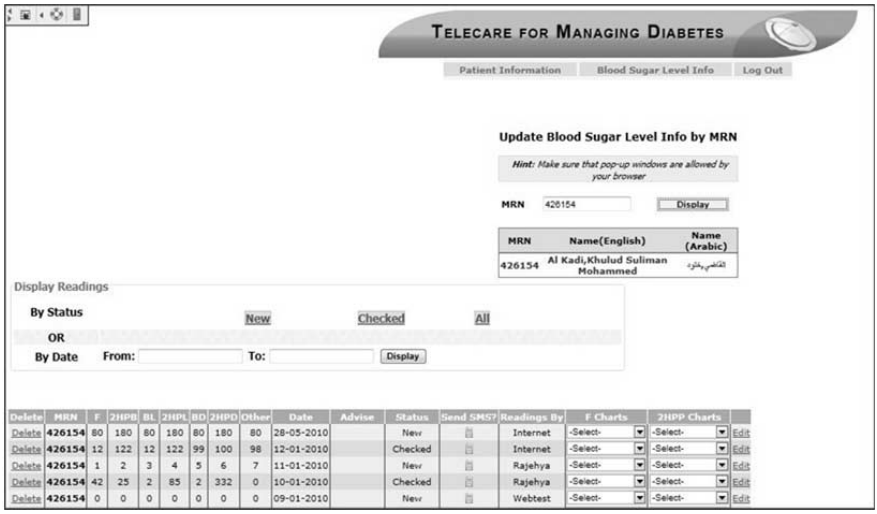

Figure 2. TeMaD DE Web Interface

Due to limitations in time and budget, the sample size is small; however, it does reflect the total population of patients at the clinic, in gender and age group ratios. The HbA1c test is used to determine the impact of TeMaD. The HbA1c test is chosen because it measures blood sugar levels over a longer period, hence better assessment of a new treatment plan. Each patient used TeMaD for 12 weeks, since blood cells may survive 8-12 weeks before renewal. This ensures an accurate follow-up HbA1c measurement is taken after the trial period. Data was later examined to determine the impact of TeMaD as an alternative method for diabetes management. The Before/After test was used, comparing HbA1c levels of our sample group before and after intervention, where:

- Pre-measurement: the value of the blood sugar level of a participating patient obtained through an HbA1c test, before using TeMaD.
- Intervention: using TeMaD for a period of 12 weeks.
- Post-measurements: the value of the blood sugar level of a participating patient obtained through an HbA1c test, after using TeMaD.
- The two measurements will be compared to evaluate whether or not TeMaD had an impact on the blood sugar levels of participating patients.

Upon completion of the study, each patient was required to complete a questionnaire. The primary goal is to reduce patient HbA1c levels by 5% or more. The following formula was used:

Reading 1 – Reading 2 = Hba1c change

(Hba1c change / Reading 1) X 100 = % of HbA1c level increase/decrease

where: Reading 1: is the Hba1c level taken before starting TeMaD, and
Reading 2: is the Hba1c level taken after completing TeMaD, and
Hba1c change: is the difference between Reading 1 and Reading 2.

5. Results

5.1. Relevant TeMaD application results

The gender ratio of the total number of participating patients is 46% male and 54% female, closely resembling the ratio of patients at the clinic between 2009 and 2010, being 42% male and 58% female. This indicates that our sample size closely reflects the clinic environment in gender ratio.

Statistics showed that 69% of TeMaD patients fall under the 16-29 age group, suggesting that younger patients are more likely to use alternative methods, especially those methods relying on technology.

In addition, only 12% of participating patients lived in rural areas. However, the urban area of Riyadh spans across 2435km2, with KAMC located at the eastern outskirts of the city. With almost 5 million inhabitants, peak hours can result in some patients requiring more than two hours to commute back and forth to the hospital. TeMaD better suited many patients saving them both time and money.

Most importantly, the primary goal of the study was achieved, with TeMaD succeeding in reducing HbA1c levels by more than 5% for 83% of participating patients, with a greater impact on females (see Figure 3). The average HbA1c level of patients was reduced from 9.2% down to an average of 8.4%.

Furthermore, out of the total number of participating patients recording drops in their HbA1c levels, approximately 37% were able to lower it by 10% or more, exceeding our expectations. HbA1c levels recorded three months after patients resumed using traditional healthcare services indicate that progress made earlier through TeMaD was reversed with an increased in the HbA1c levels of 42%of revisited patients.

5.2. Relevant TeMaD questionnaire results

- Most females rated ‘Transportation’ as a major obstacle in receiving quality healthcare services, while 29% do not have permanent access to a private car.
- Almost 62% of patients preferred dealing with the same-sex DE. This may be contributed to the sensitive nature of the Saudi society and the adherence to cultural and traditional factors which promote segregation between the genders.
- Statistics indicate that 84.6% of patients found TeMaD to be a more convenient way of dealing with their diabetes than traditional services at the clinic, while almost 98% stated that TeMaD assisted in better management of their diabetes.
- 90.4% of patients stated that TeMaD made it easier to access the clinic DEs.

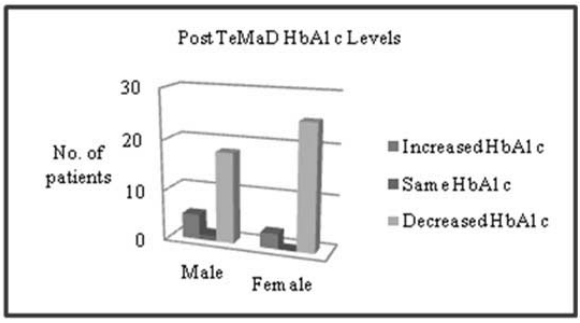

Figure 3: Post TeMaD HbA1c levels

6. Discussion

TeMaD has improved HbA1c levels of 83% of participating patients reducing the average from 9.2% to 8.4%. Three months post-trial, tested HbA1c levels showed a rise in 42% of revisited patients, indicating that TeMaD intervention contributed to improved patient health. TeMaD had a greater impact on female patients between 16-29 years, improved monitoring techniques, and patient–caregiver communication channels. TeMaD may not be suitable for older patients, due to technology resistance. Also, TeMaD is not recommended for newly diagnosed patients, since it minimises personal contact with DE, sometimes essential to assess patient psychological aspects. TeMaD has been useful to DEs in management of patient disease, time, and resources.

7. Conclusion

TeMaD is a telecare solution designed to help meet the growing needs of the Saudi healthcare system. Although it is developed specifically for diabetes, it can be used to manage other chronic diseases. TeMaD is tailored to address factors of the local culture that may affect how healthcare services are offered. More research is required to examine how technology can assist in overcoming these factors while maintaining local culture. TeMaD is a highly available system which improved communication between patients and healthcare givers and led to higher compliance with the diabetic treatment plan. TeMaD had a positive impact on diabetes management indicating the need to incorporate such solutions into existing healthcare practices.

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Telecardiology on Vancouver Island: Imagination to Implementation

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Abstract. In 2011, there were more than 97,000 people living with Heart Failure in British Columbia (BC) with a total of 17,592 within VIHA. To increase patient accessibility to specialist care, the Vancouver Island Health Authority (VIHA) implemented a telecardiology program that utilizes digital stethoscopes, telehealth technology and collaboration to deliver cardiac care remotely. The program has successfully completed 20 consultations to date in 6 communities within the VIHA. This article outlines processes and outcomes of enabling the existing VIHA cardiology program with the use of telehealth technologies.

Keywords. telehealth, heart failure, cardiology, Vancouver Island, videoconferencing, digital stethoscope, Vancouver Island Health Authority (VIHA), Provincial Health Services Authority (PHSA), telecardiology

Introduction

Telehealth refers to the use of communications and information technology to deliver health and health care services and information over large and small distances. It is about transmitting voice, data, images and information rather than moving patients, health practitioners or educators [1]. In 2006, the Vancouver Island Health Authority (VIHA), an organization in British Columbia (BC) responsible for delivering care to 750,000 people, embraced telehealth as a modality to increase patient accessibility to specialty care. VIHA telehealth has enabled several specialties (i.e. oncology, thoracic surgery, renal medicine, mental health, genetics and stroke) and 17 communities (Figure 1). The service has facilitated over 7,000 physician–patient telehealth consultations, saving over 2,700,000 km of patient travel.

Heart Failure (HF) is a chronic heart condition where the heart is weakened or damaged due to disease and/or stress (i.e. myocardial infarction, heart disease, hypertension and heart valve diseases). In 2011, the Ministry of Health identified 97,214 people living with heart failure in BC, with a total of 17,592 within VIHA [2]. In response to this, VIHA developed a telecardiology service to increase HF patient accessibility to cardiac care.

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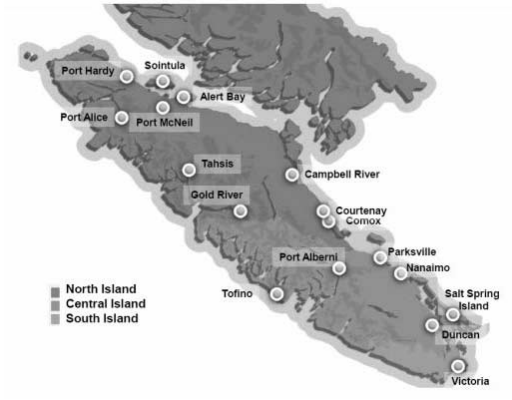

Figure 1. VIHA communities equipped with Telehealth

1. Background

The Heart Function Clinic (HFC) provides HF patients with medical and nursing assessments, education and support, exercise guidance, diagnostic interpretation (i.e. electrocardiograms and blood tests), medication reconciliation and adjustment. Currently, there are over 700 VIHA patients registered in the HFC. Many Vancouver Island residents live in communities that do not have a HFC, and are asked to travel to other communities to receive care (Table 1) [3]. On average, 7 patients per week travel to Victoria, Nanaimo or Campbell River to visit a HFC. These patients absorb the time, expense, risk and physical burden of travelling to the nearest centre.

Table 1. Communities without Heart Function Clinics: populations and distances (round trip) to HFCs

Community	Total Population	Distance to Victoria HFC (Kms)	Distance to Nanaimo HFC (Kms)	Distance to Campbell River HFC (Kms)
Duncan	57,761	130	54	204
Parksville	46,375	300	36	119
Port Alberni	31,442*	390	81	148
Tofino		632	203	270
Courtenay	65,340	440	106	45
Gold River	2,356*	710	239	92
Port Hardy	12,239*	1004	384	237
Port McNeill		926	347	200
Port Alice		1024	396	249

*Population Combined

2. Program Development

Recognizing the need for increased accessibility of service to patients with complex cardiac conditions, VIHA in conjunction with representatives from BC health authorities developed a provincial committee to foresee the implementation of a standard digital stethoscope that could be used throughout the province. Digital stethoscopes provide "…reliable and valid screening for congenital heart disease" [4],

and can be use safely over internet-based software [5]. The intent of the committee was to ensure compatibility, reliability and knowledge transfer through lessons learned.

2.1. Technical Solution

The electronic Littmann 3M 32000 stethoscope was selected as the provincial standard for telehealth programs within BC. The electronic stethoscope connects to a computer using Bluetooth, and links the provider stethoscope with that of the patient at the remote site. Once connected, providers can utilize the electronic stethoscope to assess the heart and lung sounds of remote patients.

2.2. Program Participants and Selection

Participation in telecardiology is entirely voluntary. In total, three VIHA cardiologists volunteered to participate. HF patients meeting the following criteria were given the option to have their consultation in their local community via telecardiology or to travel to the nearest HFC for a face-to-face consultation:

- lived in or near community where telecardiology is offered;
- had their initial visit in person at the HFC; and
- agreed to participate in telecardiology.

2.3. Requirements

The telehealth team conducted a thorough analysis of the current processes at the HFC. The following items were identified as essential when conducting a session: capability to capture a patient's vital signs, ability for specialist to hear patient's heart beat, and ability to see and hear the patient in real time. The following workflow processes were also examined: patient inclusion criteria, scheduling, visit types, pre-visit patient preparation, diagnostic testing, patient assessment workflow, report generation, and documentation.

3. Program Development

To ensure program success, a dedicated project team including a project manager, project analyst and telehealth nurse was assembled. The team focused on examining stakeholder engagement, patient load, resource availability, rollout, risk assessment and developed a project plan. The team also ensured site readiness in terms of both infrastructure and human resources (i.e. equipment deployment, testing, and infrastructure management; and clinical support at the patient site).

3.1. Stakeholder Engagement and training

Human resource engagement was an essential component for the success of the implementation of telecardiology. Engagement can "…be a primary antecedent to successfully implementing an organizational change initiative" [6]. All stakeholders, including executive support, physicians, assistants, and persons facilitating telehealth at

patient sites, were involved throughout the process to encourage communication, collaboration and program acceptance.

The use of the electronic stethoscope during a telehealth consultation created the need for increased training, resources and support than the typical telehealth consultation. Software, equipment and process training were delivered by the telehealth team in person and remotely over telehealth. Administrative assistants were trained in the scheduling and registration processes and nurses and physicians were trained to facilitate and prepare for the telecardiology session (i.e. flow and operating the videoconferencing equipment, stethoscope and software). Competency checklists, completed by the clinicians, were used to track proficiency and gaps in training.

3.2. Support Plan

The telehealth team developed a thorough multi-tier support plan for the various stages of the project. The plan allowed for stakeholders to communicate issues or questions through phone or email. If the issue could not be resolved immediately by the receiver, the issue would be classified and directed to someone with specialized knowledge in that area.

4. Findings

In the first 6 months of telecardiology, 20 patients from the following communities participated: Campbell River, Port Alberni, Courtenay, Parksville, Port Hardy and Salt Spring Island. So far, the service has avoided over 5,800 km of patient travel and 1,600 tones of carbon emissions.

The telehealth team has received positive feedback from participating physicians, patients and clinicians. Dr. Swiggum (cardiologist) commented that "telecardiology enhances the collaborative approach to delivering cardiac care to the patient" and that telecardiology is "… like having the patient sitting next to you". Several patients have reported substantial cost, time and travel savings.

5. Next Steps

The success of the pilot and initial sessions has prompted the telecardiology service to continue and expand. Other Health Authorities are expected to use the knowledge gained from this project to implement similar use of the digital stethoscope. At VIHA, the telecardiology model will expand to the Atrial Fibrillation Clinic. The clinic serves up to 2,200 BC patients annually. Since there are only a few electrophysiology cardiologists in the province the service is expected to save thousands of kilometers of patient and provider travel.

VIHA is exploring the use of the digital stethoscope as well as other digital medical peripherals (i.e. dermatoscope, otoscope and spirometer) to facilitate telehealth for other disciplines such as respirology, speech language pathology, and dermatology.

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Developing a Strategy for Studying Critical Thinking in a Nurse Telehealth Setting: A Participatory Approach

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Abstract: Telehealth nursing is a specialized area of nursing practice that has grown in response to the emergence of new technologies and consumer demand for health care services in the community. HealthLinkBC Nursing Services provides symptom triage and health education to residents of British Columbia and Yukon over the phone. Unlike traditional nursing care, telenurses are limited in terms of information they receive from callers. Therefore, there is a need for critical thinking skills to be developed. The purpose of this paper is to describe a participatory approach towards identifying: (1) the factors that affect telehealth nursing practice including critical thinking, and (2) developing a research strategy aimed at identifying the ways in which critical thinking can be supported in a telehealth nursing environment. A HealthLinkBC working group has begun work in developing a definition of critical thinking specific to nursing, identifying future research opportunities and methodologies.

Keywords. Critical thinking, telehealth, participatory, approaches

Introduction

Telehealth nursing is a unique and specialized area of nursing practice that has grown significantly over the last decade. The emergence of new technologies and consumer demand for health care information and services anytime and anyplace has lead to a significant rise in the use of telehealth services. Globally, governments (i.e. national and local) are investing in telehealth. With the growth and popularity of this type of health care service among the citizens of many countries (e.g. Canada, United States, United Kingdom, Australia), there has also developed an increased demand to provide more complex services and to be able to respond to emerging public health issues (e.g. emergence of a new diseases such as H1N1). Health professionals who work in these settings (e.g. nurses, dietitians, pharmacists) are increasingly addressing more complex, urgent and new types of health issues brought to them by healthcare consumers in rural and urban areas of a country. The complexity and urgency associated with this area of work places unique demands on those who provide these services that differ from those typically found in acute care or long term care settings. For example, there is a need

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for telehealth nurses to actively engage in critical thinking: (1) while speaking with a health consumer who is calling the telehealth service, and (2) when considering the types of individuals a nurse engages with at a population level in terms of their health needs, health issues and access to health services (rural versus urban). Critical thinking is an essential aspect of telehealth nursing practice. While there are many publications in the nursing and professional practice literature that focus on supporting and helping individuals to develop critical thinking skills, few of these are specific to the telehealth setting. When a search was conducted of Medline® and CINAHL® using the search terms "critical thinking" and "telehealth", only five (5) were returned. Therefore, there is a need for research at the intersection of critical thinking and telehealth. The purpose of this paper is to describe an active participatory approach towards identifying: (1) the factors that affect telehealth nursing practice including critical thinking, and (2) developing a research strategy aimed at identifying the ways in which critical thinking can be supported in a telehealth nursing environment. In the next section of this paper we provide some background and context for our work.

1. The Critical Thinking Context of HealthLinkBC Telehealth Services

HealthlinkBC (HLBC) is an integrated telehealth delivery service that provides non-emergency health information to the residents of the provinces of British Columbia (BC) and Yukon by phone, website, and print resources. This 24/7 telephone service is accessed by calling 8-1-1 where a Health Services Representative directs calls to specially trained Registered Nurses (Telenurses), Registered Dietitians (Teledietitians), or Pharmacists. In addition, it is important to note that HLBC may be the first point of contact for health care to residents, especially to those living in rural areas of British Columbia and the Yukon. When callers access 8-1-1, they initially speak with a health service representative and if the caller is experiencing symptoms, the call is transferred to a registered nurse. A telenurse will provide symptom triage as well as health education (if appropriate). To illustrate, a caller experiencing symptoms typical of a potential heart attack would require immediate intervention. The telehealth nurse has the option to advise the caller to hang up and call 911, or, to transfer the caller directly to BC Ambulance Services.

Registered nurses have a professional duty to care from the moment they speak to a caller. Therefore, it is imperative that registered nurses are able to assist callers by providing safe and appropriate health care recommendations to enable healthy outcomes. Critical thinking focused upon safety and appropriate health care is of the utmost importance to ensure healthy outcomes. In addition to responding to symptoms, a telenurse also considers factors such as age, ethnicity, medical conditions and other health risks in his or her assessment. At this point, the telenurse uses standardized protocols within the electronic decision support tool to determine a recommendation. As each call is unique in its presentation of these varying factors, it is crucial that telenurses possess a high degree of critical thinking in their assessment of callers given the factors that may influence the calls. As critical thinking is an essential aspect of telehealth nursing practice, HLBC identified that there is a need to provide ongoing support of nurses' critical thinking in the telehealth setting. A three stage participatory approach was undertaken to identify the ways in which critical thinking can be further fostered as part of a larger organizational strategy to continue to improve the health outcomes of the citizens of British Columbia (BC) and the Yukon. The first part of this

process involved identifying the factors that affect telehealth nursing practice. Some of these factors have also been identified by researchers as having an impact upon information seeking and decision making processes that underlie critical thinking in health professionals.

In this process a working group was formed consisting of representatives of the clinical team, nursing services and the University of Victoria. The group first identified the factors that affect telehealth nursing practice (see Figure 1). The nurse-caller relationship is influenced by a number of factors. For example, caller age, gender, symptoms, health literacy and location in the province influence caller use of communication technologies (e.g. telephones, cell phones, Smart Phones) and ability to communicate with the telehealth nurse and caller outcomes. Telehealth nurse technology (including electronic telehealth record and the decision support tool and knowledge base (KB) content, design and usability) in turn influence nurses' work (including) critical thinking and caller outcomes. Lastly, telehealth nurse education, years of experience, level of telehealth nursing expertise and critical thinking affect caller outcomes. In summary a number of factors influence telehealth nursing practice (including the cognitive process of critical thinking). They include the caller, nurse and the technology that is being used by callers and nurses.

2. A Participative Approach towards Developing a Critical Thinking Strategy

Currently, telenurses at HLBC use a clinical decision support tool that consists of questions, asked in a prescribed order, that are dichotomized to generate a disposition, or recommendation for care. As mentioned above, HLBC's service plan includes planned expansion of services which will require nurses to move from a more protocol driven approach to a guideline driven service delivery model. This raises the question of how telenurses can be supported in the continued delivery of safe, effective and consistent service to a varied population, or "How do nurses apply critical thinking skills to telehealth practice, and how can they be supported in developing these skills?"

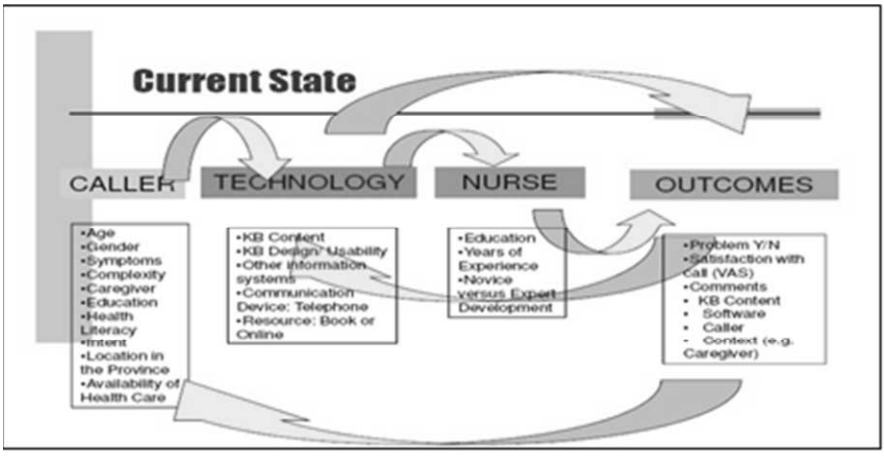

Figure 1: Factors that Affect Telehealth Nursing Practice and Critical Thinking: Development of a Logic Model

To address this question the organization first undertook the process of defining and understanding the attributes of critical thinking. Initially, a working group set out to develop a definition of critical thinking specific to the unique characteristics of telehealth nursing practice. This was followed by identifying research questions that would help to better understand describing and supporting critical thinking.

2.1. Defining Critical Thinking: An Active Participatory Approach

Part of the process involved ensuring broad stakeholder representation in the working group. As is with most research, a literature review of what defines critical thinking was undertaken. Each member of the group agreed to review the critical thinking literature independently and to present their findings at a follow up working group meeting. In addition, workgroup members asked telehealth nurses at HLBC about their personal perceptions of and definitions of critical thinking. Findings from this work revealed that "critical thinking" was not well known or understood within the telehealth nursing context. Terms such as "clinical judgment" or "nursing judgment" were more commonly referred to by working group members and the nurses that commented on the definitions. Working group members felt that some language could be added to better reflect a more specific focus on clinician and telehealth work. Following this, each member of the group developed their own definition of critical thinking, whether it was already documented in the literature or it was informally written in their own words. At the follow-up working group meeting, the definitions were reviewed by the group – the definitions were presented in Power point form. The group carefully reviewed these definitions and as such, key words were identified as vital to the definition of critical thinking. Through an iterative process that involved the review of these definitions and their key works a critical thinking definition was developed (by a sub-group of the main working group). The definition was presented to the main working group and further discussed in terms of its representativeness of telehealth nursing. This led to further refinement of the definition of critical thinking. In summary a final definition of critical thinking was developed through a process of reviewing the literature, engaging in working group discussions, consulting with telehealth nursing, review, refinement and further review and refinement of the definition – as a result a nurse centric definition was developed. For the purposes of this research, we defined critical thinking as *a systematic and active process that assesses the depth and breadth of a situation, issue or problem and is based in best practice. It assimilates past experiences and knowledge; integrated with creativity, logical reasoning, thoughtful reflection, seeking an appropriate outcome, and transforms this knowledge to the presenting situation that provides clarity for the most appropriate action, decision or judgment. Regarding nursing judgment, critical thinking is the constant overarching component, the method by which we employ clinical reasoning leading to sound clinical judgment*. In the next stage of this process the working group identified research questions involving critical thinking in telehealth nursing practice.

3. Identifying Research Questions Involving Critical Thinking

In choosing this project the team identified some assumptions: (1) critical thinking is a desirable skill for telenurses, (2) currently telenurses are at various levels of critical

thinking, and (3) critical thinking can be taught and learned. Currently, HLBC/811 services are available to all residents of BC and Yukon. Telenurses receive two weeks of orientation training and a number of preceptor shifts. Telenurses are expected to be "generalists" who provide general health information and education to callers. There are extensive resources, both electronic and in paper format, but typically the encounter requires the nurse to draw on previous education and experience as much as on the approved resources. The telenurse workflow includes listening to the client's "story", identifying priority questions or symptoms, deciding whether to offer symptom triage or health education, identifying the appropriate resource (which may involve choosing between various resources), relaying triage outcomes, recommendations and information to the client, and documenting the call. Critical thinking is essential for a number of these steps. For example, a client may identify a headache as their primary concern. The nurse conducts an assessment and applies critical thinking skills to determine that other symptoms are more serious and need to be assessed prior to the headache which meets College of Registered Nurses' professional practice standard of "Competent Application of Knowledge" [1].

There are various ways for members of the working group to identify the presence and degree of critical thinking in telenurses: e.g. listening to calls for various quality improvement purposes, focus groups, surveys, and feedback from nurses regarding clinical questions and situations that they are having difficulty with. These are regular required tasks in the group members' day-to-day jobs. In group discussion, it was identified that nurses do not all display the same level of critical thinking, and that they may apply critical thinking skills in some situations and not in others. A more formal assessment using tools such as the Watson Glaser Critical Thinking Assessment (WGCTA) or the California Critical Thinking Skills Test (CCTST) could lend more weight to this assumption. Is it possible to teach critical thinking skills? According to Chabeli, this should be an integral part of nursing curricula, "The teaching and learning activities for critical thinking, if carefully planned, will form an integral part of the teaching and learning experience for learners rather than be taken as something that distracts learners from the business of learning" [2]. Most of the research on teaching critical thinking skills has been conducted in learning environments. However, "Critical thinking is … a transferable skill which is underpinned by nursing knowledge" [3]. The challenge for the working group is to develop strategies to help practicing telenurses develop and enhance critical thinking skills, to ensure their ability to provide ongoing safe and consistent care by being able to respond to a large variety of clinical situations.

4. Conclusions

There were a number of benefits arising from this work. First, a partnership was developed between faculty and HLBC. Several key research questions, methodologies and approaches were identified for use in the telehealth nursing setting. This collaboration assisted in facilitating a streamlined and step-wise process in identifying areas of research. In the next stage, we also plan to extend our work to stakeholder representation of all appropriate services (i.e. pharmacy and dietitian). Each member would provide a contextual understanding of critical thinking based on their work portfolios and experience. Furthermore, our team of experienced professionals came from various nursing and social work backgrounds; this allowed for a fulsome

retrospective of the various steps of this journey. In terms of the actual work performed in the process (i.e. brainstorming, literature review, and the collaborative development of a definition of critical thinking), it is worthy to note that each of these phases offered an abundance of relevant information to work towards our research objectives. This information was consequently framed into knowledge (our definition of critical thinking) which triggered the excitement of research question ideas and methodologies.

5. Future Work

Over the next year there will be a number of opportunities for research into critical thinking/clinical judgment. Telenurses have identified some challenges when dealing with specific population groups. One example is parents of newborns calling with breast-feeding concerns. An HLBC working group has met with community breast-feeding educators and developed a learning lab for the telenurses in order to deepen knowledge and understanding and ensure HLBC is aligned with the information provided by community care nurses. It would be interesting to review a number of breast-feeding calls before and after roll-out of these labs. Working with telenurses in the form of cued recall or focus groups could show possible changes in the application of critical thinking. As a part of the extension of this work we plan to identify criteria for measuring critical thinking; for example, measurement criteria could include the call length, number of topics accessed, number of topics that were shared with the caller vs. topics that were merely looked at by the nurse, without information provided to the caller. In addition to formal testing as mentioned above (WGCTA or CCTST) there could also be a qualitative aspect to assess how the nurses felt they were applying critical thinking. In order to support nurses' development of critical thinking, another option would be to identify "expert" nurses possibly by their educational or practice backgrounds, assessing their calls in their specialty area and determining ways of conveying their knowledge and practice to others.

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A "Realist Review" Approach to e-Health: The Case of Type 2 Diabetes in Youth

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Abstract. As e-health technology becomes more ubiquitous in our health and health care environments, a flexible, robust understanding of what works and under what circumstances is needed. Traditional meta-analyses tell us how frequently a technology has worked for previous populations, but not why. Realist Reviews can contribute to understanding why interventions work and by extension how results of past studies can be applied to emerging health challenges. The utility of such a method is considered in e-health interventions to address the serious growing challenge of Type 2 diabetes and metabolic syndrome in young people.

Keywords. Diabetes Mellitus, Health Care Research, eHealth

Introduction

As we adopt e-health technologies into our health and health care environments, we need a flexible, robust understanding of what works and where. Without this, the many studies and evaluations of e-health technologies, in a variety of contexts, leads to challenges in accumulating evidence for clear-decision-making. When a new health challenge emerges, or e-health solutions become available, it may not be evident how previous research applies, suggesting more research is needed.

There is no simple answer as e-health technologies are complex interventions acting on complex social systems and therefore "are not 'magic bullets' that will always hit their target" [1]. Rather their success is dependent on context and implementation. This paper explores a "Realist Review" approach proposed by Pawson, et al. [2] to understand the mechanisms for why e-health technologies work and in what contexts, in order to better adapt future technologies in response to emerging health challenges.

1. Background

1.1. Introduction - Type 2 Diabetes in Youth as an Emerging Health Challenge

An increase in Type 2 diabetes and metabolic syndrome in young people is presenting a new health challenge. In 2009, within Alberta alone, nearly 3,000 children and

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adolescents were living with diabetes and over 400 new cases were identified in the under-20-year-old population [3].

As well, obesity rates tripled among 12-17 year olds between 1979 and 2004 [4-5]. Compared to children of normal weight, overweight and obese children experience higher blood pressure, more abnormalities in serum lipid levels and higher levels of insulin resistance. These conditions are all hallmarks of early metabolic disease, diabetes and susceptibility to cardiovascular diseases [5].

1.2. Use of e-Health Technologies in Diabetes Management

A literature search in CINAHL and MEDLINE databases was conducted to examine trends in e-health technologies used to support diabetes care. Search terms including telehealth, e-health, telemedicine and mhealth were combined with diabetes and resulted in 67 relevant articles.

Many factors contribute to optimal diabetes self-management, including timely information on blood glucose levels, nutrition, physical activity, medications, medical examinations and laboratory test results. Successful management is demonstrated through changes in three areas: behavioral (adherence to diabetes control recommendations), psychological (self efficacy) and physiological (HbA_{1C} levels). Technologies can contribute to this success through enabling patient–provider interactions; collecting, summarizing, and responding to data; or providing education and reminders. Examples of each of these illustrate the diversity in this literature.

1.2.1. Enable Patient-Provider Interaction

Coaching calls have been used primarily with families and children with Type 1 diabetes where adherence issues were a problem. Type 2 diabetes has been called a "life style" disease and coaching calls have also been effective in helping seniors stay active as well as regular telephone calls to assist adults with self-management and education.

1.2.2. Collect, Summarize, and Respond to Data

A variety of interventions have been used to automatically collect and send information to people with diabetes via Short Message Service (or SMS), telephone and websites. Daily text messages have been used to help youth with Type 1 diabetes to enhance self-efficacy, stabilize insulin injections and improve overall self-management. Messages have also been customized using patient biochemical profiles and clinical status on file.

1.2.3. Provide Education and Reminders

Patients have frequently used phone calls and video-conferencing to connect with diabetes educators. Another version of this interaction has been to customize education as a result of submitting personal data. Examples include patients calling an automated system weekly to receive tailored feedback and education on self care as well as uploading step count data from pedometers to receive feedback and motivational messages.

1.2.4. Combining Interaction, Monitoring and Feedback

There is a growing interest in technologies that may work particularly well with a younger population. For example, using a Smart phone as both a glucose monitor and insulin pump [6], cell phone voice and text message interventions [7], or a Personal Health Application may address many of the factors in optimal Type 2 diabetes management [8]. A promising mobile phone-based system includes an integrated suite of applications including blood glucose meter, a tailor-made step counter, software for recording food habits and providing feedback on how users performed in relation to their own personal goals [9].

2. Realist Review Approach

2.1. Brief Introduction to Realist Reviews

Traditional systematic review methods determine how many times an intervention has produced the expected change. They typically do not provide information on why the intervention worked or did not work when it was applied in different contexts, deployed by different stakeholders, or used for different purposes. In contrast, Realist Reviews ask how interventions bring about their effects and the limits of when and where they work [1-2].

A Realist Review focuses on explaining the relationship between the mechanism (M) by which an intervention works, the context (C) in which the intervention is applied, and the outcomes (O) which are produced (Figure 1). A review cycle has four stages [2, p.84-85]:

a. develop a *theory* around what would explain regularities in implementing the intervention (including M,C,O);
b. *hypothesize* what might work for who and in what circumstances;
c. *observe* what works and for who using multi-methods to collect data and analyses using M,C,O, which allows patterns to emerge;
d. specify *program generalizations* that identify what works for whom and in what circumstances.

The goal is to look for evidence of "empirical uniformities," i.e. regularities that occur in the field, and in doing so establish limits to the intervention as well as inform theory.

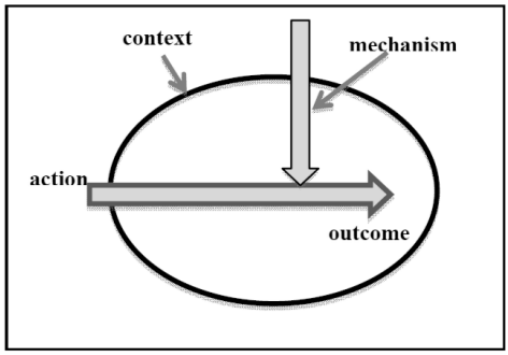

Figure 1: Generative Causation [2]

2.2. Realist Reviews Applied to e-Health Used for Type 2 Diabetes in Youth

The usefulness of a Realist Review is illustrated through examining examples of e-health technologies currently being used to support diabetes management and identifying regularities (Table 1). Two key aspects of managing Type 2 diabetes in youth are important in informing a theory for e-health intervention:

a. *mechanism* – like adults with Type 2 diabetes, they need longer-term lifestyle management strategies. In Type 2 diabetes accumulating health damage is not visible or seen as life threatening so behavior change may not be readily connected to outcome. It has apparently less urgency than Type 1 diabetes suggesting the intervention must be more widely accessible.
b. *context* – similar to youth with Type 1 diabetes, they need strong family and peer support. Adolescents need additional coping strategies as well as support from their families, the education team, and friends their own age to manage their diabetes [10]. Structural family factors (e.g. single parent families, supportive or non-supportive environments) are important contextual factors. Along with being a teenager, other influences include socio-economic status, language and minority populations [11] that are important to consider in establishing the boundaries of what works and where.

With respect to the intervention itself, youth may consider themselves savvy technology users, but this does not always extend to "e-health literacy" (knowledge and skills needed to interact with technology to address health information needs), which may be taken for granted [12].

Regardless of the context, mechanism or e-health technology, the intervention is expected to improve health outcomes. This is relatively easy to measure in diabetes care as the "gold standard" is maintaining an HbA_{1C} within normal limits. However, intermediary outcomes contributing to this goal such as monitoring blood glucose as well as managing dietary intake and exercise are more difficult to measure and sustain. Relating outcomes to behavior is in an additional challenge for youth with Type 2 diabetes who are not experiencing symptoms.

Table 1 – Realist Review and "CMO" Examples

Intervention	**Context**	**Mechanism**	**Outcomes**
Health coaching via telephone [13]	**C_1:** Urban adolescents at risk for Type 2 diabetes -Existing school-based curriculum	**M_1:** peer support	**O_1:** coping skills
12-month Diabetes TeleCare program - self-management education intervention [14]	**C_2:** 3 individual and 10 group sessions; underserved community	**M_1:** peer support	**O_1:** behavior change
Community-based cell-phone assisted diabetes self-management [15]	**C_3:** Chartered Health Family Clinic – low income; monetary incentives	**M_2:** access to education, provider support	**O_1:** behavior change (high drop-out rate: lack of use)

3. Conclusions

Many studies in diabetes management suggest e-health technologies can be effective. However, little or no information is provided on the limits of these technologies – when or where they work or do not work; and who they work or do not work for. These are important questions to answer in order to determine the "empirical uniformities" that can guide further theory development.

Youth who are overweight, pre-diabetic or diagnosed as Type 2 diabetics are at much higher risk of cardiovascular damages much earlier in their lives than adults likewise diagnosed. A strategy to manage this upcoming health challenge must draw on multiple theories and technologies to address lifestyle choices in different contexts: at school, out with friends and at home. In order to get the mechanisms right, youth should be involved in the design, testing and implementation of the interventions. A Realist Review approach can contribute to understanding the strengths and limits of e-health technologies, to develop theory and inform decisions for the future.

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Designing the Community Multi-user Health Kiosk

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Abstract. This paper discusses the design and development of a multi-user health kiosk intended for independent use by underserved populations. The modular integration of physiological sensors and psycho-social assessments provides an extensible, customizable platform for research. We present the development of the kiosk's feature set and user interaction mechanisms through iterative user testing, in addition to some technical challenges and solutions resulting from our design choices.

Keywords. kiosk, telehealth, user-centered design

Introduction

The Community Multi-user Health Kiosk (Figure 1) was designed to give people who are currently underserved by the healthcare system a way to monitor their health and communicate with their healthcare provider. The Quality of Life Technology Engineering Research Center focuses on the elderly, those with disabilities, and people of lower socio-economic status and supports the design and development of the health kiosk.

Rather than a fixed function device, the kiosk is a platform that can support a variety of psycho-social assessments and peripheral monitoring tools. It consists of a mobile desk that has a computer running the Windows-based kiosk software program, a printer, a movable touchscreen, and a drawer that contains any peripheral medical devices needed for the kiosk's assessments. In the first use case, the kiosk was intended for the common areas of senior high rise buildings. Potential sites have expanded to include primary care offices, pharmacies, public libraries, and other community gathering places.

In contrast to many commercially available telehealth monitors, the kiosk is designed to be multi-user, individualized, customizable, and extensible. Each user's self-monitoring health information is conveyed to their healthcare provider via multiple possible mechanisms. Both the assessments and the results display can be customized by clinicians to meet the specific needs of their patients, and an internal messaging feature offers secure communication between the two. In addition, the modular design makes it easy to switch hardware manufacturers/models and add or remove

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assessments. Because this design is substantially different from commercially available devices, this paper will describe the design and development of the multi-user kiosk.

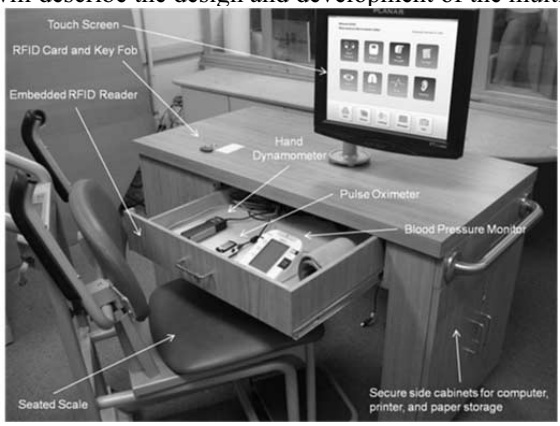

Figure 1. Health Kiosk

1. Features

1.1. Standard assessments

"Assessment" is a term used broadly for any value measurable with the kiosk and can include both physical as well as psycho-social measurements. In its current baseline configuration, the kiosk has peripheral device-based, self-report and manual entry assessments. The peripheral off-the-shelf devices include a pulse oximeter, blood pressure monitor, seated scale, and hand dynamometer. The devices communicate with the computer via USB or Bluetooth.

Self-report assessments are ones where a user answers questions. An example use case would be a clinician scheduled annual depression screening. The default surveys on the kiosk are the Geriatric Depression Scale [1] the Epworth Sleepiness Scale [2], the Pittsburgh Sleep Quality Index [3], the Medical Outcomes Study 36 Item Short Form Survey [4], the Morisky Medication-Taking Adherence Scale [5], and the Cost-Related Nonadherence to Medications Survey [6]. Our community-based usability testing has validated the reliability in translating these instruments to the kiosk.

To accommodate these various response formats, the kiosk supports a number of response options: multiple choice, sliding scales, date and/or time entry, and free text responses. The instrument engine also supports branches in the survey - that is, making questions dependent on previous answers. The kiosk can automatically score instruments with standard scoring metrics like summing. Automatic scoring of other instruments with non-generic scoring algorithms is possible with minor software modifications. Adding a new self-report assessment consists of formatting the content according to a straight-forward XML specification. No programming knowledge is necessary. In all cases, every user that sees, changes, or deletes an assessment result is logged by an audit trail to ensure accountability and security.

1.2. Customization

To increase user engagement, customization has been an ongoing theme in the kiosk development. In addition to minor personalization features, such as welcoming each user by name, clinicians can select assessments for individual patients and set patient-level guideline parameters for assessment results. For example, each assessment can be made available or unavailable globally (all kiosks), at selected kiosks, or for selected individual users. The kiosk prompts the user to complete the assessment at the clinician's specified interval. The kiosk can notify health care providers for alert values via multiple contact strategies including text message, email, or fax.

A user's view of their own results is one of the clearest examples of software tailored to the patient. Results are visible to the user in three ways –the current assessment results, a summary of all a session's results, or as a historical view encompassing the last 3, 6, 9, or 12 months. Both numerical and categorical results are color-coded for easy comprehension; desirable values are green and less desirable are yellow, orange, or red. In the default settings, the color-coding stems from population guidelines, but a clinician can customize this to emphasize a "personal best" for a patient (Figures 2 and 3).

Figure 2. Historical view of categorical result.

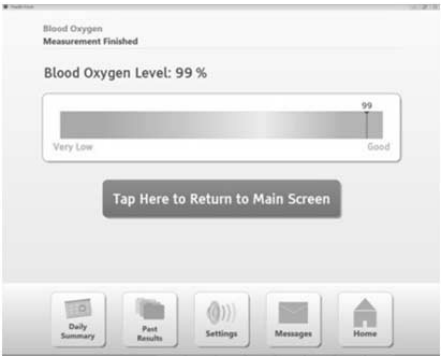

Figure 3. Immediate view of numerical result.

1.3. Extensibility

Designed as an expandable software platform, adding a new device-based assessment to the kiosk is often simple enough for an average programmer to do in less than a day. One recent extension is a trio of assessments based on the Microsoft Kinect sensor to conduct several common mobility tests.

2. Design and Development

From the beginning of the project, we defined our user base as broadly as possible to include older adults, clinicians, and health care providers. Our emphasis on user-centered design governed a number of initial decisions about the structure and content of the health kiosk. For instance, concerns about participant falls led to use of a seated scale rather than a traditional step-up model. This choice prompted the design of a unique push-through drawer mechanism so wheelchair users could access the kiosk

devices without moving the seated scale. Clinician concerns about blood-borne pathogens resulted in a design choice to have participants type in blood glucose values rather than perform testing on a kiosk-based glucometer. The target population for the kiosk also led to some user interaction challenges. Many of our older users were not familiar with computers or touchscreens (Figure 4). In early prototypes that labeled buttons with the verb "Press", we observed people pressing but not releasing. Most buttons are now labeled "Tap." Many common software metaphors had to be eliminated or made more explicit.

Figure 4. Revised welcome screen.

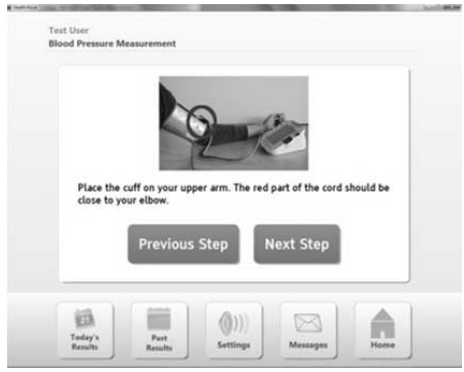

Figure 5. Revised blood pressure instruction.

Instructions for device-based assessments, in particular, underwent numerous revisions (Figure 5). CogTool [7], an application that produces a predictive user performance model based on screen design, was used to analyze our user interface design and supports our observation that a single step per screen is better for inexperienced computer/kiosk users and is not a major barrier for advanced users. Some assessments were switched to audio instructions where appropriate. When possible, we supplement the instructions with direct feedback. After watching some participants put the blood pressure cuff on upside down, we added a mercury tilt switch with an open source Arduino microcontroller. This enabled the kiosk to guide participants through placing the cuff correctly.

3. Technical Challenges

The benefits of using off-the-shelf devices include easy replacement of hardware; low cost; and the potential usability of consumer-oriented products. The disadvantages are a lack of standardization and, potentially, poor reliability. To mitigate these issues, our general strategy was intensive upfront development of a modular and fault-tolerant architecture, component testing, and user-driven hardware and software modifications to minimize error. Table 1 lists some of the complications we encountered in the development process, their effects, and solutions.

For example, hardware defects were an unanticipated problem, and especially difficult when the defect was subtle. Our first pulse oximeter occasionally displayed a dramatically different result on the device screen than appeared on the kiosk, with disastrous results for user confidence. After ruling out other potential sources of error,

we concluded that the hardware was at fault and changed the brand of oximeter, which was quick and painless due to the modular nature of the kiosk software.

Issue	Effect	Solution
No device drivers	No access to device's data	Write custom driver, using provided APIs or packet sniffing Use scripting language to run 3rd party software in background
Hardware design flaws	Confusing or unusable devices lead to user frustration and errors	Hardware customization or substitution
Hardware defects	Incorrect results, distrust from users	Component testing and verification, substitution
No hardware standardization	No generic way to collect data or know in advance what data will look like	Code to a generic interface, customize implementations as needed; minimize hard-coding
Poor architecture leads to cascading failures	Lack of fault-tolerance in 3rd party hardware/software compounds errors	Anticipate noise, errors, and the unexpected and handle gracefully

Table 1. Issues encountered during design and their resolution

4. Discussion

Lab and community-based user testing with over 40 individuals has led to a system that, while continuing to evolve, is very usable for people in our target demographic. We have also demonstrated that the initial investment in a modular, robust architecture pays ample dividends when requirements change or the inevitable hardware problems occur. Building upon this work, we are conducting pilot work for kiosk-based health interventions and working with health organizations on kiosk data integration.

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Public Reporting of Hospital Infection Rates: Ranking the States on Credibility and User Friendliness

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Abstract. Health-care associated infections ("HAIs") kill about 100,000 people annually; most are preventable, but many hospitals have not aggressively addressed the problem. In response, twenty-five states and the U.S. Department of Health and Human Services require public reporting of hospital infection rates for at least some types of infections, and other states and private entities are implementing such reporting. The websites and related reports vary widely in ease of access, ease of use, usefulness of information, timeliness of updates, and credibility. We report on work in progress, in which we assess the quality and suitability of different state websites and reports for different target audiences (ordinary consumers; physicians, and infection control professionals) and the extent to which they meet best practices for online communication, including Stanford's "Fogg" Guidelines for Web Credibility and user-friendliness metrics developed by other researchers. We find wide variation in quality, and substantial correlation between measures of website credibility and user-friendliness. We identify ways to improve usability, usefulness, and tailoring for information to different target audiences. Our analysis suggests that the "one website (and report format) fits all users" model may not work well in delivering complex, technical information to users with widely varying needs and sophistication.

Keywords. health-care quality; health-care public reporting; health-care associated infections; performance measurement; website usability

Introduction

Health-care associated infections (HAIs) are a huge public health problem. Of roughly 39 million annual hospital admissions in the U.S., about 1.7 million (4.5%) result in HAIs and 100,000 HAIs result in death [1]. The direct healthcare costs of HAIs are estimated at $45 billion, and total annual costs likely exceed $100 billion [2, 3]. In response, twenty-five states and the federal government currently require hospitals to publicly report infection rates for at least some types of infections; other states have

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adopted laws that will require reporting in the near future; and private entities have created their own public reports. The effectiveness of these reporting requirements in informing consumer choice and reducing infections is unknown [4]. Moreover, and the focus of this study, "we do not just want to know if public reporting works (efficacy); we want to know who it works for and in what situations (effectiveness)" [5].

HAI public reporting presents an ideal environment in which to examine the effectiveness of public delivery of health care information. Each state maintains a website; most also provide downloadable reports, but each uses its own unique reporting format. There is wide variation in websites, and reports, across any metric one might consider: how easy the websites and reports are to find, which infections are reported; how infections or infection rates are measured; what information about them is reported; time periods covered; level of technical difficulty, readability levels, and so on.

We report here on work in progress in which we evaluate how effective each state's website and public reports are at communicating information. We focus on website credibility, user-friendliness, and usefulness of information for three target audiences with different needs and ability to understand technical information, including typical healthcare consumers; physicians (and other more sophisticated users); and infection control professionals.

1. Methodology

To assess website credibility we use ten criteria based on psychological research on persuasive technologies [6]. The specific factors are as follows:

- Is it easy to verify the accuracy of specific statements, by clicking through to supporting information/data?
- Demonstration that a "real" organization is responsible?
- Expertise in the area is highlighted?
- Evidence of trustworthiness?
- Easy to contact those responsible?
- Is site professionally laid out?
- Easy to use and useful?
- Updated recently?
- Limited promotional content?
- Any [reasonably apparent] mistakes?

Five of these criteria are yes/no questions; we give each 3 points for a "yes." Five call for more qualitative assessments; we create a detailed 1-5 scale for each, specifying the attributes needed for each score. We sum the scores, to develop an overall "Fogg score" (5~35). The weights are arbitrary but our results are not sensitive to the weighting.

To assess "user-friendliness", we adapt measures suggested in research by other scholars of public reporting of health care performance [7-9]. We identified five factors (and are in the process of developing a more refined list of factors):

- Provides good introduction to HAIs
- Helps consumers to integrate information from multiple indicators
- Uses both numbers and graphs/symbols to convey numeric or statistical

information
- Straightforward to find results for a particular hospital
- Website and report length and complexity is appropriate for consumer audience

As with the Fogg guidelines, we developed a detailed description of the attributes needed to receive each score. Each factor was scored on a 1-5 scale, for an overall 5~25 scale. We applied these factors separately to the website and to the formal reports on state's websites. In this paper, we focus on the formal reports.

Finally, for "usefulness," we developed and then assessed a number of factors, including:

- Was the state website easy to find?
- Within the website, was pertinent information easy to find?
- Are the explanations clear?
- Was it easy to find information on a particular hospital?
- Types of infections covered
- Type of rate reported ("raw" [crude], risk-adjusted, risk-stratified, or a combination)
- Were number of infections reported?
- Is statistical significance reported?
- Is historical data available?
- If yes, is the format consistent over time?
- Can users compare hospitals online, how many, and using what selection criteria?
- Are similar hospitals compared to each other?
- Overall, was the website understandable and useful?

We assess usefulness for three target audiences. One important audience is average consumers. We assumed that these users have roughly a high school reading level and limited understanding of statistics and medical terminology. A second audience is physicians, who can counsel patients, make decisions on which hospital to admit their patients to, and push hospitals for change. This audience is likely to have better than a college graduate reading skills, moderate understanding of statistics and healthcare terminology, but limited knowledge about particular HAIs. A third audience is infection control professionals, who can use the reports to benchmark their hospital against peers. These persons are likely to have a college graduate reading level; be familiar with measurement and coding issues for HAIs, but have limited understanding of statistical analyses. At many hospitals, infection control is assigned to registered nurses. Only at major hospitals, often with academic affiliations, is the head of infection control likely to be an epidemiologist with advanced statistical training. Thus, we judged that a typical infection control professional would know more about HAIs but less about statistics than a typical physician or other sophisticated user. Manifestly, we must exercise judgment in deciding what criteria to measure, how to measure them, and what target audiences to assume; we do so based on the expertise developed in our previous research on these subjects. [10-11]

Thus, each state is scored on five metrics: website credibility, user friendliness of website, user friendliness of public reports; usefulness of website for each target audience, and usefulness of public reports for each target audience. Initial scoring was by a law student at Northwestern. We are in the process of assessing inter-rater

reliability. A spreadsheet including all criteria and results will be publicly posted on Professor Black's website at Northwestern University.

2. Results

We present here partial results from our analysis, focusing on Fogg website credibility scores and user friendliness scores for the public reports from the perspective of an ordinary consumer. Scores are based on the reports and websites as they appeared in August, 2012. We also plan to assess changes in websites and reports over time. Higher scores reflect better performance on the specified measures. Fogg scores have a theoretical range from 5 to 40; in practice, they ranged from 24 (Vermont) to 39 (California). Public report usability scores have a theoretical range from 5 to 25; in practice, they ranged from 9 (Rhode Island and Washington) to 25 (Massachusetts). The close-to-maximum scores on each measure for some states reflect not perfection, but our effort to define criteria that made a top score reasonably achievable.

Figure 1 indicates the scores on both measures for each state that currently has public reporting of HAIs. Figure 1 also includes the Canadian province of Ontario. We plan to expand our analysis to include the Hospital Compare website run by the Department of Health and Human Services, and the websites operated by the Leapfrog Group and Consumers Union.

It also provides a correlation line between the two measures. The Pearson correlation coefficient is strongly positive at 0.58 ($t = 3.46$). There is thus a strong tendency for states to do either well or poorly on both measures.

One might expect larger states, which usually have greater resources, to do better, but this was not universally true. For example, New Hampshire did well on both measures, while Florida did poorly on both measures.

Finally, rankings may change dramatically if states redesign their website. For example, Washington's current Fogg Score is 27 but an earlier version of Washington's website had a Fogg score of 36. The mean (median) Fogg score was 31.2 (30.5) for our entire sample of 25 states and Ontario, so the redesign dropped Washington's score from substantially above-average to below-average.

3. Discussion

Public reporting of HAIs is widespread, but little attention has been paid to how to design websites and public reports to reach the multiple target audiences. We report on work in progress in which we systematically quantify the effectiveness of existing websites and public reports, across a variety of general metrics (credibility, user friendliness, and usefulness) for three different target audiences. For ordinary consumers, we find substantial correlation between website credibility and user-friendliness of each state's public reports.

One issue that is missing from current discussions of credibility and user friendliness, but substantially complicates any analysis of these issues, is the variety of potential target audiences. HAI data can be quite technical, and assessing its value requires an understanding of statistics and confidence intervals. To be readable and understandable for a typical consumer, some website and reports have been deliberately "dumbed down" to a level that is likely to prove inappropriate and frustrating for more

sophisticated users.

Another issue that is missing from current discussions is "usefulness." Assessing the usefulness of HAI information requires in-depth knowledge of the goals of reporting and the information being reported. For example, a time-series of data is usually more reliable than a snapshot of a short time period. Reports that tell users only whether a hospital is above, average, average, or below average (with 95% or more graded as average) are easy to understand, but not very useful. Some states provide more granular information, but most do not. A comparison of the CLABSI (central line-associated bloodstream infection) rates at a small community hospital to the rate at major tertiary hospitals may mislead, rather than inform. And so on.

Finally, many websites and reports seem to focus on a single target audience, even though more tailored information would be useful. Serving multiple audiences through a single website and report format is challenging. In the future, we will analyze the extent to which states have recognized and addressed this problem.

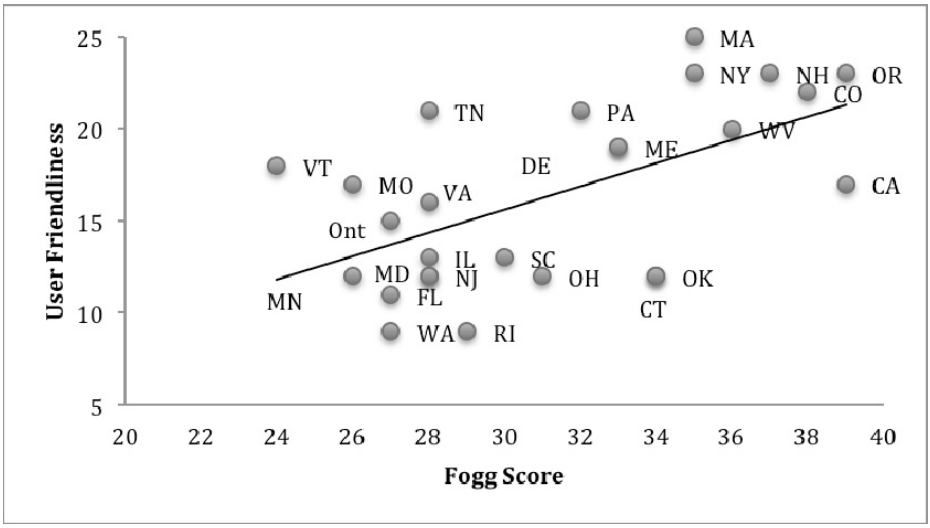

Figure 1. Fogg Website Credibility Score vs. User- Friendliness Score for Public Reports

Fogg website credibility scores and HAI report user friendliness (for ordinary consumers) scores for 25 states plus Ontario with public HAI reporting (as of August 2012). See text for scoring method.

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Methodological Approaches to Comparing Information about Bicycle Accidents Internationally: A Case Study Involving Canada and Germany

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Abstract. The use of bicycles as a mean of healthy and eco-friendly transportation is currently actively promoted in many industrialized countries. However, the number of severe bicycle accidents rose significantly in Germany and Canada in 2011. In order to identify risk factors for bicycle accidents and possible means of prevention, a study was initiated that analyses bicycle accidents from selected regions in both countries. Due to different healthcare systems and regulations, the data must be selected in different ways in each country before it can be analyzed. Data is collected by means of questionnaires in Germany and using hybrid electronic-paper records in Canada. Using this method, all relevant data can be collected in both countries.

Keywords. Bicycle Accidents, Data Collection, Trauma Registry

Introduction

Cycling is a healthy and eco-friendly way of transportation. The use of bicycles is currently actively promoted in many industrialized countries. However, cyclists belong to the group of the so-called "vulnerable road users". According to the German FederalStatistical Office (Destatis), 65,573 bicycle accidents occurred in 2010, and 381 cyclists died in these accidents in Germany. After years of declining accident numbers, the number of bicycle accidents rose significantly in 2011, when 76,351 cyclists were injured and 399 died [1]. Fatality rates of cyclists in British Columbia also rose from 9 in 2009 to 11 in 2011 (mountain bike accidents were excluded) [2]. In the year of 2009-2010 (fiscal year), 4,324 people were hospitalized in Canada due to bicycle accidents. Compared with the other provinces, the largest number of bicycle crashes occurred in

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British Columbia (along with the Yukon Territories) (22.1 per 100,000 population, age-adjusted) [3]. A high rate of underreporting was revealed by a study in Münster, Germany. The accident rates were up to 3 times higher than the officially reported rates [4]. Head injuries were the main cause of hospitalization in Germany and Canada, and one of the leading causes of death among cyclists. To get a better overview of the real situation of bicycle accidents and related injury patterns, a prospective study funded by the German Federal Highway Research Institute was initiated in May 2012. In this paper, we will describe the methodology by which accident data from the two countries with different healthcare systems and transport regulations can be collected.

1. Vancouver Island and Germany – The Bicycle Accident Perspective

Vancouver Island covers an area of 31,285 km^2 (approximately 10% of the area of the Federal Republic of Germany), and has a population of 748,937. Almost half of those (367,572) reside in Victoria, the capital of British Columbia. Victoria has been named repeatedly by the Canada's Cycling Magazine "Pedal" as the "Bicycle Capital of Canada" as a result of its bicycle-friendly infrastructure and the many biking (hiking) trails available. Due to its geographical location, outdoor activities are very popular on the island. This is also reflected by a high number of bicycle accidents.

In Germany, the accident data are collected within the Trauma Network North-West (TNNW). The TNNW is a consortium of 37 trauma care hospitals in the regions of North Rhine-Westphalia/Southern Lower Saxony. The TNNW represents an area of approximately 14,000km^2 and a population of about 4 million comprised from the states of North Rhine-Westphalia, Lower Saxony, as well as part of the Netherlands, and is one of the largest trauma networks in Germany. In contrast to the more urban-centered trauma networks, such as that of Berlin, the TNNW also includes a large number of rural regions.

Assuming that the area of the TNNW is representative of the Federal Republic of Germany, approximately 3,000 bicycle accidents happen in this area per year. To include the issue of under-reporting (i.e. approximately only 2/3 of actual cases are reported), approximately 9,000 bicycle accidents involving personal injury occur in the area of the TNNW per year. Based on the results of the Münster bicycle study, 11.1% of all injured persons were hospitalized, which means that the expected number of hospitalized patients was around 1,000.

2. Collecting the data – A Tale of Two Worlds

2.1. Goals of the study

The Münster bicycle accident study led by Münster University Hospital has shown that, due to the high underreporting, the currently available statistics cannot provide reliable information about the actual situation of bicycle accidents. However, the Münster bicycle accident study was limited to the city of Münster, and is, therefore, not a representative sample for Germany.

In order to allow for a detailed analysis of bicycle accidents, the data of all patients requiring hospital medical care in the region of the TNNW and on Vancouver Island

due to bicycle accidents will be collected for a period of one year. The study aims to provide answers to the following questions:

- Where did the accident occur (city/country)?
- When did the accident occur?
- Are there any common accident attributes?
- Do these accident attributes vary regionally?
- What injury patterns occur in a bike accident?
- What are the economic consequences of bicycle accidents?
- Does the type of bike (especially pedelecs/eBikes) have an impact?
- How often were protective aids used (i.e., helmet, reflective vest, etc.)?
- Can intoxication have an effect on the injury rate?

The study must thus combine data concerning medical issues and data concerning issues related to the type and circumstances of the accident (Figure 1).

2.2. Data Collection in Germany

Currently, no standardized electronic data set exists for emergency departments. There is a great variety ways in which physician and nurses document the reason for admission, the health status and complaints of the patient, etc. in German hospitals. This ranges from free text on paper to highly standardized electronic forms, which, unfortunately, is often an exception to the rule. The police collect data on accidents and hardly any detailed data on type of accident can be found in patient records. Due to privacy and other legal issues, these databases cannot be linked. The nationwide German Trauma Registry includes only the severely (life-threatening) injured patients and does not contain detailed data on the type of the accident. Currently, no standardized emergency dataset or electronic health record exists.

Thus data collection in Germany is heavily dependent on questionnaires. Analogous to the established methodology of the Münster bicycle accident study, accident data are collected by patient questionnaires and hospital chart reviews. Questionnaires are distributed to the patients in the clinics of the TNNW. In addition, the patient data can be collected on the spot, and can later be entered by a student assistant (SA) into an anonymous database. 23 hospitals in all regions of the TNNW have declared their commitment to take part in the study.

A FileMaker Advance Pro 12 ® database is used to collect the data. Each SA runs a stand-alone application which can export the data to the main database. These stand-alone applications are available in English and German.

The data will be entered into an anonymous database. Each record will be identified by accident time, patient age, accident site, and hospital name. In cases where patients will be relocated to another hospital within the TNNW, the records will have to be updated accordingly. This method of collecting data in Germany has been approved by the Ethics Committees of the University of Münster and Munich.

2.3. Data Collection in Canada

Due to the low density of population on Vancouver Island, injured cyclists can visit not only hospitals, but also clinics throughout the island. As a result, using questionnaires for data collection on Vancouver Island would not be feasible.

As compared to Germany, a standardized electronic ambulance record and dataset exists in British Columbia, in which the circumstances of the accident (e.g. protective gear, weather etc.) are also documented. In addition, every trauma patient admitted to a hospital is entered into the BC Trauma Registry, which also includes data on accident type and pre-clinical emergency care. In addition to this, the Vancouver Island Health Authority (VIHA) has an Island wide hybrid, electronic patient record system with both paper and electronic components. Patients who receive care following a bicycle accident at VIHA have nearly all of their data residing in databases that are part of the electronic patient record.

The School of Health Information Science of the University of Victoria will access the data provided by the electronic data sources. The data will need to be accessed and linked from database repositories located in different parts of the province. This requires application to local ethics bodies and meeting legislative and privacy requirements in the province of BC.

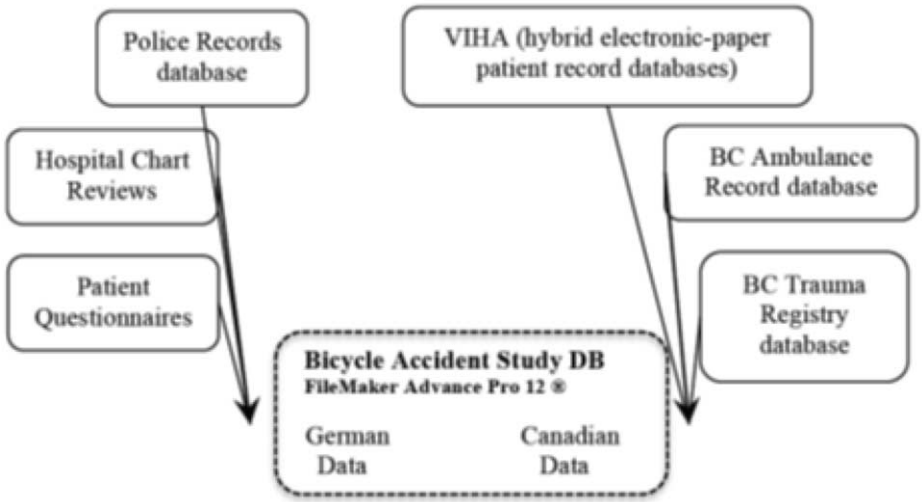

Figure 1. Graphical overview of data collection methods in Germany and Canada.

3. Discussion

In order to improve the safety of cycling and promote the use of bicycles, a deep and thorough understanding of bicycle accidents is crucial. Unfortunately, most bicycle accidents are not officially reported, so that using the official statistics does not show the complete picture.

Despite the large number of accidents and fatalities, research on bicycle accidents remains scarce. Most research focuses on severe or fatal accidents [5], while minor injuries are often not investigated.

Different healthcare systems, transportation systems and regulations, and different ways of documenting data are a challenge for collecting accident and medical data in different countries. However, by identifying the needed variables and the possible sources of information, ways can be found to collect the same data in different countries.

An electronic health record can be a valuable source for health service research. Using existing electronically available data avoids the need for paper-based questionnaires with their drawbacks (single-source approach). eHealth can thus also be useful to generate data for injury prevention.

The data collection of the described bicycle study will be finished at April 30th, 2013. Preliminary results will be presented at the end of 2012. The final results will be published in a BASt-report in German language and presented in Canada in the fall of 2013. We will be integrating our study of bicycle accidents in both countries with our prior work in simulation modeling and other studies. [6].

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The Development of a Standardized Software Platform to Support Provincial Population-Based Cancer Outcomes Units for Multiple Tumour Sites: OaSIS - Outcomes and Surveillance Integration System

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Abstract. Understanding the impact of treatment policies on patient outcomes is essential in improving all aspects of patient care. The BC Cancer Agency is a provincial program that provides cancer care on a population basis for 4.5 million residents. The Lung and Head & Neck Tumour Groups planned to create a generic yet comprehensive software infrastructure that could be used by all Tumour Groups: the Outcomes and Surveillance Integration System (OaSIS). The primary goal was the development of an integrated database that will amalgamate existing provincial data warehouses of varying datasets and provide the infrastructure to support additional routes of data entry, including clinicians from multiple-disciplines, quality of life and survivorship data from patients, and three dimensional dosimetric information archived from the radiotherapy planning and delivery systems. The primary goal is to be able to capture any data point related to patient characteristics, disease factors, treatment details and survivorship, from the point of diagnosis onwards. Through existing and novel data-mining techniques, OaSIS will support unique population based research activities by promoting collaborative interactions between the research centre, clinical activities at the cancer treatment centres and other institutions. This will also facilitate initiatives to improve patient outcomes, decision support in achieving operational efficiencies and an environment that supports knowledge generation.

Keywords. Clinical research informatics, population based outcomes research, cancer therapies, clinical decision support, data integration, data mining.

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Introduction

Understanding the impact of treatment policies on patient outcomes is essential in improving all aspects of patient care. Within the British Columbia Cancer Agency (BCCA), the development of several Outcomes Units (ie. Breast, Ovarian Units) have influenced treatment protocols and patient outcomes[1, 2]. Although many Tumour Groups are eager to develop their own databases, the associated expertise and expenses are prohibitive. Rather than develop databases for each tumour group, the authors planned to create a generic yet comprehensive software infrastructure that could be used by all groups: the Outcomes and Surveillance Integrated System (OaSIS).

The BCCA provides province-wide population based cancer control strategies for the residents of British Columbia and the Yukon. Diagnostic services, consultations, chemotherapy, radiation therapy and supportive care are delivered through five regional cancer centres and over forty community clinics. All treatments in BC are delivered by standardized protocols established by Provincial Tumour Groups; clinical cases are reveiwed at multidisciplinary Tumour Boards that are video-linked to all cancer centres and participating community hospitals. The BCCA has been very uniquely successful in the accumulation and electronic storage of disparate population based health information ie. the provincial cancer registry. The Pharmacy Program maintains a provincial data mart that tracks every chemotherapy course dispensed in BC; the radiotherapy planning and delivery system is on a central server for all five cancer centres - every radiotherapy course in BC is archived in one database. Until now, these data warehouses have not been linked to each other or to clinical endpoints.

1. Limitations of Current Clinical Research Databases

Although some BCCA Outcomes Units have been very successful, most use software programs with limited functionality (ie. Microsoft Excel, Access). Frequently, data is collected on paper or are extracted from the chart retrospectively, then manually entered. This process is labor intensive, expensive and error-prone; ideally, data should be entered once, and used multiple times. These programs often cannot support multiple users across many sites, multiple modules/disciplines, customized role-based security access, clinician/patient data entry, or direct data linkages.

2. OaSIS – Required Functions

In order to support large-scale, multi-disciplinary outcomes research on a provincial basis, the OaSIS authors leveraged modern information technologies to develop a customized integration system. The primary goal is to be able to capture data related to patient characteristics, disease/treatment details and side effects. Data will be directly imported from existing data warehouses wherever possible. These data points will be augmented by additional fields which will be both patient and clinician generated. The ability to support simultaneous users in multiple centres with role-based security permissions requires a robust, customizable and scalable solution; OaSIS is built on the Microsoft Internet Information Services platform using SQL 2008 Server (Enterprise Edition), Visual Studio and .Net Client Server Framework.

Because data entry is a challenging and expensive barrier for any outcomes project, there will be three processes to accommodate data entry:

2.1. Data Entry By Health Record Administrators

This process will support the use of paper forms (ie. Staging and Follow-up). Document distribution and data entry will be facilitated by the Data Quality & Registry department. This is the traditional workflow used by most Outcomes Units currently, and requires ongoing operational costs.

2.2. Direct Clinician/Patient Entry

Clinicians (Oral Oncology, Pathology and Oncology Nutrition) and patients (side effects) will be able to enter data directly into OaSIS. This will omit the use of paper forms, thereby reducing costs and errors associated with distribution and entry. It is well recognized that patient generated quality of life data is more accurate and less prone to bias [3, 4].

2.3. Direct Data Linkages

The OaSIS system will support direct data linkages to existing data warehouses; this provides the most efficient and accurate method for data collection. The system is currently connected to the Cancer Agency Information System (CAIS, clinical information), provincial cancer registry, and the provincial chemotherapy warehouse. Additional linkages are in progress ie. direct access to dosimetric radiotherapy data.

3. OaSIS Implementation Road Map

The OaSIS road map includes four phases.

3.1. Phase One: Clinical Integration

In September 2008, the Lung and Head & Neck Tumour Groups invited multidisciplinary leaders to develop their own modules ie. discipline-specific data elements. Data dictionaries are mandatory for each module, and each data element is limited to discrete variables. These multidisciplinary modules include:

- Patient Demographics (including Tumour Stage, Risk Factors)
- Follow-Up (Clinical Outcomes)
- Pathology (Histological Subtyping, Molecular Markers)
- Chemotherapy
- Radiotherapy (non-dosimetric datasets)
- Oral Oncology
- Oncology Nutrition
- Patient and Family Counselling (PSCAN Psychological Screening)
- Quality of Life Tools (Patient and Physician Generated Assessments)

Each module is a combination of imported data and additional data collected by clinicians. The Patient Demographics module imports information from the registry (ie.

tumour site, histology) and CAIS (ie. BCCA ID). Additional factors are recorded on paper (ie. tumour stage, smoking history, performance status) and entered later.

The Pathology and Nutrition modules primarily consist of clinician generated data. Pathologists enter molecular markers, and histological sub-typing at the time of central review, whereas nutritionists record weight, eating related side effects and feeding tube complications in "real time" at the time of the patient encounter by the clinician.

The Chemotherapy module is unique since all of the data is imported from the pharmacy system; this includes every chemotherapeutic drug that was ordered and dispensed by the BCCA, including dose, and how, when and where it was administered. Over 99% of all chemotherapeutic agents dispensed in BC is captured in this system. Additional functionality includes filters (ie. dates, drug names, number of cycles and days per cycle) used to automatically generate chemotherapy "courses".

After an initial testing phase, prospective data entry was initiated in May, 2011. As of October, 2012, OaSIS is supporting 12 unique research projects and includes:

- Patient Demographics: 7,374 records
- Follow-Up: 1,934 events (loco-regional and distant recurrence)
- Chemotherapy: 2,538 courses
- Oncology Nutrition: 189 assessments
- PSCAN Psychological Screening: 10,245 assessments

The Pathology and Oral Oncology Modules will launch in 2013.

3.2. Phase Two: Radiotherapy Dosimetric Repository

The Radiotherapy (RT) Module introduced in Phase One extracts basic and generic RT data from the Cancer Agency Information System (CAIS). These fields include RT start and finish dates, total radiation dose, treatment technique, and treatment region. Although these continue to serve as useful end points, they do not provide any spatial information specific to a particular treatment course. To fully understand the effects of radiotherapy dose on irradiated organs and target structures, investigators require access to the full three-dimensional dose matrix ie. how much dose was delivered to a particular part of a structure; additionally, the detailed coordinates of relevant structures also need to be archived with their respective radiographic image sets (CT, MRI, and/or PET/CT). For example, is radiation dose to a certain part of the tongue result in worse dysgeusia than another part of the tongue? The second Phase will create a three-dimensional dosimetric repository, or a "dose bank", linked to clinical outcomes.

Although investigators have proposed the concept of a dosimetric library, they are typically not linked to comprehensive population based clinical outcomes. Our ability to correlate and analyze clinical endpoints, on a large scale, with three-dimensional dosimetric data sets will provide investigators with unprecedented research potential. This platform will allow investigators to answer important questions related to radiation response and normal tissue durability. Initial work at the BCCA on a much smaller scale (<100 patients) regarding salivary function and partial volume dosimetry have already made a clinical impact[5].

Software development was initiated in September, 2011, in conjunction with the Faculty of Medical Physics, UBC. This included initial architectural design and review of functional requirements ie. prior to any dosimetric analysis of a structure, the module must be able to identify it correctly. Identification will be based on parsing the name, and double checking its geographic location within the body. For example, if a

structure is labelled “L paro”, the module will correctly identify it as the “left parotid gland” by parsing the name, and ensuring the structure exists in the correct geographic location in the body. Automatic dose calculations within sub-segments of a structure is now being developed. This work will result in improved understanding of the effect of radiation dose to certain parts of normal structures, which will lead to fewer side effects in irradiated patients.

3.3. Phase Three: Research Module, Patient Portal

Due to the uniquely disparate nature of the data elements in OaSIS, the Research Module will include data mining tools using a combination of existing and custom developed querying applications. This work will be done in conjunction with the Faculty of Computer Science, UBC.

A multidisciplinary team will develop patient generated surveys which will capture information during a patient’s cancer journey via a web-based Patient Portal. As cancer therapies improve, quality of life becomes an increasingly significant endpoint.

3.4. Phase Four: Research Integration and Additional Tumour Sites

The research integration phase will see the addition of other tumour groups who wish to participate ie. the Testes Module will be added in early 2013. As well, linkages will be created to other data repositories, including the BCCA Tumour Tissue Repository.

4. Summary

The OaSIS platform will provide a powerful and customizable, integrated multidisciplinary outcomes database for the BC Cancer Agency Tumour Groups. Unlike existing outcomes databases which capture uncomplicated data fields, the OaSIS system will leverage unique and unprecedented connectivity with existing provincial data warehouses, including the cancer registry, provincial chemotherapy and radiotherapy data repositories. The correlation of clinical outcomes and other patient and treatment related parameters in a central database will allow for unique analyses that will result in improvements in patient care, clinical decision support and treatment delivery.

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Neuroanatomical Basis for Recognition Primed Decision Making

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Abstract: Effective decision making under time constraints is often overlooked in medical decision making. . The recognition primed decision making (RPDM) model was developed by Gary Klein based on previous recognized situations to develop a satisfactory solution to the current problem. Bayes Theorem is the most popular decision making model in medicine but is limited by the need for adequate time to consider all probabilities. Unlike other decision making models, there is a potential neurobiological basis for RPDM. This model has significant implication for health informatics and medical education.

Keywords: decision making, neuroanatomy, medical education, health informatics

Introduction

Human decision making continues to be debated in psychology. In medicine, decision-making is not merely academic; it affects lives. Many models purport to explain how medical decision-making occurs. One of the largest revolutions in medicine in the late 1990s was the dissemination of evidence-based medicine, that formalized decisions based on the available literature. Other forms of decision-making were derided as less scientific.

The long-standing debate over the variety of medical decision-making models neglect one aspect; time limitations on arriving at the correct decision. Additionally, many decisions need to be made with incomplete information and concurrent with treatment. Zakay and Wooler [1] demonstrated that effective decision-making ability fell precipitously as time pressure increased. Even when decision-making skills were taught prior to the experiment, the ability to make correct decisions declined with available time.

These findings support the notion that teaching decision-making strategies are helpful when time permits option consideration. However, in fast-paced situations, formal decision-making procedures and instruction are essentially useless. This means that alternative models for decision-making under time-pressured situations need to be developed.

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Recognition Primed Decision Making

The recognition primed decision making (RPDM) model was developed from cognitive psychology in the mid-1980s by Klein et al. [2]. As a model, it has described decision-making for time sensitive situations, employed by fire-fighters, tank commanders, naval officers, and airline pilots [3]. However, there is a paucity of medical literature using this model. The only published work in medicine involved an emergency situation in an ophthalmology clinic [4] where the author described a successful resuscitation based on early recognition and anticipation of patient deterioration.

RPDM was originally developed using fire command officers [5]. In post-incident interviews, the researchers found that fire commanders followed a series of steps to make decisions based both on available information and prior experience. The investigators developed a model wherein the person presented with a situation made an initial assessment and decided whether it fit a familiar pattern [5]. If the situation was recognized, then the level of familiarity was graded by comparing it to previous cases and cues present at that time. The individual then considered whether the intended goal was feasible in the current circumstance, considered issues in the contemporary case that needed to be accounted for, and finally considered possible actions.

If the current situation was not recognized, RPDM was unlikely to be effective, further information was sought, and the situation reassessed in order to generate a recognizable pattern [5]. Failing this, the decision-maker had the option to choose other strategies to seek an answer. However, in the case where the situation was recognized and a reasonable match found from past experience, the decision-maker could mentally simulate the solution and try to anticipate problems that may occur. If this simulation suggested a satisfactory outcome, it was enacted. If the simulation suggested difficulties, then the situation required reassessment and plan modifications. All these steps occurred automatically with little conscious effort. [5].

Several features make RPDM distinctive from other decision-making strategies [5]. As a decision-maker develops more experience, only feasible options are considered, and long lists of random options - many of which will not work - are obviated. RPDM, then, renders faster, more efficient decisions. As well, decision-making is not intended to find the best possible solution, but to find the first satisfactory option for the current situation. Better options may present themselves subsequently, but they do not delay action. This “satisficing” means that the goal in the decision-making is to find the most reasonable, but not necessarily the best option, to accomplish the goal. As opposed to other decision-making models, no formal instruction in RPDM is required. The process is intuitive and built on experience. Finally, the use of mental simulation also allows decision-makers to put the task into context and allows for preliminary testing to ensure feasibility of the option.

Neuroanatomical Basis for Recognition Primed Decision Making

A recent hypothesis has suggested that the main function of the cerebral cortex is to act as a memory storage unit and recognition/prediction engine [6]. Consider the example of a conversation in a noisy room. The only way to follow the conversation is to be able to predict and fill in the unheard gaps. The memory of words and common sentences with an ability to predict the next phrase makes this possible.

At only 4 mm thick, the cerebral cortex is a new evolutionary invention found only in vertebrates. Mapping studies over the entire cortex have demonstrated different functional regions throughout the brain. However, the microscopic structure of each region is the same throughout the brain [7]. Thus, different regions are functionally distinct because of their connections, not because of their structure.

The cortex can be divided into six layers - layer VI is the deepest, I is the most superficial [6]. Inputs enter the cerebral cortex via VI and travel upwards for processing. The different layers are structured such that cells in one layer will receive multiple inputs from the cells below and send inputs to higher levels and laterally through interneurons. Inputs arriving at the cortex will tend to stay within the same region as they progress up the layers. Thus the cortex can be considered being divided into columns. Sensory input sequences (vision, touch, sounds etc.) ascend up the cortex through each cortical layer and interact with descending signals from higher memory levels [6]. These higher memory level signals are representations of complex, often multi-sensory sources used to predict incoming sensory input.

The cortex as a prediction engine has been modelled successfully by Rao and Ballard [8] using an artificial retina attached to electronic simulation of a neuronal column. In the model, a prediction of expected input based on previous input flows downward from higher level neurons and interfaces with an input signal. The difference between prediction and input signal generates an error signal which travels back up the simulated cortical column through successive layers of interaction with the prediction algorithm to modify the expected input. In this simple model, the simulator successfully anticipated and predicted incoming inputs. Interlayer feedback interacted with the incoming signal and was an efficient way to encode the visual image.

If the cortex can be considered a prediction/error recognition engine, then RPDM has a neuroanatomical foundation. When faced with a situation, sensory stimulation enters the cortex via level VI. These inputs ascend individual columns towards level I. When the signal is recognized, associative interneurons connect to related columns. These columns are now anticipating an incoming signal. When it arrives, the column performs sequential error checking of the signal. If the incoming signal matches then it is recognized and the process repeats with other associative interneurons. Consider the example of hearing a series of odd numbers from one to nine. By the time the number five is heard, the sequence is clear and interneurons have sent signals to the columns involved in processing the numbers seven and nine. When seven is heard, there is a no error signal in that column and it is considered to be recognized. If the next number is ten, an error signal is generated which requires processing in higher cortical layers and the sequence is now not recognized.

Applications in Health Informatics

RPDM is relevant to health informatics, most obviously in education. Currently, undergraduate and postgraduate medical and nursing education teach decision-making using evidence-based medicine or Bayes theorem. There is no focus on rapid decision making strategies. However, the challenge with RPDM is that it cannot be formally taught. This method requires experience. This means that educators must recognize the value of clinical experience and ensure sufficient exposure to permit expertise development. Educators also need to ensure learners understand the potential for

misuse of this decision-making model and associated potential cognitive errors as has been pointed out by Kahneman [9].

RPDM also allows us to understand the phenomenon of the experienced nurse calling for help before the crisis occurs. As a patient deteriorates, a series of stimuli are generated. These inputs are processed in the lower cortical layers and recognised. The associative interneurons then to connect to alarm centres that tell the nurse that there is something wrong and to call for help. Often the nurse will be unable to explain the reason for the recognition because it occurred in the lower layers and did not generate error signals that required higher level processing. This re-enforces the importance of experience and exposure in education. Reading a text about a patient deterioration will not generate the same recognition pathways as experiencing it.

Conclusion

In this paper, recognition primed decision making as a model for medical decision making has been described. Originally studied in non-medical situations, it represents an important addition to understanding how experienced clinicians decide. Unlike other decision making models, there appears to be a neuroanatomical mechanism for RPDM. This is based on the hypothesis that the cerebral cortex functions as a memory storage and recognition/anticipation engine. The implications for education and health informatics are significant.

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Use of Knowledge Discovery Techniques to Understand Nurse Practitioner Practice Patterns and Their Integration into a Healthcare System

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Abstract. The objective of this study is to assess the feasibility of applying knowledge discovery techniques to identifying nurse practitioner practice patterns and enacted scope of practice. For the research, we plan to use data extracted from a Ministry of Health database. The data items are focused around: nurse practitioner demographics, health authorities, and encounter types. This analysis produces patterns that indicate relationships between the demographics, scope of practice and practice settings of nurse practitioners working in British Columbia.

Keywords. Knowledge Discovery, Data Mining, Nurse Practitioner, Practice Patterns, Nurse Practitioner Integration

Introduction

Since 2005, when legislation enabling the nurse practitioner (NP) role was enacted in British Columbia (BC), integrating the role into clinical practice settings has been a priority. To date, $62.6 million has been invested to support and resource the integration of NPs, however, no evaluation of their impact on the BC health system has been conducted. At this time, it is imperative that we: a) begin to determine the changes that occur for patients and the implications to the health care system when NPs become part of the care process, b) assess the impact of adding an NP to the functioning of collaborative health care teams, and c) continue to monitor the practice settings and scope of practice of NPs working in BC. A mixed method, multi-year study is currently being undertaken to evaluate the integration of NPs into the BC healthcare system, with the intent to establish an evaluation framework. The overall study is designed to address the following broad questions: (1) What are the practice settings and the scope of practice of NPs working in BC? (2) What changes result for patients and, what are the implications for the health care system when NPs become part of the care process? (3) What is the impact of adding an NP on the functioning of collaborative health care teams?

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In this paper we report on our planned use of knowledge discovery techniques to analyze NP data from a Ministry of Health (MoH) database. This work will lead to a better understanding of NP practice patterns and the integration of NPs into the health care system in BC and will be used to answer the questions outlined above.

1. Review of Relevant Literature

Although the NP role is new to BC, it has existed in other Canadian provinces and the United States for more than 40 years. The role has been studied more than any other role in health care [1]. The evidence accumulated over these years has consistently demonstrated that NPs provide safe, effective care [2]. Researchers consistently find that patients are satisfied with the care received from NPs, trust NPs [3], feel that NPs take their problems seriously and discuss their concerns, have expert communication skills and are approachable [4].

Sidani, et al. [5] found that, when other variables were controlled, patients cared for by an NP in acute care were satisfied with their care, and also had higher physical and social functioning than those cared for by other providers. Others compared NPs to physicians and found that NPs had longer consultation times and patients received more information and counseling [6]. In addition, NPs placed more emphasis on health promotion and self care management of chronic and acute conditions than did their physician colleagues [7]. Researchers have consistently found that NPs provide patient-centred care, spend time with patients, and emphasize health promotion and chronic disease self-care and, when compared to physicians, the physical outcomes of care are similar [6, 8]. Nonetheless, there is a need to expand our evaluative efforts to understand the value-added impact of NPs in the BC context. It is time to evaluate the consequences or improvements in the overall health and wellbeing of patients that might be attributed to such NP practice activities.

At the time the NP role was implemented in BC, the MoH developed encounter codes to be used by NPs to track their activities. Encounter codes are unique numbers, similar to ICD-10 codes, assigned to specific types of patient care services performed by NPs. NPs are expected to submit an encounter code to the MoH at the end of each patient encounter. Encounter code data are stored in Population Data BC databases.

2. The Knowledge Discovery Process (KDD)

Data mining is "an integral part of knowledge discovery in database (KDD), which is the overall process of converting raw data into useful information" [9]. In other words, it is the process of automatically discovering useful information in large data repositories (e.g. data warehouses). The KDD process consists of four major transformation phases. They include the: (1) problem definition phase, (2) data pre-processing phase, (3) pattern recognition phase and (4) pattern validation phase (see Figure 1) [10] .

In the **problem definition phase** we are attempting to answer the broad question: What are the practice settings and scope of practice of NPs working in BC?

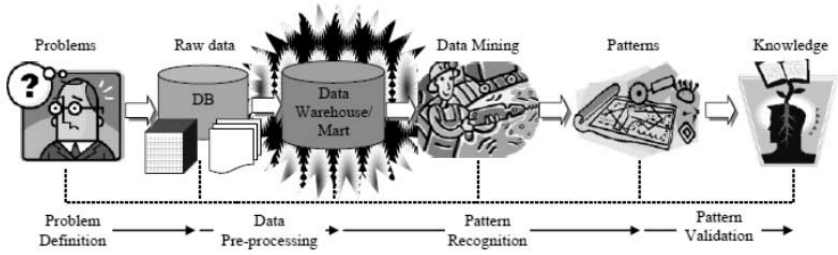

Figure 1: A generic process of knowledge discovery

In the **data pre-processing phase** raw data is transformed into an appropriate format for subsequent analysis. Furthermore, real-world data tend to be incomplete, noisy and inconsistent. Data cleaning routines attempt to fill in missing values, smooth out and correct inconsistencies in the data. In the **pattern recognition phase** one chooses the proper data mining algorithm(s) to discover the patterns. In this study, we propose the *Apriori* algorithm [11] to execute association analysis on the NP patient diagnosis, health authorities and encounter types. The algorithm employs an iterative approach known as level-wise search, where *k*-itemsets are used to explore *(k+1)*-itemsets. Then, association rules are generated, which is an implication of the form X→Y, where X and Y are disjoint subsets of all the possible data items. The strength of the association rule can be measured by its *support* and *confidence* as follows:

Let $I = \{i_1, i_1, \cdots, i_m\}$ be a set of items and $X, Y \subset I$, then the support of an association pattern is defined as equation (1).

$$support(X \rightarrow Y) = P(X \cap Y) \quad (1)$$

, and the confidence of the association pattern is defined as equation (2).

$$confidence(X \rightarrow Y) = \frac{support(X \cap Y)}{support(X)} \quad (2)$$

Support determines how often the data items in a rule are present together in a transaction in a given data set and is simply the count of transactions that contain X and Y. Support is used to determine if a rule is of interest since high support indicates that the rule occurs often in the data. Confidence is used to determine the reliability of the inference made by the rule and is an estimate of the conditional probability of Y given X. It says “If X is present in a transaction, how likely is it that Y is also present”. The generated rules suggest a strong co-occurrence relationship between the given data item subsets. Finally, in the **pattern validation phase** we undertake the process of assessing how well the mining models perform against real data. It is important that the mining team validates the discovered patterns before deploying them into a production environment. There are several approaches for validating the patterns [12]. For example,

- Use statistical validity to determine whether there are problems in the data or in the model - A number of statistical methods may be used to evaluate the data mining model quality or pattern accuracy, such as Cross Validation and Receiver Operating Characteristic (ROC) curves.
- Separate the data into training and testing sets to test the accuracy of patterns - It is common for the data mining algorithms to find patterns in the training set which are not present in the general data set. To deal with the so called "over-fitting" issue, the validation uses a test data set which the data mining algorithm was not

trained on. The learnt patterns are applied to the data set and the resulting output is compared to the desired output.

- Ask domain experts to review the results of the data mining to determine whether the discovered patterns have meaning in the targeted scenario – In this study, the research team composed of domain experts in the fields of NP education/research (ESG, RS) and nursing/health informatics (EB, MSK) will be involved in the validation process to interpret the accuracy of the patterns.

3. A Hypothetical Case Study

We are planning to use data extracted from the MoH database from BC. In this paper, since our human research ethics approval is pending, we use a test dataset with 25 records to test the feasibility of the proposed method. The data are encoded as numbers for data analysis (see Figure 2). In the dataset, there are 4 health authorities (named VIHA, VCH, FHA and NHA). Each health authority has 3 NPs whose age is between 20 and 59. The encounter types used by NPs are coded using unique number; for example, 36360 is a prenatal visit, 36365 is the insertion of an intrauterine device, 36413 is repair of a minor laceration and 36255 is newborn care.

Applying the KDD techniques to this simple dataset has yielded some interesting patterns/information as follows:

Pattern 1: Male NPs use more encounter types than female NPs (4-types/8-encounters (50%) vs. 3-types/17- encounters (18%)).

Pattern 2: Older NPs (age group 4) use more encounter types than other age group of NPs (age group 1~4: 1/2(50%), 4/7(57%), 3/12(25%) and 3/4(75%)).

Pattern 3: NPs in the Northern Health Authority (NHA) use more encounter types than those of other health authorities (health authority 1~4: 3/7(43%), 3/9(33%), 3/5(60%) and 3/4(75%)).

Pattern 4: Female NPs insert more intrauterine devices (36365) than male NPs. The confidence is 86%.

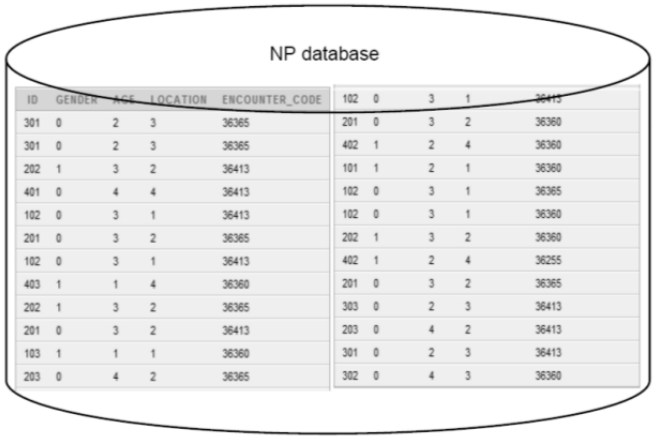

Figure 2; A hypothetical data set with 25 records

Pattern 4 suggests additional analysis is needed. This pattern shows that female NP's insert more intrauterine devices than male NPs. Further analysis will be undertaken to determine if there are other activities that female NP's undertake more often.

4. Conclusion

Integrating the NP role into clinical practice settings is new in BC. An evaluation of its impact on the BC health system is important. In this study we assessed the feasibility of applying knowledge discovery techniques to analyze NP data and to generate some interesting patterns/information. This work will lead to a better understanding of NP practice patterns and will be used to answer the study questions. This analysis data involved the use of test data (as we determined the feasibility of employing data mining techniques). Future work will involve extracting data from BC MoH databases. Patterns generated from our analyses in this study do not reveal the real nature of the associations between NP demographics, geographic locations and encounter types. Future work will use MOH NP data, and domain experts will be involved in the validation process to interpret the mined patterns. This should increase the value of our work in that we will be able to determine how generalizable the approach is.

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Decision Support for Evidence-Based Pharmacotherapy Detects Adherence Problems but Does Not Impact Medication Use

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Abstract. Although evidence-based pharmacotherapies are a principal component of patient care, 30-50% of patients do not take their medications as prescribed. We conducted a randomized trial of two clinical decision support (CDS) interventions in 2219 patients: patient adherence reports to providers (n=744), patient adherence reports to providers + email notices to care managers (n=736), and controls (739). At 18-month follow-up, there were no treatment-related differences in patient medication adherence (overall, by medication class, and by medical condition). There also were no treatment-related differences in patient clinical and economic outcomes. Thus, while this study's CDS information interventions were successfully delivered to providers and care managers, and were effective in identifying medication adherence deficits and in increasing care manager responses to medication adherences issues, these interventions were not able to alter patient medication behavior.

Keywords. Clinical decision support, Population health management, Managed care, Health information exchange, Health network, Medication adherence

Introduction

The Institute of Medicine's (IOM) Quality Chasm report highlighted 20 priority areas in which improvements in care delivery could significantly impact health quality.[1] Although evidence-based pharmacotherapies (EBP) are a principal component of patient care in many of these areas (asthma, diabetes, depression, heart failure, COPD, hypertension, ischemic heart disease and stroke), 30% to 50% of patients do not take their medications as prescribed.[2]

Medication adherence is a result of two processes: (1) clinicians prescribing EBP to their patients, and (2) patients taking their EBP medications as instructed by their clinicians.[3] However, effective approaches for assuring that these processes are completed have not been effectively integrated into routine clinical care. This lack of

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effective integration has led to calls for new care models that address appropriate medication use and make it a part of the patient care process. The present study sought to use clinical decision support (CDS) to increase EBP adherence within a vulnerable population and to assess the impact of this CDS technology on service use and medical costs.

1. Methods

1.1. Study Setting

The Northern Piedmont Community Care Network (NPCCN) provides care management services for Medicaid beneficiaries residing in five adjoining counties located in north central North Carolina.[4] This network's community-based care management team includes nurses, social workers, community health workers, nutritionists, and health educators. Services provided by the care management team include: home assessments, in-home health education and dietary instruction, assistance scheduling and keeping clinic appointments, and support for obtaining and taking medications. Team members routinely interact with other network partners including physicians, nurse practitioners, nurses, and pharmacists. Clinic partners for the present study included 7 administrative groups with 5 distinct patient appointment scheduling systems operating at 16 clinic sites.

NPCCN is supported by a regional health information exchange (HIE) and a care management documentation tool known as COACH, which facilitates communication between team members collaborating in the care of network patients.[5] This system receives patient demographic and eligibility data from the North Carolina Office of Rural Health and Community Care, and clinical, scheduling and billing data from partner sites. These data include encounter and pharmacy claims data from the State Medicaid Office and billing data from 9 clinics and all 5 hospitals in the network's service region. Data collected by the system include: 1) administrative data (demographics and identifiers, services used, provider associations and audit trails); 2) care management data (care management encounters, health risk and environment assessment, socio-economic data, special needs and care management plans); 3) claims/billing data (encounters, problems/procedures, and medications); 4) scheduling data (pending and missed appointments); 5) clinical data (allergies, laboratory results, and disease-specific care plans) and 6) data on communications (messages and alerts, referrals and notices of new information). The network is supported by a CDS tool that uses Web service technology to receive patient data from a client application.[6] It then processes these data according to an application-independent, pre-programmed set of rules (e.g., clinical algorithms and guidelines), and returns patient-specific recommendations to the client application. These recommendations are then used to notify network personnel of key health events occurring within their patient populations. Examples of these events include hospital and emergency department admissions, missed outpatient appointments and the need for well-child visits.

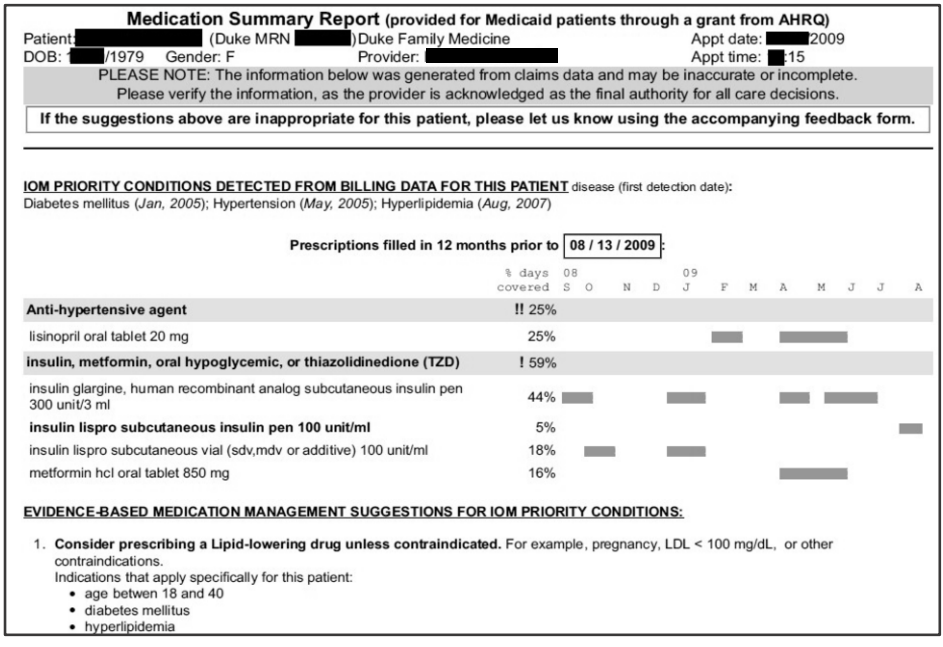
1.2. Study Population

Subjects in the present study included NPCCN Medicaid beneficiaries with at least one of six targeted IOM priority conditions who were continuously enrolled during the

intervention period. The six conditions included persistent asthma, diabetes, hypertension, congestive heart failure, ischemic heart disease and stroke. These IOM priority conditions were identified from claims data using CDS algorithms modeled after the Healthcare Effectiveness Data and Information Set (HEDIS) with medication claims criteria excluded to avoid bias inherent in the selection of subjects who were more adherent to their medications. Because medication information is required to identify subjects with persistent asthma, we conducted chart audits on all 1,064 subject who had an asthma diagnosis code in their claims data. These audits identified 617 cases of persistent asthma, 112 cases of intermittent asthma and 335 cases that were indeterminate.

1.3. Study Interventions

The two study interventions included CDS alerts delivered as reports to primary care clinics (Figure 1) and email notices sent to network care managers (Figure 2). The first intervention included reports with a summary list of filled prescription claims along with a numeric calculation of medication adherence and a graphical depiction of "days covered" over a 1-year period along with recommendations addressing possible deficiencies in medication therapy prescriptions relative to EBP guidelines. These medication summary reports were delivered to the point of care at the time of a patient's scheduled visit at their primary care clinic. The second intervention included email notices to care managers for patients with 1) low medication adherence; 2) no primary care clinic appointments in the previous 6 months; and 3) no appointments scheduled for the future. Table 1 summarizes the pharmacotherapeutic rules used in this study and their criteria for activation. Our methods for developing and testing these interventions have been previously described.[7, 8]



Medication Summary Report (provided for Medicaid patients through a grant from AHRQ)

Patient: [redacted] (Duke MRN [redacted]) Duke Family Medicine Appt date: [redacted]2009
DOB: [redacted]/1979 Gender: F Provider: [redacted] Appt time: [redacted]:15

PLEASE NOTE: The information below was generated from claims data and may be inaccurate or incomplete.
Please verify the information, as the provider is acknowledged as the final authority for all care decisions.

If the suggestions above are inappropriate for this patient, please let us know using the accompanying feedback form.

IOM PRIORITY CONDITIONS DETECTED FROM BILLING DATA FOR THIS PATIENT disease (first detection date):
Diabetes mellitus (*Jan, 2005*); Hypertension (*May, 2005*); Hyperlipidemia (*Aug, 2007*)

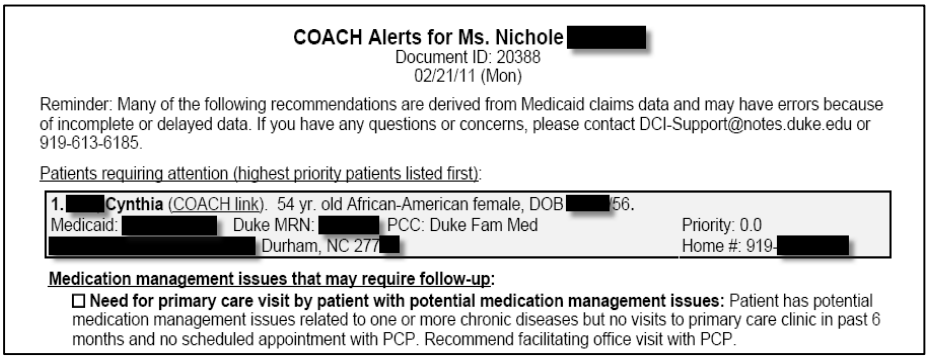
Prescriptions filled in 12 months prior to 08 / 13 / 2009 :

	% days covered	08 S	O	N	D	09 J	F	M	A	M	J	J	A
Anti-hypertensive agent	!! 25%												
lisinopril oral tablet 20 mg	25%												
insulin, metformin, oral hypoglycemic, or thiazolidinedione (TZD)	! 59%												
insulin glargine, human recombinant analog subcutaneous insulin pen 300 unit/3 ml	44%												
insulin lispro subcutaneous insulin pen 100 unit/ml	5%												
insulin lispro subcutaneous vial (sdv,mdv or additive) 100 unit/ml	18%												
metformin hcl oral tablet 850 mg	16%												

EVIDENCE-BASED MEDICATION MANAGEMENT SUGGESTIONS FOR IOM PRIORITY CONDITIONS:

1. **Consider prescribing a Lipid-lowering drug unless contraindicated.** For example, pregnancy, LDL < 100 mg/dL, or other contraindications.
   Indications that apply specifically for this patient:
   - age betwen 18 and 40
   - diabetes mellitus
   - hyperlipidemia

Figure 1. Sample Medication Summary Report


COACH Alerts for Ms. Nichole [redacted]
Document ID: 20388
02/21/11 (Mon)

Reminder: Many of the following recommendations are derived from Medicaid claims data and may have errors because of incomplete or delayed data. If you have any questions or concerns, please contact DCI-Support@notes.duke.edu or 919-613-6185.

Patients requiring attention (highest priority patients listed first):

1. [redacted] **Cynthia** (COACH link). 54 yr. old African-American female, DOB [redacted]56.
Medicaid: [redacted] Duke MRN: [redacted] PCC: Duke Fam Med Priority: 0.0
[redacted] Durham, NC 277[redacted] Home #: 919-[redacted]

Medication management issues that may require follow-up:

☐ **Need for primary care visit by patient with potential medication management issues:** Patient has potential medication management issues related to one or more chronic diseases but no visits to primary care clinic in past 6 months and no scheduled appointment with PCP. Recommend facilitating office visit with PCP.

Figure 2. Sample Notice to Care Manager

Table 1. Summary List of Pharmacotherapeutic Rules and Criteria for Activation

Medication Class	Activation Criteria
Statin	Diabetes + Age > 40 Diabetes + Coronary Artery Disease if Age < 40 Stroke + LDL Cholesterol ≥100 (Age>17) Stoke + Diabetes + LDL Cholesterol≥70 (Age>17) Prior Myocardial Infarction (Age>17) Stroke + Coronary Artery Disease (Age>17)
ACEI (ARB)	Prior Myocardial Infarction or Coronary Artery Disease + Hypertension (Age>17) Left Ventricular Systolic Dysfunction (Age>17) Prior Myocardial Infarction or Coronary Artery Disease + Diabetes (Age>17) Prior Myocardial Infarction or Coronary Artery Disease + Chronic Kidney Disease (Age>17)
B-Blocker	Prior Myocardial Infarction (Age>17) Left Ventricular Systolic Dysfunction (Age>17)
Warfarin	Stroke + Mech Valve (Age>17) Stroke + Valvular Heart Disease (Age>17) Stroke + Afib (Age>17)
Anti-Hypertensive	Hypertension (Age>17) Diabetes+ Hypertension (all Ages) Stroke + Hypertension (Age>17)
Anti-Diabetes	Diabetes (all Ages)
Inhaled Steroid or Montelukast	Persistent Asthma + Age>36 mo
B-Agonist	Persistent Asthma + Age>24 mo

1.4. Study Design

NCPPN enrollees were randomly assigned using a 1:1:1 allocation by family unit using a pseudo-random number generator. Subjects assigned to the first group received usual care, those assigned to the second group received the first intervention (clinic reports) and those assigned to the third group received both interventions (clinic reports and care manager notices). In place of informed consent, potential study subjects were sent a letter explaining the study and a response card to allow them to opt out of the study. The Duke University Medical Center Institutional Review Board approved this study's protocol on December 18, 2007 (Registry Number: Pro00002524) and ClinicalTrials.gov registration was obtained on August 27, 2009 (Identifier: NCT00979225). The 12-month intervention period began on December 7, 2009, and

ended on December 6, 2010. Study subject follow-up ended on August 30, 2011. The primary study outcome measure was medication adherence across all drug classes and conditions. Table 2 contains a complete list of study outcome measures. Estimates for study outcomes and between-treatment group comparisons were generated using generalized estimating equation models with a working correlation matrix to account for clustering by family unit. Primary analyses were performed for the entire study population, following the intention-to-treat principle. Secondary analyses were performed for the subset of patients who generated an alert or medication summary report to focus on patients who actually received an intervention ("touched" subjects).

Table 2. Study Outcomes Measures

Measurement Focus	Measures
Clinical Outcomes	Medication adherence across all drug classes and conditions (all subjects and touched subjects)
	Medication adherence by drug class (all subjects and touched subjects)
	Medication adherence by disease condition (all subjects and touched subjects)
	Outpatient encounters per 100 pt years (all subjects and touched subjects)
	ED encounters per 100 pt years (all subjects and touched subjects)
	Hospitalizations per 100 pt years (all subjects and touched subjects)
Care Coordination	Care Manager contacts (all subjects and touched subjects)
Costs / Revenues	Outpatient costs (all subjects and touched subjects)
	ED costs (all subjects and touched subjects)
	Hospitalization costs (all subjects and touched subjects)
	Pharmaceutical reimbursement (all subjects and touched subjects)
Satisfaction	Clinician opinions

2. Results

2.1. Study Population

A total of 2910 subjects met this study's inclusion criteria. Of these, 155 declined to participate by returning their opt-out letter, 497 could not participate after their clinic sites installed new electronic health record (EHR) systems and were unable to send patient appointment scheduling information to the network HIE, and 39 transferred to clinical sites not included in this study. A total of 2219 subjects were included, of which 739 were assigned to usual care, 744 to have the clinic reports intervention and 736 to have both the clinic reports and care manager notices interventions (Figure 3).

2.2. Baseline Characteristics

Patients in the control and intervention groups were well matched with regard to baseline characteristics. Overall, study subjects were predominantly female, African-American and young. Most subjects had a history of persistent asthma, diabetes or hypertension. Given this population's age, it is not surprising that relatively few subjects had a history of congestive heart failure (CHF), ischemic heart disease (IHD) or stroke.

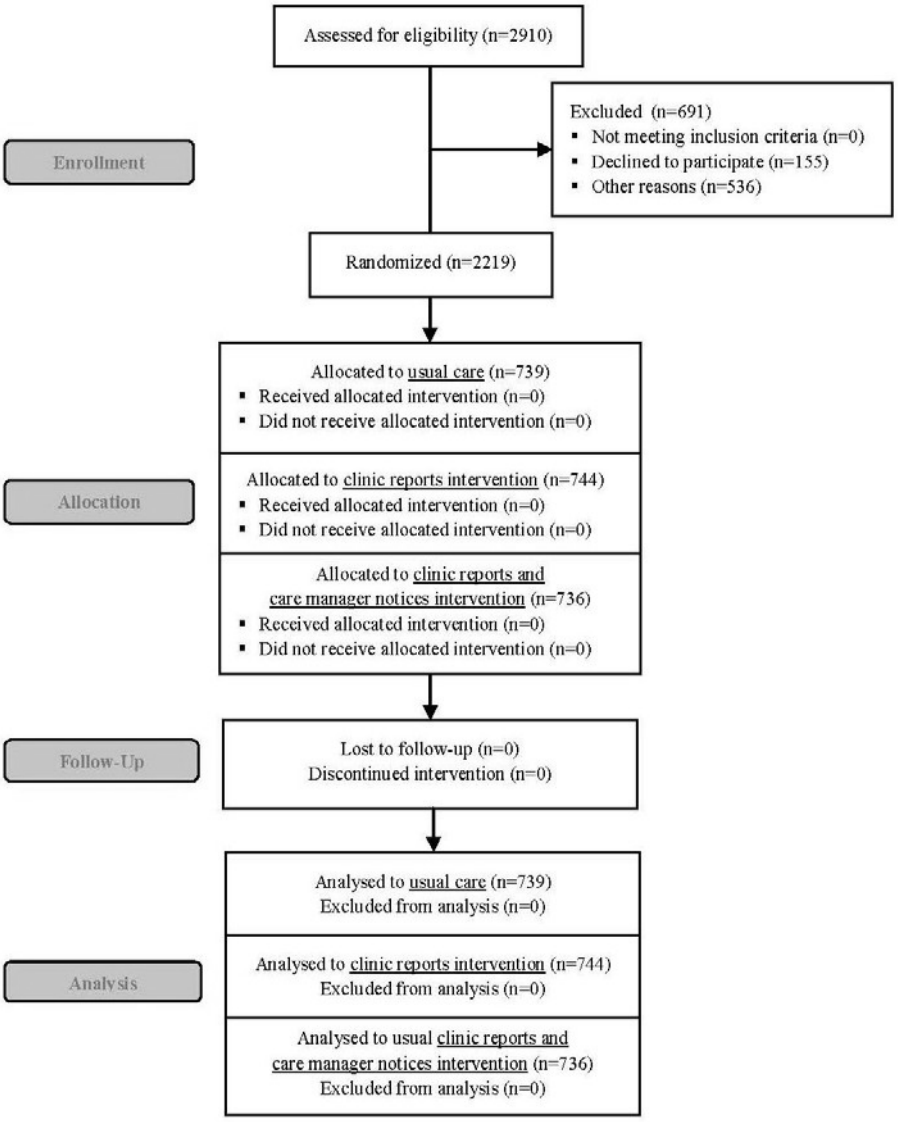


Figure 3. Consort Flow Diagram

2.3. Study Interventions

Study interventions were generated for all study subjects meeting CDS criteria but were only sent to those randomized to groups 2 or 3 (Table 3). Overall, the numbers of medication management reports and care manager notices generated did not differ significantly by treatment group; however, the volume of clinic reports was 5 times that of care manager notices (5948 versus 1052) as anticipated because the criteria for generating care manager notices were more stringent than for generating clinic reports.

Table 3. Study Intervention

	Control	Clinic Reports		Clinic Reports + Care Manager Notices	
	N=739	N=744	P=*	N=736	P=**
Reports					
Generated	2061	1951	0.44	1936	0.71
Sent	0	1951		1936	
Notices					
Generated	353	336	0.69	363	0.52
Sent	0	0		363	

Note: * Clinic Report vs. Controls; ** Clinic Reports + Care Manager Notices vs. Controls

2.4. Medication Adherence

There were no treatment-related differences in medication adherence rates overall and for specific medication classes and medical conditions (Table 4, Table 5). Adherence rates were lowest for individuals receiving medications for persistent asthma and highest for those receiving medications for stroke. When we examined 6-month adherence rates following the first contact (or potential contact) with an intervention among patients for whom an intervention was generated (but not necessarily sent), adherence rates (not shown) increased slightly. However, there were no treatment-related differences between groups.

Table 4. Adherence by Medication Class

Group		Arm #1 (Control) Adherence N=739	Arm #2 (Reports) Adherence N=744		Arm #3 (Reports+) Adherence N=736	
Medication Class		%	%	P=	%	P=
All Classes		41.3	41.2	0.82	42.9	0.35
Statin	All conditions (age >17)	54.0	61.0	0.12	56.3	0.63
ACEI (ARB)	All conditions (age >17)	69.7	68.4	0.85	64.2	0.52
B-Blocker	All conditions (age >17)	55.2	58.3	0.54	57.1	0.76
Warfarin	All conditions (age >17)	48.3	56.1	0.54	37.8	0.26
Anti-Htn	All conditions (age >17)	62.8	61.1	0.88	63.9	0.71
Anti-DM	Diabetes (all ages)	54.3	53.8	0.90	57.1	0.49
Inhaled Steroid	Persistent Asthma +age>36 mo	36.9	36.4	0.73	41.8	0.23
B-Agonist	Persistent Asthma + age>36 mo	25.4	23.9	0.85	24.7	0.84

2.5. Clinical and Economic Outcomes

Six-month encounter rates per 100 subjects and medical costs per subject (total and by type) were similar across treatment groups. As expected, the highest encounter rates were for outpatient care and the greatest costs were for pharmaceuticals and outpatient care.

Table 5. Adherence by Medical Condition

Group	Arm #1 (Control) Adherence	Arm #2 (Reports) Adherence		Arm #3 (Reports+) Adherence	
isease Condition	%	%	P=	%	P=
All Diseases	40.6	39.3	0.77	40.6	0.76
Persistent Asthma	27.7	29.0	0.29	27.2	0.47
Diabetes	49.6	50.3	0.83	51.3	0.62
Hypertension	56.6	53.7	0.29	55.8	0.74
CHF	55.8	62.7	0.32	53.9	0.83
IHD	52.4	51.8	0.92	61.6	0.30
Stroke	61.2	54.1	0.62	50.3	0.22

Table 6. Clinical and Economic Outcomes

Group	Arm #1 (Control)	Arm #2 (Reports)		Arm #3 (Reports+)	
Encounter Rates	#	#	P=	#	P=
Outpatient	46.0	46.6	0.42	44.5	0.81
Emergency Department	0.87	0.84	0.77	0.89	0.47
Hospitalization	0.19	0.21	0.96	0.21	0.92
Total	47.0	47.7	0.49	45.6	0.81
Medical Costs	$	$	P=	$	P
Outpatient	4417	50	0.42	4423	0.75
Emergency Department	423	4	0.58	420	0.07
Hospitalization	154	1	0.95	184	0.93
Pharmaceuticals	5579	66	0.15	5703	0.79
Total	10.573	123	0.32	10.730	0.76

3. Discussion

This study sought to use CDS to increase EBP adherence within a vulnerable population, and to assess the impact of this CDS technology on service use and medical costs. We demonstrated significant technical advancement for CDS for promoting medication adherence by intervening at both the level of the PCP clinic and the population. Unfortunately, even though the interventions were successfully delivered, neither the clinic-based intervention (point-of-care reports to clinicians), nor the population-based intervention (notices to care managers) resulted in increased medication adherence to EBP. From a positive perspective, we demonstrated that a CDS intervention can successfully identify medication adherence issues relative to EBP and mobilize the provider workforce. We detected that the notices sent to care managers significantly increased the extent of contact that care managers had with study subjects. One potential weakness of this population-level intervention was that care manager contact was limited to encouraging patients to arrange follow-up with their PCP clinic (where a medication management report would be available). Care managers were permitted to inquire about possible reasons for medication nonadherence, such as financial or transportation issues. However, they were not permitted to give clinical advice because such an intervention exceeded their scope of practice. Perhaps a more effectual population-level intervention would have been to engage clinical pharmacists or advanced practice nurses to directly address

nonadherence with EBP.[9]

We can conclude from our negative clinical outcome that a printed summary of medication adherence information based on filled claims and delivered to the point of care was insufficient to impact overall adherence for EBP. The study was originally powered to detect an absolute difference in medication adherence of 6.5%. These calculations were based on a two-sided Type I error rate of 0.025, 80% power, and a sample size of 1120 per group. With the observed sample size of approximately 740 per group and a Type I error of 0.05, this study had greater than 80% power to detect differences larger than 7.3%. In addition to the possibility that patients were refractory to provider-driven efforts to change their medication adherence, three additional primary points of failure need to be considered: 1) the report content was not useful; 2) the reports were not effectively integrated into the clinical workflow; and 3) the clinical setting was not conducive to addressing medication nonadherence issues effectively. The root cause for low adherence can be quite complex and fixing it may require more intensive behavior change interventions than a brief talk with the PCP.

Based on findings from our clinic site visits, contextual evaluation, and clinician surveys, we surmise that the failure to impact EBP adherence was not due to report content. Our qualitative data indicate that clinicians found the medication report content helpful for addressing medication nonadherence issues and many anecdotes were provided in which the reports directly led to discussing medication adherence issues with a patient. Notably, a majority of clinicians who were interviewed three months following implementation of the reports rated the reports as helpful or very helpful.[10] The usefulness of the medication reports is perhaps most strongly supported by a decision of the leadership of NPCCN to fund conversion of the study interventions to an operational system so that the reports continued to be available after this research study ended.

While the qualitative data support the utility of the reports, they indicate a breakdown in workflow as a possible point of failure. In spite of carefully analyzing work practices at each clinic site in order to customize an approach for delivering the medication reports to the point of care, we discovered from our site visits that between 15% to 50% of reports were often not available to clinicians at the time they interacted with a patient. Consequentially, patients did not receive the full benefit of the intervention because reports were not always available. As most stakeholders suggested for future effectiveness, reliable report delivery can be enabled by direct integration of the reports into existing practice IT systems. From the qualitative analysis with regard to the third possible point of failure, we also learned that on many occasions even when reports were available clinicians did not take time to address issues related to EBP nonadherence. Accordingly, we postulate that the many competing demands during the clinical encounter may hinder clinicians from addressing nonadherence issues. As suggested in the contextual evaluation, more resources (time and personnel) and possibly other team members (e.g. pharmacists) and venues outside of the exam room may be more conducive to resolving medication nonadherence issues effectively than the reports provided to clinicians at the point of care in this study.

To summarize, we point out that having information about medication nonadherence and having tools/resources to address it are two different things and that, in this group of high risk patients, the knowledge did not beget effective action. That result does not mean that the knowledge is not useful, but that the path to action needs to be developed.

Acknowledgements.

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Analysis of Continuous Oxygen Saturation Data for Accurate Representation of Retinal Exposure to Oxygen in the Preterm Infant

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Abstract. Maintaining blood oxygen saturation within the intended target range for preterm infants receiving neonatal intensive care is challenging. Supplemental oxygen is believed to lead to increased risk of retinopathy of prematurity and hence managing the level of oxygen within this population is important within their care. Current quality improvement activities use coarse hourly spot readings to measure supplemental oxygen levels as associated with targeted ranges that vary based on gestational age. In this research we use Artemis, a real-time online healthcare analytics platform to ascertain if the collection of second by second data provides a better representation of retinal exposure to oxygen than an infrequent, intermittent spot reading. We show that Artemis is capable of producing more accurate information from the higher frequency data, as it includes all the episodic events in the activity of the hour, which provides a better understanding of oxygen fluctuation ranges which affect the physiological status of the infant.

Keywords. Oxygen, SpO_2, Retinopathy of Prematurity, Clinical Decision Support, Quality Improvement

Introduction

Medical and technological advances in neonatal intensive care over the past 50 years have increased survival rates for preterm infants whom are <37 weeks gestational age (GA) and weigh <2500 grams. In 2009–2010, the Canadian Institute for Health Information reported that one in 12 infants (8%) are born prematurely in Canadian hospitals, and that more than 6% of those infants weigh <2500 grams [1]. Physiological immaturity is a precursor to many imminent complications involving the lungs, brain, and eyes which result in the use of supplemental oxygen therapy to aid with the pulmonary inadequacy [3]. In the preterm infant population, optimal oxygen saturation ranges are still unknown and evidence based practices have set guidelines for oxygen administration at 85-92% to maintain and reduce the risk of complications while increasing the benefits of oxygen [8]. Supplemental oxygen exposure is an established risk factor for Retinopathy of Prematurity (ROP) as the immature retina is susceptible to injury [4, 5]. ROP is described as a vascular disorder of the retina, which occurs after birth, among preterm infants and involves prolonged oxygen

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administration and fluctuation of oxygen, associated with hyperoxia and hypoxia [4]. At birth the immature retina is exposed to an excess of oxygen saturation which decreases the sensitivity of cells due to the over exposure of oxygen therefore, reduces the normal stimulus for development of the blood vessels and encourages abnormal retinal vascular migration [5].

We use the Artemis platform, a real-time analytic system that captures and analyses high fidelity physiological data streams from bedside medical devices in the NICU. Its multidimensional approach uses time-series data and temporal data mining to identify relationships between the data streams and specific clinical conditions that affect the preterm neonate. The primary goal of this exploratory study was to determine if the collection and analysis of high fidelity blood oxygen saturation levels (SpO_2) provides a better representation of the immature retina's exposure to potentially damaging oxygen levels than infrequent, intermittent spot recordings of SpO_2.

1. Related Works

Recent research has shown that not only hyperoxia but also hypoxia and fluctuations in retinal oxygen levels can contribute to the development of ROP [3,6,8]. A study by Hagadorn et al., showed that SpO_2 is in the intended target range for 50% of the time as there is considerable fluctuation above and below the intended target range [8]. Hagadorn et al. have also shown that preterm infants less than 28 weeks gestational age experience fluctuations in SpO_2, but these episodic events are frequently transient and/or have resolved by the time the nurse observes the baby, and therefore opportunities for intervention are limited [8]. Current research is exploring how new technologies can help to control oxygen delivery so to better understand fluctuations in SpO_2, and consequently, improve target range compliance [6, 8].

2. Methods

In this exploratory study, we used the Artemis platform to capture high fidelity data for SpO_2, to document retinal exposure to oxygen. We extracted SpO_2 values both hourly and at the frequency of 1Hz, for a preterm infant who was receiving supplemental oxygen over a consecutive 4 day period. The representations of retinal exposure to oxygen of these two approaches for capturing SpO_2 were compared. The infant was enrolled in a REB approved nosocomial infection research project being conducted in the NICU at The Hospital for Sick Children, Toronto.

2.1 Data Collection

For this study, the Knowledge Extraction component of Artemis was used to extract raw SpO_2 values (collected by Masimo SET pulse oximeter) over days 27, 28, 29, and 30 of a study month, on a convenient sample data of a de-identified infant <32 weeks GA [9]. The top of the hour spot readings were extracted as a subset of that dataset.

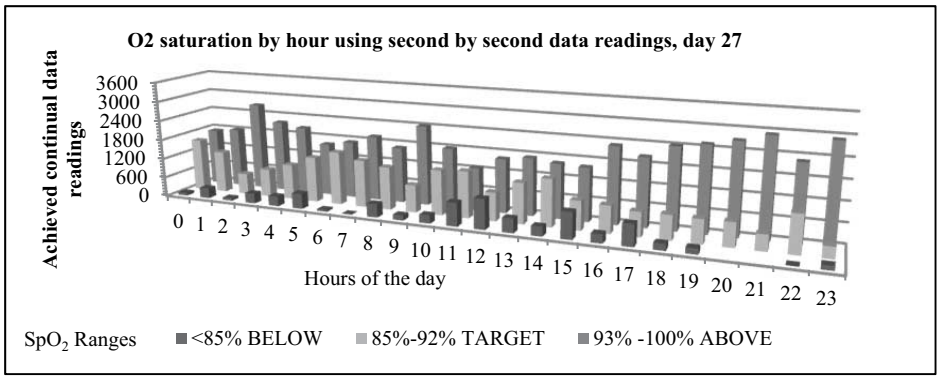

Figure 1. Frequency histogram for Day 27 of SpO_2 from Artemis Data.

2.2 Statistical Methods

In order to understand the copious amounts of data that Artemis produces on a continual basis, we used the univariate analysis on the raw data, this enabled us to focus on three characteristics of the data; distribution, central tendencies and dispersion of values around the central tendency. Frequency histograms were constructed with hourly readings summarized into SpO_2 ranges of; <85%, 85%-92%, 93%-100% representing 'below', 'target', 'above' respectively. Further analysis for shift windows was also performed.

The representation of retinal exposure to oxygen for the high fidelity data stream was compared to that of the spot readings by analysing the dispersion of values around the central values using the paired sample t-test with $p < 0.05$.

3. Results

The characteristics of the continual collection of achieved SpO_2 data using day 27 are shown in Figure 1. The availability and capture of the infants' machine acquired bedside SpO_2 transcutaneous oxygen saturation value achieved per hour was examined.

On day 27, ten of the 24 hourly periods showed oxygen saturation average values which fluctuated more than 5% values from the top of the hour value, within this 24 hour period, one of those hours fluctuated 12%. Similar differences were noted on the other three days within the study.

Achieved oxygen saturation readings between two shift windows, using the Artemis second by second data readings (Figure 2) and the top of the hour spot readings (Figure 3) were compared and examined for all days. Using the data on day 28 seen in figures 2 and 3, we observed that the appearances of the two histograms are dissimilar. The percent values for each SpO_2 range represent a different value in both the day and the evening shift. Both values were represented by the frequency percent which is derived from the number of times the achieved SpO_2 value was captured in the % range divided by the total data readings captured for the shift.

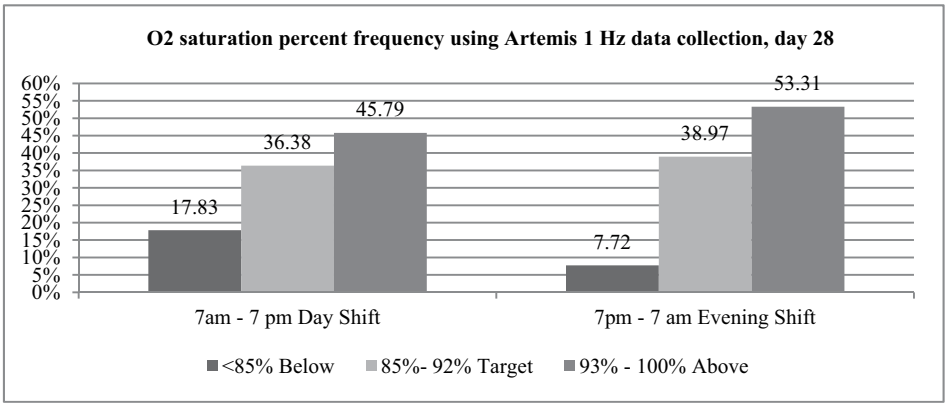

Figure 2. SpO_2 percent frequency using Artemis 1 Hz data collection, day 28

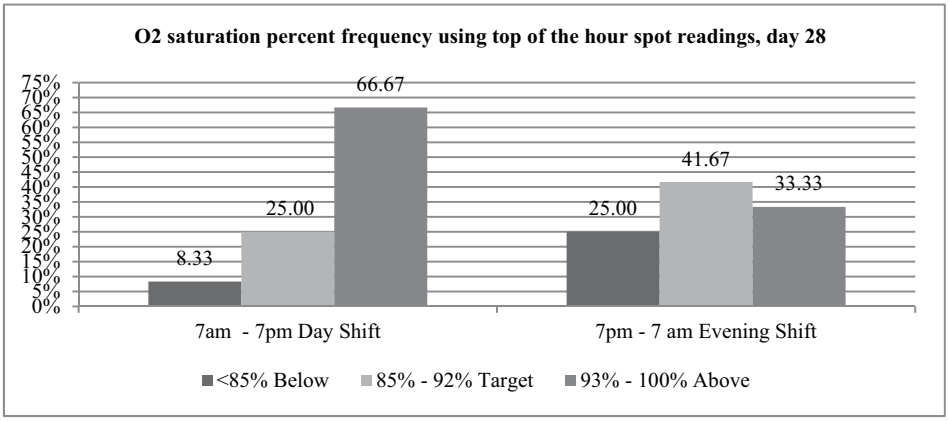

Figure 3. SpO_2 percent frequency using top of the hour spot readings, day 28

As can be seen in figures 2 and 3, there is a significant difference in the distribution between below, target and above for the day shift. The Artemis data demonstrates that there was less above target range oxygenation across the shift and more under oxygenation during the shift by 21% and 9% respectively.

Within the night shift the below target was 18% lower in the Artemis data and the above target was 20% higher.

4. Discussion

This exploratory study has shown potential that higher fidelity oxygen saturation data collection provides greater detail of retinal exposure to oxygen than infrequent, intermittent spot readings. The high frequency data collection provides a better representation of all activity occurring in the full hour as episodic events are captured and included to represent a clear picture of SpO_2 occurring during each hour. As a result this approach provides a greater ability to understand the retinal exposure to oxygen values and percentages with more accuracy.

In addition to what has been reported in this paper, Artemis provides more in-depth information than that of a single spot reading. It allows for detailed information to be extracted from the raw data such as; ranges, times, frequency, hourly approaches and outliers which can be used to help expose what is occurring at a particular time, for any particular length of time. This aids in the tracking of hypoxia and hyperoxia and provides a better understanding of the patient's current level of oxygenation. Using this detailed level of data can provide a more comprehensive data set inference from than just a single value, in a single time frame which, would lack the connectivity and relevance of the oxygen saturation which occurred during the hour. Analyzing rapid and wide fluctuations in an hourly dataset can provide extensive information for the many neonatologists, residents, fellows, nurses, and respiratory therapists to draw from. This has great potential to improve adjustments in titrating the transcutaneous blood oxygen saturation levels at the bedside. The ability to accurately reflect the activity of the hour and convert copious amounts of data into visual charts and graphs, provides a better understanding of the information which can be passed on to another health professional at the end of the shift as a clinical and educational tool.

The Artemis platform has the capability to support clinical research to quantify the relationship between retinal exposure to oxygen and ROP more precisely and accurately. There is also potential for the discovery of other relevant causative factors.

5. Conclusion

This paper has presented an exploratory study to compare the target range analysis for blood oxygen saturation levels SpO_2 when data is only recorded as top of the hour readings verses analysis of the readings each second. The analysis was performed using data collected via the Artemis platform. High fidelity blood oxygen saturation data provides a better representation of retinal exposure to oxygen than infrequent, intermittent spot readings. In future research publications we will report on our research to study the association of the SpO_2 values recorded in Artemis and the association with ROP risk scores.

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Tailoring Decision Support to Suit User Needs: A Diagnostic Imaging Example

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Abstract. Unnecessary diagnostic imaging (DI) examinations raise concerns for patient safety and place stress on human and financial resources. To reduce unnecessary DI examinations, several Canadian pilot studies have investigated how decision support systems (DSS) could be utilized. Based on interview results from our previous research, in addition to a literature review, themes emerged that influenced the features and design of a DI DSS prototype. Features include having the referring professional indicate how the results of the examination will be utilized (i.e. for diagnosis or patient management), increasing communication between referring physicians/nurse practitioners and radiologists, and displaying previous DI examinations (or orders that are scheduled to take place) to avoid duplicate orders. Presenting a patient's cumulative radiation exposure, and having resources for information support to guide physicians through challenging clinical decisions are two other features included in the DSS prototype. By incorporating physician perspectives and current literature into the design, this DSS aims to promote the appropriate use of DI resources by supporting physicians and nurse practitioners in their DI ordering practices.

Keywords. diagnostic imaging, medical imaging, decision support tools, decision support system, appropriateness, radiation exposure, patient safety, order entry system, prototype

Introduction

According to the Canadian Association of Radiologists (CAR), 30% of diagnostic imaging (DI) in Canada may be unnecessary [1, 2]. These unnecessary DI examinations strain financial and human resources. As well, some DI modalities (for example, x-ray, computed tomography [CT], and positron emission tomography [PET]) expose patients to radiation [3], making the unnecessary examinations a patient safety concern. Unnecessary, or inappropriate, DI ordering refers to situations where the most ideal imaging is not selected, when imaging would not change or support patient management, when the examination is performed too early, or when a duplicate order is placed [3]. Again, these inappropriate orders place stress on human and financial resources and raise patient safety concerns.

In the author's previous work, Canadian physicians (both general practitioners and specialists) were interviewed regarding their DI ordering practices [4]. Specifically, the researcher was interested in how physicians proceed with DI decision making, as well

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as what methods of information support physicians would seek during challenging clinical scenarios. Physician participants were also asked to describe what factors contribute to inappropriate ordering. Lastly, participants identified potential solutions to inappropriate ordering [4]. This previous study, accompanied by a literature review, formed the basis of a DI decision support system (DSS) prototype. DSSs are "computerized tools that aim to improve patient care by putting best-practice recommendations directly onto computer and hand-held devices of physicians" [5]. The prototype was created using Microsoft's® PowerPoint tool. The prototype is strictly visual, and is being used as a communication tool to illustrate what features are important to include in a real system and to elicit further feedback from future users. For example, the prototype could be used to communicate what is expected from computer programmers, or to demonstrate to funders how their contributions will be spent.

A DSS prototype may be incorporated into an electronic health record and may be used to learn about physician perceptions and reactions to the DSS design. For example, in a DSS pilot project in New Brunswick, Canada, physician participants expressed frustration with logging on to a separate system (i.e. the DSS). They also noted the inconvenient physical location of the technology [6]. Thus, this DSS prototype was integrated into an electronic health record.

1. The Prototype

In this paper we describe a DI DSS prototype. In the prototype, a tab on the horizontal menu bar on the electronic health record supports physician navigation of the DI portion of the system. By scrolling over this tab, physicians can access previous DI examinations through the picture archiving and communications system, view current guidelines, or order DI. When proceeding to order DI, physicians/nurse practitioners are presented with a series of closed-ended questions in order to provide end-users with the most relevant decision support. After answering these questions, the system displays the recommendation. This feature is modeled after a DSS used at a hospital in the US that produces a utility score to indicate the appropriateness of a DI examination [7].

After a recommendation is produced in the DSS prototype, the physician or nurse practitioner can accept or override the recommendation. If the recommendation is rejected, the end-user must provide rationale in a free-text box. If the recommendation is accepted, the physician may proceed to order the DI. Not only does the DSS suggest the most suitable type of DI, it also recommends an urgency classification that is used for booking the appointment. The order entry component of this DSS suggests multiple dates and locations for the appointment. The patient will leave their consultation with a confirmed DI examination appointment.

2. Derivation of Prototype Features

Based on findings from a previous study [see 4], and from a literature review, features emerged that could be considered for inclusion in future DSS development. These features included questioning the utility of the DI examination, increasing communication between referring physicians/nurse practitioners and radiologists, and

displaying previous DI examinations (or orders that are scheduled to take place) to avoid duplicate orders. Other features include presenting a patient's cumulative radiation exposure, and having resources for information support to guide physicians through challenging clinical scenarios. Overall, results from our previous work [see 4], formed the basis for the features included in the DSS prototype described below.

2.1. Utility of DI Examination

To better understand DI decision making, physician participants in the author's previous work [4] were asked to describe their thought processes when presented with a challenging clinical scenario (i.e. when they were unsure of whether to order DI, or unsure which modality to use). Participants described questioning the utility of a DI examination, whether it was to reach a diagnosis, to support patient management, or both. This is similar to CAR's definition of a useful DI examination: "one in which the result—positive or negative—will alter clinical management and/or add confidence to the physician's diagnosis" [3]. Thus, the prototype includes an initial question, asking the physician to select whether the DI examination is for diagnosis, patient management, or both. This step provides the radiologist with more information, and requires the referring physician to consider the utility of the DI examination.

2.2. Requisition Communication

In research conducted by the author [see 4], physician study participants suggested that there is a need to increase opportunities for physician communication when completing DI requisitions. Providing physicians with opportunities to communicate could help to promote more appropriate DI ordering. More specifically, participants noted the importance of providing sufficient information on the requisition; however, some requisition formats (paper and electronic) restricted the amount of wording referring physicians could enter. Thus, this prototype includes requisition order entry features with a large free-text space for additional comment. Physicians can click a button if they require more space than is provided (see Figure 1).

2.3. Duplicate Orders

In previous research work [4], physician participants were asked how they determine if a DI examination has already been performed or scheduled to take place. Interestingly, 67% expressed they would ask the patient directly [4]. The remaining participants described using an electronic system to determine if the examination had been performed or scheduled, but could only do this within their jurisdiction [4]. Thus, the prototype includes a pop-up alert to warn physicians if a duplicate order has occurred. This alert includes the date and type of DI examination. The alert does not cancel the requisition being placed, as some duplicate orders may be necessary.

2.4. Radiation Dose Monitoring

Certain DI examinations expose patients to radiation (for example, X-ray, CT, and PET). For example, a CT examination of the abdomen or pelvis exposes a patient to approximately 4.5 years worth of natural background radiation [3]. As noted previously,

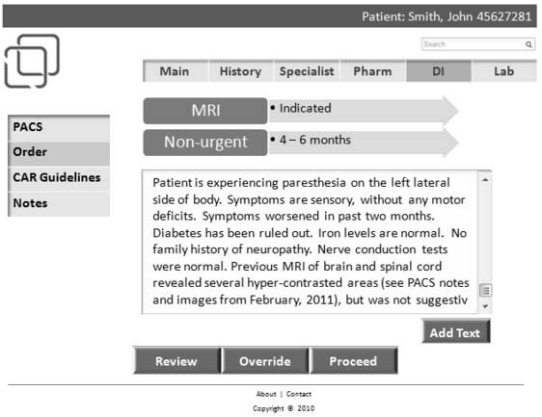

Figure 1. Requisition Communication

physicians may ask their patients directly to determine if previous imaging had been performed. Having this information available could help physicians make more informed decisions and promote patient safety.

2.5. Information Support

As described in the previous study [4], physician participants noted consulting a physician (either a colleague/specialist, or radiologist), or searching the literature (using UpToDate®, "an evidence-based, peer-reviewed medical information resource" [9], or Google Scholar) as their top methods of obtaining information to guide challenging clinical decisions with respect to DI. This is similar to another study where physician participants rated consulting a radiologist or, searching the literature through UpToDate®, a specialty journal, or Google's search engine as their top methods of obtaining information support [8]. Common to both of the studies, consulting another physician or searching the literature were used for information support. To support end-user preferences for obtaining information support, the prototype includes buttons to directly access UpToDate®, specialty journals, and an internet search engine. The prototype also includes a button to access a directory of physicians and their contact information to support physicians who wish to consult another physician. Therefore, including direct access to the top methods of information support that physicians identified using in their work could promote more appropriate ordering.

3. Discussion and Conclusion

Inappropriate DI ordering places stress on human, and financial resources and raises patient safety concerns. Several Canadian DI DSS pilot studies have demonstrated there is an interest in utilizing this technology to promote more appropriate ordering. Results from previous research and a literature review formed the basis for the development of this DSS prototype. The prototype included features such as having the end-user identify the utility of the DI examination as well as increasing opportunities for communication between referring professionals (physicians and nurse practitioners) and radiologists. In order to prevent repeated DI ordering, this DSS prototype displays

examinations that have already been performed or are scheduled to take place. The prototype also displays the cumulative DI-related radiation exposure a patient has received to help physicians make more informed decisions. As well, the top reported methods of information support used by referring physicians (i.e. using UpToDate®, Google®, specialty journals, and contacting other physicians) were incorporated into the prototype to support decision making involving challenging cases. As inappropriate DI ordering raises concerns for patient safety and places a strain on human and financial resources, investigating ways to reduce such ordering has become critical. As described in this paper, based on interviews from our previous study, and from a literature search, several themes arose that influenced the introduction of specific features into this DSS prototype. Future work will focus on the usability testing of the prototype described in this paper.

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Supporting Cystic Fibrosis With ICT

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Abstract. ICT use in cystic fibrosis management provides an alternative means of information supply to individuals, families, health care professionals and other stakeholders. The purpose of this paper is to present the evolution of a series of projects culminating in a project that translates the previous research into practice. In this paper the sequential nature of the projects will be detailed. The three projects explored are *the Pathways Home for Respiratory Illness Project (Pathways Home), Enhancing Self-Efficacy for Self-Management in People with Cystic Fibrosis* and *the Tasmanian Community Fund Project (myCF pilot).*

Keywords. ICT supported chronic disease self management, cystic fibrosis, incremental project development

Introduction

The use of information communication technology (ICT) in chronic disease management has been the subject of various reviews [1-3]. Incorporation of ICT in chronic disease self-management has the potential to provide an alternative means of information supply to individuals, families, health care professionals and other stakeholders [4]. Understanding the motivating and influencing factors that underlie consumer engagement in eHealth initiatives is an important contextual requirement for the successful running and implementation of ICT projects.

The purpose of this paper is to present the evolution of a series of inter-linked projects culminating in translation of the previous research into practice. The drivers for each project's conceptualisation, methodology and development, will be detailed. Finally, the influence of the combined results of the projects will be discussed.

Three projects, undertaken by a multi-disciplinary team, are explored, *the Pathways Home for Respiratory Illness Project (Pathways Home), Enhancing Self-Efficacy for Self-Management in People with Cystic Fibrosis (CFA Project)* and *the*

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Tasmanian Community Fund Project (myCF pilot). Each project is discussed from a health informatics perspective.

1. *Pathways Home*

Pathways Home for Respiratory Illness was a joint research project involving the Schools of Medicine, Nursing and Midwifery, and Computing and Information Systems at the University of Tasmania. The project was funded by the Commonwealth Department of Health and Ageing, under the Australian Health Care Agreement.

A major aim of the *Pathways Home* project was to investigate interventions that offered the potential to facilitate the development of self-management skills and self-management self-efficacy in people with cystic fibrosis (CF). The project responded to a range of challenges presented to people with CF in Tasmania including: the high birth incidence of CF in Tasmania; a geographically dispersed CF population receiving care through regional healthcare facilities rather than via the conventional centralised CF Centre care model and the resultant impact on regular, physical clinic visits; and the fact that people with CF are surviving well into adulthood.

The CF arm of the Pathways project, which also assessed ICT support for older patients with chronic obstructive disease (COPD)[5], aimed to investigate whether the introduction of an ICT tool in CF, specifically a mobile phone application, could be used for daily symptom monitoring to encourage the development of self-management self-efficacy. The study explored whether individuals with CF would use the tool and if its use would make a difference to their self-management behaviours and quality of life.

A total of 19 participants across Tasmania participated in the investigation. These participants were randomised into 3 groups;

- Intervention 1: Given access to health-mentoring to foster self-efficacy for self management (face-to-face and via telephone).
- Intervention 2: Given access to health-mentoring to foster self-efficacy for self management (face-to-face and via telephone) and also provision of an ICT supported self-monitoring program (via mobile phone).
- Control Group: Continued to receive normal level of care.

The project ran for 6 months with a 6-month washout. Both qualitative and quantitative data was collected at commencement; 3 and 6 months; and 6 months post completion. The initial evaluation of the results of *Pathways Home* indicated that there was sufficient evidence to undertake further evaluation of these intervention types. The project also demonstrated that mentoring did assist in developing self-efficacy for self-management behaviours, but the pilot study was too small to make definitive conclusions on the ICT arm, but the feasibility of this approach was confirmed [5].

2. *Improving self-efficacy in adolescents and adults with Cystic Fibrosis*

The second project was funded by the Australian Cystic Fibrosis Foundation and extended the *Pathways Home* project that had been conducted in adults into adolescents and older children with CF. The project was conducted in Queensland through collaboration with the Royal Children's Hospital and their CF outreach service. This project examined two self-management related strategies, task-specific self-

efficacy and self-monitoring, designed to improve self-management behaviours and quality of life amongst CF patients.

The project participants' ages ranged between 12-19 and they were recruited from the Royal Children's Hospital and Gold Coast Hospitals outpatient and outreach clinics. Participants were randomised to one of three groups:

- Intervention 1: Health-mentoring initiated and reviewed by a mentor who may or may not have been resident in the local area, thus allowing remote mentoring by telephone to be assessed. The ICT application was accessed either through a mobile phone provided by the trial or via a desktop PC and allowed the individual to record their symptoms via a daily electronic diary.
- Intervention 2: Participants undertook the self-efficacy program and allocated a mentor, without the daily diary or use the ICT application.
- Control: Participants in this arm received normal multi-disciplinary CF care.

A total of 43 participants were recruited for this project. 15 participants received health-mentoring plus the ICT application. Participants took part in the trial for six months, with a further six months of follow up. Data collection involved both quantitative and qualitative assessments collected at base-line, 3, 6 and 12 months.

The electronic diary consisted of a set of questions and an additional randomly generated question to improve data quality. Participants were able to view a summary of their clinical data as feedback on how their symptoms were tracking. The project mentors were also able to review their patients remotely.

The design of the *CFA Project* included the electronic patient dairy that could be accessed through a mobile phone or a PC; a mobile server that captured and sent clinical information to the participants using the mobile phone application; and a database with a web-based interface that stored the data present in the platform.

The outcomes of the *CFA Project* provided sufficient positive response from the qualitative interviews and usage statistics to indicate that further investigation with a broader scope encompassing a more sophisticated suite of products to support the CF community may be beneficial. Useful information was also obtained on aspects of self-monitoring that were not viewed favourably by these younger CF patients such as the need to enter diary data on a daily basis, which not surprisingly was not an attractive option for young adolescents.

3. *myCF*

The acknowledgement of the potential beneficial supportive role of ICT in a health-mentoring environment, and the desire to assist the Tasmanian CF community in raising levels of self-efficacy for self management led to the development of the *myCF* project, utilising web based resources that can also be accessed via a mobile phone. The Tasmanian Community Fund provided support for this current project.

MyCF has three main aims:

1. To improve access to educational material on CF; A web based information portal which will contain expert reviewed health information sheets and links to other relevant sites.
2. To increase Community Support; Availability of community support from peers and families located in Tasmania through a secure online chat room.

3. To develop a Health-Mentor System: Introduction of a health-mentor system of trained health professionals to encourage the development of self-monitoring and increase self-awareness about their condition.

The *myCF* project is an evolution of the *Pathways Home* and *Australian Cystic Fibrosis Foundation* projects and incorporates the daily symptom diary into a web portal, allowing integration of educational, enhanced communication and self-monitoring facilities into the one 'virtual' location. The *myCF* website design continues to undergo iterative development in order to deliver a clean, accessible site for users.

The combined platform of a web-based delivery, incorporating a mobile phone application as an additional input device, integrates ICT in a way that allows individuals with busy lives to access the portal daily if they wish to do so, but frequency of use is dictated entirely by the individual. Thus, the mobile phone allows daily symptom input with minimal interruption to everyday routines.

The project pilot was staggered and consisted of an active 6 week trial of the symptom monitoring diary of the myCF website, conducted between June 2011 and September 2011. Participants of the pilot were 15 Tasmanian individuals with CF. The potential project participants were identified through attendance at one of the Tasmanian CF clinics. Participants were randomly recruited from different age groups; paediatric, adolescent and adults to allow for a more comprehensive assessment of how each age group would interact and use the myCF website. Data collection involved both quantitative and qualitative assessments collected at pre and post pilot periods.

The *myCF* project endeavours to facilitate the implementation of an ICT support model for clinical care in Tasmania for CF. Throughout the planning stage of the *myCF* project, diary baseline questions were developed and loaded into a database to provide the reference base for the self-monitoring aspect of the site. The core questions developed as part of the *Pathways Home* project have been enhanced and added to. The participant can select the questions that are relevant to their disease manifestations, i.e. predominantly bowel or respiratory-related and they receive quantifiable data feedback in graphical form based on their subjective diary entries. This re-work of the diary questions for the *myCF* project pilot ensures applicability for the individual with CF.

The *myCF* project pilot study demonstrated that participants perceived the single platform containing educational, mentoring and symptom-monitoring elements to be beneficial. Pilot study participants also indicated that the use of a symptom-monitoring diary would be of far more benefit if performed in conjunction with health-mentoring or peer support.

4. Discussion

The succession of three projects building on each projects' findings enables the research team to ensure the *myCF* project takes its place as a translational research project in the model of CF care in Tasmania. The feedback from the series of projects suggested that not only was online symptom monitoring feasible but that it is most likely to be beneficial when combined with access to health-mentoring opportunities and educational resources. The progression from single platform offerings to that of a platform (*myCF*) with multiple functions was aided by knowledge from the previous projects. The *myCF* project pilot additionally combined the web platform and ability to be mobile in order to overcome some of the limitations highlighted by participants from the sole use of the mobile phone or PC.

The *myCF* project pilot was trialled by representatives of the three generations; older children, adolescents and adults. This application allowed for a holistic representation of the CF community, removing the adult only or adolescent only focus of the previous two projects. The recruitment strategy reflects the applied nature of research into practice of the *myCF* project pilot.

The evolution of *Pathways Home, CFA Project* and *myCF* represents a natural progression and the challenge now is to determine which components of the *myCF* project pilot are of most benefit and why. By monitoring usage of myCF we will be able to explore how patients and their families interact with particular components of the ICT tool and gain better understanding of how myCF may be used to support chronic disease self-management.

The size of the sample populations and at times difficulty with ensuring sustainable use of the IT interventions were some of the limitations of these projects. This paper does not explore the findings of each project in detail, rather presents an overview of each project to highlight the method of building on the previous projects.

5. Conclusions

ICT use in chronic disease support has increased in use from a health consumer's point of view. This paper follows the journey of three projects involving clinicians and eHealth researchers that explored health mentoring supported in some cases by ICT with the aim of improving self-management and self-monitoring activities for those with chronic disease, in particular, cystic fibrosis.

The potential for ICT use in self-monitoring, particularly using mobile devices, has been highlighted by all three projects. The *myCF* pilot combines an on-line symptom diary with educational material and peer support with the aim of improving care for people with cystic fibrosis who live remote from specialist CF services such as the patient population residing on the island state of Tasmania.

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Information Accountability and Usability: Are There Any Connections?

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Abstract. Availability of health information is rapidly increasing and the expansion and proliferation of health information is inevitable. The Electronic Healthcare Record, Electronic Medical Record and Personal Health Record are at the core of this trend and are required for appropriate and practicable exchange and sharing of health information. However, it is becoming increasingly recognized that it is essential to preserve patient privacy and information security when utilising sensitive information for clinical, management and administrative processes. Furthermore, the usability of emerging healthcare applications is also becoming a growing concern. This paper proposes a novel approach for integrating consideration of information accountability with a perspective from usability engineering that can be applied when developing healthcare information technology applications. A social networking user case in the healthcare information exchange will be presented in the context of our approach.

Keywords. Information Accountability, Usability Testing, Healthcare Information Technology (HIT), Health Informatics, Information Governance, Electronic Healthcare Record (EHR), Electronic Medical Record (EMR)

Introduction

The creation of health information silos, and the generation of thousands of Electronic Healthcare Record (EHR), Electronic Medical Record (EMR) and Personal Health Record (PHR) systems around the globe are seemingly unstoppable. Furthermore, the explosion of information sharing using public social networking and related links is accelerating in an ever-increasing rate. Recent statistics show that around 3.7 billion people around the globe are using the Internet [1] (this is >50% of world population), while 40 billion photos are deposited [2] in Facebook. An important aspect of capturing the positive impact of such developments is to integrate those social activities with health information exchange (HIE), a powerful tool [3] yet to be realised fully. Health information sharing in a general context is not new, however, in the digital world, this increasing social interaction demands further scrutiny for several reasons. Health

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information sharing in clinical settings [4] is timely, and supporting informed qualitative clinical decision-making processes in digital medicine is needed.

Research evidence shows that Healthcare Information Technology (HIT) can make a positive impact on reducing healthcare costs, for example real-time remote diagnostics and health monitoring (e.g., telemedicine) by using smart mobile devices and Internet technologies. Although HIT is becoming part of the critical infrastructure for improved digital health scenarios, the evolving process of adoption and use is slow among practitioners and patients, with both groups indicating concerns about information security and privacy. One of the key inhibitors is patient liability when using HIT for medical and health related decision-making processes, whilst another main barrier is physician dissatisfaction with these systems. This dissatisfaction is often related to time commitments for unfamiliar and sometimes unreliable (e.g., the technology not being user friendly) computer applications and the time taken to learn such new processes, protocols and how to use new information systems. Furthermore, adoption of HIT leads to demands for social value, like user acceptability where there are compelling reasons why the system must be used. However, a number of issues continue to arise, including cost factors (e.g., time commitments, potential loss of productivity and efficiencies of using the system) and poor levels of usability (e.g., user friendliness), which have been cited as being some of the biggest obstacles [5]. These factors often do not receive enough consideration when HIT applications are developed and integrated with healthcare systems that aim to improve the healthcare processes in long run. This is predicted to change as physicians and medical practitioners become more comfortable with computers and web-based healthcare offerings and in conjunction with telemedicine vendors devising more convenient technology and helpful applications. However, in order to support these endeavours, it is important and timely to evaluate factors such as HIT usability and information accountability when developing healthcare applications, which will form the focus of this paper.

1. Information Accountability

Information accountability focuses on the concept of monitoring use of personal information and holding the users of that information accountable if that information is misused [6][7]. Information accountability is not a new concept but rather this phenomenon had been used for other systems like accounting and financial systems for a longer time. Information accountability in the digital healthcare paradigm is bedrock for effective clinical governance and a catalyst for healthcare information technology [7]. In general, accountability for processes can form a good building block for further work, such as measuring actual outcomes of care [6, 7].

2. Usability

Broadly speaking, usability can be defined as a measure of ease of use and usefulness of an information system in terms of its: (1) effectiveness, (2) efficiency, (3) enjoyability, (4) learnability, and (5) safety [8]. These attributes or dimensions of usability are useful in focusing attention on key aspects of the use of systems in the design and evaluation of health information systems. For example, to lead to uptake and adoption by end users, health information systems need to both effective and

efficient. Learnability is also essential, as is safety in order to ensure that information systems in healthcare do not inadvertently cause users to make medical errors. Furthermore, systems must be satisfying for end users. Poor usability has been cited as being one of the main reasons for lack of end user adoption of systems and health professional dissatisfaction with HIT [9]. To ensure that systems are usable, a variety of methods from the field of usability engineering have been applied to HIT and continual evaluation of the usability of systems under development has been recommended through iterative cycles of design and testing [9].

3. What is the connection between Information Accountability and Usability Testing?

Both information accountability and usability have a number of similarities when considered in comparison. Firstly, both can be considered as being key requirements for development of effective HIT. Along these lines, both can be considered as being "non-functional requirements", i.e. critical requirements that need to be considered for system success that are neither functional requirements nor technical requirements [10]. In order to lead to improved chances of HIT success and adoption, information accountability and the key aspects of usability (i.e. system effectiveness, efficiency, learnability and safety) need to be considered. Furthermore, both high levels of information accountability and good usability can be considered as being "soft goals" to be achieved through successive planning and iterative analysis [10]. Both are ultimately required to lead to uptake and adoption of HIT by both patients and health professionals. In this regard, methods for usability testing that focus on user experience can be expanded to include consideration of user perceptions, comments and thoughts about the accountability of information contained in health information systems they are interacting with during usability testing.

4. Healthcare Information Technology, Information Accountability and Usability Testing

In considering the broad definition of usability given above, it is argued in this paper that adding information accountability to the list of attributes/dimensions of the concept of "usability" could practically lead to improved systems and consequently more effective user adoption of HIT. From a practical point of view, studies can be designed to assess the following from the perspective of end users interacting with HIT: (1) effectiveness, (2) efficiency, (3) enjoyability, (4) learnability, (5) safety, and (6) *information accountability (this non-functional requirement is a critical consideration for HIT applications that adequately protect information privacy and security)*. This will be essential as systems that have been deemed to have met requirements of the first 5 attributes above may still not be accepted by end users without explicit consideration of making information accountable to all classes of end users. Nowhere is this more important than in designing systems intended for end users who are patients or citizens, as described in the next section.

5. Use cases and Scenarios

Our preliminary experiences to date in integrating the concept of information accountability with usability have involved planning for evaluation of PHRs and social media. Issues related to both usability (as it has been described above [8]) merged with a perspective from information accountability are being explored [7]. In terms of modeling system requirements for PHRs, we are working on including information accountability as an essential non-functional requirement (along with the other "classic" usability dimensions discussed above).

The approach we are working on is more towards a patient, public partnership (depicted in the use case scenario in Figure 1) by identifying partner participations as social interactions. Figure 1 depicts a general use case for the public with several social networking accounts. The approach is to develop protocols to integrate them all within one profile (e.g., MPM: Multiple Profile Manager) when using health information sharing and exchange (e.g, HIE). This scenario is already active without public knowledge of information sharing in the digital world (e.g., sharing through interconnected EHRs, EMRs, and PHRs). While, this social interaction is value added to health information exchange (HIE), without considering appropriate information accountability (e.g., authentication, authorization and synchronization) and without applying usability testing to obtain user input and perceptions about accountability, the acceptance of such HIT applications (e.g., the Multiple Profile Manager, -MPM [11-13]) and the sustainability of the approach will be jeopardized.

Along these lines, we are also including assessment of the end user's perceptions about needs for information accountability within the design of upcoming usability testing of several PHRs being implemented in Canada and in Australia.

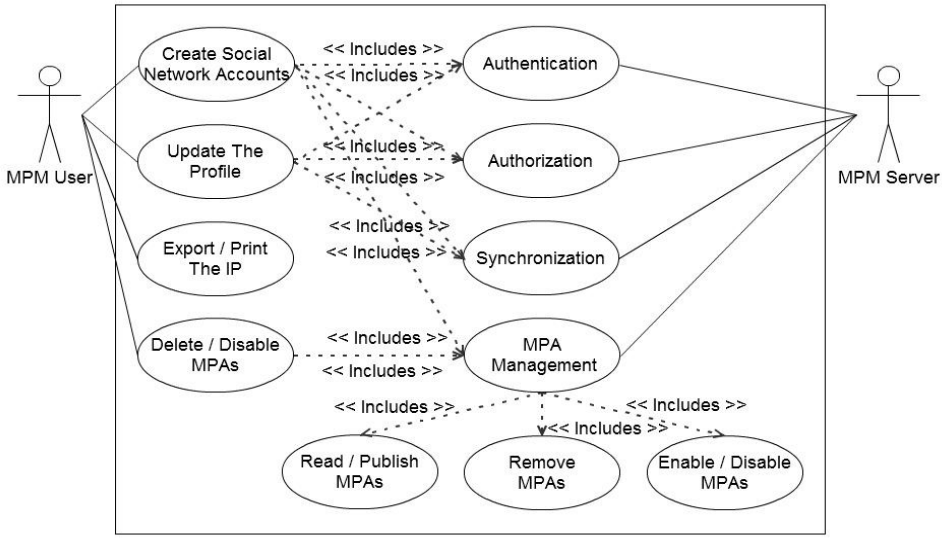

Figure 1: User Case scenario in a multiple social networking set-ups [12][13]

6. Discussion

Healthcare is an information intensive, complex, large-scale, adaptive, distributed and evolving system [14]. With advancement of technologies in particular information and communication technologies (ICT), digitalization of healthcare processes and protocols are developing in an alarming rate. While this advancement represents positive growth for the digital economy, information privacy and security are still open ended questions and there is a long way to go to for assessing end users needs. A simple approach would be to empower the patient with usability and information accountability protocols where patient become a partner in the healthcare decision making processes as well as HIE processes. This attempt might be debatable for some clinical settings however establishment of practicable usability testing and implementation of active and accurate information accountability protocols would help the sustainability of HIT and thereby lead to a reduction in mounting healthcare costs.

We have proposed a novel approach to consideration of HIT and HIE where there is integration of usability analysis with analysis of information accountability needs, with both being considered as essential non-functional requirements for patient centric HIT applications that must not be ignored. Further studies assessing end users' perception and the need for information accountability are being planned within the design of upcoming usability testing of several PHRs.

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A Review Of Healthcare Information System Usability & Safety

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Abstract. Healthcare information systems have been designed to increase the efficiency and safety of healthcare processes. Systems such as electronic health records and pervasive computing devices have been shown to improve the safety of healthcare. However, increasing research has indicated that the design of such systems, in particular the user interface, may be related to increased incidence of other types of error. In this review, the relationship between human factors and usability will be considered in the context of designing safe and effective healthcare applications, with a focus on hand-held computing devices. Medline was searched for the specific terms listed below and restricted to the date ranges 2006-01-01 through to 2011-03-03: (error AND technology AND human factors); (error AND (CPOE OR (Computerized AND provider AND order AND entry))); (Technology AND Induced AND Error). The returned list of papers was screened by examining titles and abstracts to select candidate papers for further review. The initial search yield was 239 papers. On reviewing the title and abstract, 186 were rejected and 51 papers remained for analysis. New technology, such as CPOE, offers improvements over traditional paper tools and it is shown to have a positive effect on patient safety. New technology also creates the opportunity for new errors to occur and lead to the coining of the term "technology-induced error". The magnitude of the usability-testing needs is larger than it may seem.

Keywords. Usability, technology-induced error, simulations, health information systems, patient safety, CPOE, EHR, health informatics, biomedical informatics

1. Introduction

Information systems have been designed to increase the efficiency and safety of healthcare processes. The predominant paper technology is inadequate for meeting the needs of modern healthcare [1]. Mobile devices, such as smartphones and tablets, are a pervasive technology. They can facilitate messaging, time management, education and telephony. They also have the ability to easily retrieve and run health-related software 'apps' from online repositories. Consequently, mobile devices are now capable of many assistive roles, particularly the ability to display and manipulate medical information in clinical settings. In Canada, health information systems (HIS) adoption rates lag behind those of other countries [2]. Considering the low HIS adoption rates and the rapid mobile device adoption rates, it is not unreasonable to suggest that adoption of these pervasive devices will outpace the adoption of HIS systems – if they have not already done so. The issue for safety is the evidence that new technologies, despite their clear advantages over paper technology, can be the root cause for new

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kinds of errors. Research in this area has indicated that the design of new technology, in particular the user interface (UI), may be related to increased incidence of new types of error [3], [4]. In this paper, the relationship between human factors and usability will be considered in the context of designing safe and effective healthcare applications, with a focus on computing devices.

2. Methods

Medline was searched for the specific terms listed below and restricted to the date ranges 2006-01-01 through to 2011-03-03:

1. (error AND technology AND human factors)
2. (error AND (CPOE OR (Computerized AND provider AND order AND entry)))
3. (Technology AND Induced AND Error)

3. Findings

3.1. Search results

Table 1. The Medline search resulted in 239 papers. After reviewing the title and abstract, 186 papers were rejected and 51 papers remained for review.

Inclusion Criteria		**Title Exclusion**	***n***	**Abstract Exclusion**	***n***
User Errors		Not data-related	37	Wrong device	20
Data entry		Other tools	27	Not medical app	17
Data access		Tablet is medication	16	Not clinician	9
Computing		Surgical devices	13	Review off topic	17
HCI		Not medical	5	Inaccessible	4
User interfaces		Education	3	Duplicates	4
Usability		Workflow	3	Education	13
In English					
Remaining	*239*		*135*		*51*

3.2. Categorized selected papers

Table 2. The remaining papers were classified into the following sets. Countries abbreviated as per ISO 3166 standard

Paper Type	***n***	**Research**	***n***	**Technology**	***n***	**Country**	***n***
Critical Reviews	1	Case Studies	4	CPOE	27	US	21
Lit. Reviews	10	Interventions	10	Devices	2	CA	10
Methods	10	Observations	3	HIS	18	NL	9
Research	30	Prospective	1	Paper	3	AU	4
		Retrospective	4	Workflow	1	DK	2
		Simulations	6			IL, FR	2
		Surveys	2			IR, IT	2
						LB	1
Column Totals	*51*		*30*		*51*		*51*

3.3. CPOE themed papers

CPOE themed papers in this review demonstrated that this specific IT implementation caused the following: a positive effect on safety, particularly when coupled with a decision support system (DSS) [5], increased compliance and improved legibility [6].

A review by Reckmann reported that between 1998 and 2007, the evidence that CPOE interventions reduced errors is limited and not compelling [7]. Another review by Weant [8] reported that errors increased during a paper to CPOE transition. Further, inappropriate alerting, alert fatigue, inappropriate dose defaults, workflow disruption and multitasking effects experienced and measured after CPOE implementation, all contributed to a reduction of patient safety. Errors caused by features unique to the IT implementation can be considered technologically induced errors. Many of the papers call for further investigation and ask new research questions: What cognitive processes contribute to alert overriding? Can heuristics be used to detect prescription errors? Can frequently overridden alerts be safely disabled?

3.4. Paper-based fieldwork on CPOE interventions

Paper itself is a common theme in this search, primarily because CPOE implementations or interventions are done to replace the traditional paper-based workflow. Paper-themed research using qualitative semi-structured interviews [9] identified 11 distinct reasons for using paper, they are: efficiency, ease of use, memory, preference, awareness, task specificity, task complexity, data organization, time management, trust and data security. The study discusses these findings in detail and concludes that in some cases paper was a valuable tool, i.e., as a cognitive short-term memory aid, and in some cases an impediment to safety, i.e., when paper was used to circumvent the intended use of the EHR, a potential path to error.

Miller, describing an interesting example of an *in situ* study, uncovers a basic truth missing from many of the technology-implementation papers in this review. For five days at the bedside of five terminally ill patients, researchers recorded clinical conversations. The participants were the clinicians caring for these. The researchers were investigating the merits of paper as a clinical technology prior to a CPOE installation to test two hypotheses A) that paper-based tools are used in different ways by doctors, nurses and other professionals, and B) that different paper artefacts (forms) support different decision-making processes. The statistically significant results of the investigation supported the hypotheses and led to two design principles 1) that effective information systems must support interdisciplinary interactions, and 2) that they must support decision processes, information flows and practice in addition to data entry. Miller's paper argues that the IT solution should not be used to replace paper-use as a record-keeping system; rather, and more importantly, that they replace the functions of the paper-based tools provide to clinicians while they go about their daily activities, i.e., paper forms and worksheets are seen as tools of collaboration not merely tools for data. Therefore, IT systems aimed at replacing paper-based systems need to consider the users' needs for collaborative enablers and not just data storage and retrieval [10]. This notion was also discussed in [6] where the authors concluded that the workflow impediments introduced by the paper-replacing CPOE system caused error-inducing conditions which led to safety concerns and as a result, new systems must address the communication needs that integrate the work of nurses and physicians. Hysong et al, contributed to the body of methods by proposing a protocol consisting of qualitative

methods and a human factors approach to evaluate systems and processes that lead to diagnostic and medication error. The resulting protocol describes methods adapted from human factors and psychology to analyze the ways in which providers currently use CPOE to communicate and identify barriers to effective electronic communication [11]. Fieldwork by the foregoing researchers has provided valuable insight into the nature of teamwork paper-use and the introduction of new technology.

3.5. Simulation methods and effect of realism

Many more studies advocated and used simulation methods in their investigations. Lilholt, in a paper responding to published concerns about applications being unsuitable for clinical use, devised and tested a usability evaluation to investigate problems in an EHR system by combining methods from laboratory tests and field studies [12] and applying them in a realistic ward-simulator using an actor to play the part of a patient. Lilholt concluded that some of the usability issues encountered only manifested due to the realistic setting, suggesting that if the scenario were not realistic, some usability issues would not have been revealed. Papers reporting high quality simulations seemed to have fewer stated limitations seemed more effective and perhaps left less room for doubt or criticism due to the effects of a simulated environment. Although simulations may seem limited by their implicit lack of realism, their safety-related use in other industries, notably aviation and nuclear power control, is widespread.

3.6. Technology-induced error and the role of simulation

In 2009, six papers were published describing and advocating simulation-based research methods on new technology and human error. Five of these, from the University of Victoria Department of Health Informatics, deal specifically with research methods to: test, analyse root causes, develop heuristics and prevent [13] technology-induced error in healthcare. Carvalho et al, on a similar theme, found that simulation methods may be used with success to prospectively evaluate clinical hardware and software and, using heuristic evaluations, predict the likely error-rates of systems before they are procured and deployed in large numbers [14]. The simulation methods differ from Lilholt's study in that much simpler methods are advocated and no highly realistic environments are necessary. For example, a researcher could gather data by video recording and screen-recordings of a clinician sitting at an ordinary desk. The coding and analysis may be done elsewhere, even in a different country separating the low-skilled data collection from the expert analysis. Another example given is a cognitive walk-through where software can be assessed by an expert using a set of research-derived heuristics and evidence-based metrics [15]. This body of research recommends that more evidence-based usability studies be done on the ever-growing list of available electronic medical devices, hardware and software. All technology-induced error studies reviewed here also advocate the utility of using mixed-methods primarily to investigate the human factor of the new errors manifested in the use of new health IT systems.

3.7. Usability testing to predict unsafe technologies

Usability tests are performed to analyze a system that consists of three parts: hardware, software and the users. Papers from studies of human factors – beyond the scope of this review, but still relevant – show that older and younger adults use the same tools in different ways, suggesting that life experience and risk-taking play a part in the cognitive processes of decision-making [16]. People vary in ability, skill, familiarity, competence, confidence and style. According to the reviewed papers, many clinical tool devices and systems do not offer any adaptation to users' variability. User interfaces are criticized for inflexible login modes, poor medication models, rigid controls, inflexible processes, ordering formats, rigid design and rigid workflows [17]. Examining a tool for usability can reveal these issues and potentially predict the likelihood for and magnitude of technology-induced error.

The need for more granular usability studies is evident in the reviewed papers. Buchel found "that devices which are already on the market differ drastically in their usability [… and] that unsatisfying usability bears a high risk in health care." [18]. That one device proves to be usable, does not mean that another similar device or its software, is automatically similarly usable. One cannot state with confidence that because a particular EHR app is deemed 'usable' on one tablet computer with a touch screen as its main input device, will be just as usable on a similar tablet that uses a stylus. Ideally, every device-software combination should be vetted for its error-inducing potential as part of the procurement process. New technology arrives regularly in the form of mobile hardware and cross-platform software. Improvements and major changes to both are also frequent and can come with radical user interface changes that fundamentally alters the way the device-software is used – rendering any previous usability analysis, published or unpublished, as superfluous.

The variety of mobile devices is increasing. The need for either more usability assessments or tighter restrictions on their use in the clinical setting will be needed to measure and control patient safety issues.

4. Conclusion

New technology, such as CPOE, offers improvements over traditional paper tools and it is shown to have a positive effect on patient safety. New technology also created the opportunity for new errors to occur and led to the coining of the term *technology-induced error*. The human factors of device and technology use, in particular transitioning from the team-based use of traditional tools discussed in this review, show that this area is under-investigated.

Fieldwork is essential to assess the validity of simulation studies and to gain insight on the working practices of teams. Likewise, realistic simulations are useful to demonstrate the minutiae of device use when an actor-patient is present. The bulk of actual usability work is better done using simulation methods. The bulk of actual simulations for usability research can be done using low-cost methods. This is important because of the great volume of testing needed due to the ubiquity of mobile devices and access to clinical and clinical-style software available to owners of these devices. Ideally, each device-software pair should be assessed for its error-inducing properties. To cope with the increasingly rapid growth of this area of technology more usability testers and facilities will be required. Further research-methods studies and

evidence-based metrics are needed to generate more efficient and simpler usability protocols. The scope of this usability-testing problem is larger than it may seem given the current proliferation and global distribution of new, sophisticated mobile devices and un-vetted access to health-related software.

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Commercial versus In-Situ Usability Testing of Healthcare Information Systems: Towards "Public" Usability Testing in Healthcare Organizations

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Abstract. The need for improved usability in healthcare IT has been widely recognized. In addition, methods from usability engineering, including usability testing and usability inspection have received greater attention. Many vendors of healthcare software are now employing usability testing methods in the design and development of their products. However, despite this, the usability of healthcare IT is still considered to be problematic and many healthcare organizations that have purchased systems that have been tested at vendor testing sites are still reporting a range of usability and safety issues. In this paper we explore the distinction between commercial usability testing (conducted at centralized vendor usability laboratories and limited beta test sites) and usability testing that is carried out locally within healthcare organizations that have purchased vendor systems and products (i.e. public "in-situ" usability testing). In this paper it will be argued that both types of testing (i.e. commercial vendor-based testing) and in-situ testing are needed to ensure system usability and safety.

Keywords: human computer interaction, usability, usability testing, in-situ

Introduction

The usability of healthcare information systems has been recognized as being critical to the successful deployment, adoption and appropriate use of these technologies. Over the past several decades a wide range of usability engineering projects, efforts and laboratories have emerged to address these issues. However, despite these efforts, the usability of healthcare IT (HIT) is still reported as being problematic, particularly when commercial vendor systems, such as electronic health record (EHR) and electronic medical record (EMR) systems are deployed in offices, clinics and hospital settings. The reporting of a considerable number of usability problems and issues with these systems is not just localized to Canada but is an international phenomena [1]. Many vendors and developers of healthcare software are now applying usability engineering methods, such as usability testing. However, despite this, the usability of HIT is still considered to be problematic and many healthcare organizations that have purchased systems that have been tested at vendor testing sites are continuing to report a range of

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usability and safety issues [2]. In this paper we explore the distinction between commercial usability testing (conducted at centralized vendor usability laboratories and limited beta test sites) and usability testing that is carried out locally within healthcare organizations that have purchased vendor systems and products (i.e. public "in-situ" usability testing). It will be argued that both types of testing (i.e. commercial testing) and in-situ testing are needed to ensure system usability and safety. It will further be argued that on-site in-situ usability testing can provide organizations who have purchased vendor HIT systems with critical feedback for: (a) customization of those systems to improve usability, (b) improved user training, and (c) evidence to present back to vendors in cases where usability is deemed to be extremely poor, leading to potentially "unsafe" installations of HIT. It is also argued that there is a need for closer collaboration between vendor usability efforts and efforts to improve usability that are spearheaded at local healthcare institutions and which purchase HIT from vendors.

1. Low-Cost Rapid Usability Engineering Conducted "In-situ" in Local Healthcare Settings

In this part of the paper we will describe the low-cost rapid usability engineering approach we have developed and refined that can be applied within local healthcare organizations (e.g. medical offices, clinics and hospitals) for doing usability testing. We will refer to this approach as "in-situ", as it is conducted in the real-life settings in which healthcare IT is deployed (e.g. electronic health record deployment within the hospital setting the system will be implemented in). Figure 1 shows a continuum from vendor-based testing (conducted at vendor usability labs or beta test sites) to "public" in-situ usability analyses carried out at the actual institutions where the healthcare IT is being deployed. We have found that in-situ usability testing can be carried out effectively by IT staff or health informaticians at local healthcare organizations without requiring extensive training in the methodology, as the approach has been streamlined for deployment for a variety of settings and locations both nationally and internationally.

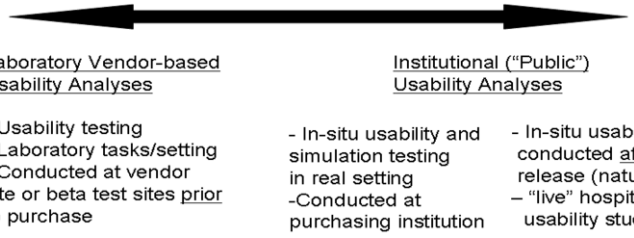

Figure1. A continuum of usability testing from vendor analysis to "public" usability studies

The applications evaluated range from the evaluation of a medication order entry system (using bar-coding technology) prior to its deployment in a hospital in Japan [3] to the study of an introduction of an EMR at major American medical center (involving in-situ testing both before and after system going live) [4].

Applying our approach to in-situ usability testing, our work is typically carried out in real clinical settings (e.g. a physician's office, in a clinic or even in an operating room after hours). The approach typically involves asking between 8-10 subjects (e.g. nurses or physicians) to interact with a system under study (e.g. an EMR) to carry out tasks (e.g. to enter medications from a medication list). In addition, subjects may also be asked to "think aloud" while carrying out the task, which is audio recorded. Overt physical activities of the subjects (e.g. checking information in the computer against paper records on their desk) are recorded using one or more low-cost portable digital cameras. The computer screens are also recorded as a digital movie, using free screen recording software installed on the computer running the system being tested (we are currently using Hypercam©). When running this software (by simply plugging a microphone into the computer) the result will be a movie of the user-computer interaction with the audio track of the subject's verbalizations (i.e. "thinking aloud"), which can be played back for immediate informal review and analysis. Thus data collected consists of digital movie files showing what users are doing on the computer which are linked to audio recordings and which can also be linked to the external video view of physical activities if needed. Using this approach we have carried out studies of HIT in environments ranging from physician offices to patients' homes. An extension of the approach involves continuing to record users interacting with the system once it is released for real use (obtaining of course, ethical approval).

In order to substantiate the benefits of this approach, recent work by Baylis, Kushniruk and Borycki involved conducting a formal cost-benefit analysis of conducting in-situ usability testing on a disease management software system to be released throughout a healthcare system at a provincial level [5]. From this work, it was found that in testing only a small subset of the system's functionality the total cost (including one-time cost of buying a laptop for testing purposes) was approximately $8,000 with the most conservative estimate of benefit from this analysis being in the range of $50,000 (and with the benefits considerably greater if the cost associated with potential medical error is considered).

2. Data Collection and Recommendations for System Improvement

The analysis of the data collected from local in-situ usability testing can vary from informal playback of recordings of user interactions (e.g. playing back digital movies of user interactions with an EMR) at IT meetings, to more formal coding and analysis of identified user problems and even statistical analysis. Most of our work involves an analyst viewing the data and developing qualitative categories of problems (e.g. navigational problems, problems users have in interpreting information presented and other types of usability problems) and then quantifying the occurrence of the problems (e.g. tabulating the frequency of the most common usability problems). The result of this analysis can then fed directly back to the local system implementation team and prioritized for remedial action (e.g. either through local customization, or feedback to local user training). In cases where usability problems are deemed to be critical to fix at

the local level, but the nature of the software (or the nature of the contract with the vendor) precludes fixing at the local level, the data collected (and recommendations made) need to be reported back to the commercial vendor for making more fundamental changes to the software. Some of our work has involved applying low-cost portable in-situ testing to identifying potential technology-induced errors that may be caused by a system (e.g. inappropriate medication defaults in an order entry system), or by poor user interface design [6]. It should be noted that by testing systems in their real environment of use (as opposed to testing them in a vendor usability laboratory, or only conducting usability testing at some beta test site), then problems and issues that would only arise in the local setting (i.e. the hospital which purchased the system) can be detected, analyzed and prioritized prior to system release. Along these lines, many of the issues noted in the literature with the deployment of HIT are related to local conditions, contexts and work environments, making this approach to usability testing important to detect problems that would otherwise go unnoticed until a vendor system is actually running live within a healthcare organization. This local testing is essential for ensuring not just the usability but also for ensuring the safety of HIT deployed in real-world contexts.

3. Experiences to Date

We have applied the methodology described above at varied locations internationally. Our first work applying the approach involved testing an electronic record system being deployed at a major American medical center in New York. From this work it was calculated that the in-situ testing resulted in a ten-fold decrease in usability problems (with a cost for conducting the analysis of under $10,000) [7]. A range of usability problems were identified and prioritized for fixing (based on frequency of occurrence and cost of fixing) including user interface consistency problems, problems in matching of terms used in the system to user selected terms and problems in representing temporal data. This study was conducted within the hospital setting over several days. More recently, we have employed our refinement of the method to examine the impact of clinical best practice guidelines on physician workflow using an electronic medical record system at a second major American hospital center in New York [4]. This involved both in-situ testing of users interacting with the guidelines both (prior to widespread release) as well as naturalistic testing of the system after deployment for use with real patients (using the same unobtrusive recording technology and set up in both cases). This analysis involved three phases of work. In phase one usability testing was conducted with 8 physicians who were asked to interact with the guidelines embedded in a major commercial EMR. After fixing the surface level usability problems identified from the first phase, as second phase was conducted where a new group of physicians interacted with the guidelines while interviewing a "digital" simulated patient. This work led to fixing of problems that occurred in the triggering of guidelines under realistic conditions. Finally, we are currently examining naturalistic data we have continued to collect on real use of the guidelines within the organization. It should be noted that all three phases were conducted in the real hospital setting, using the commercial vendor based system that was deployed at the institution. The analysis detected usability problems that were corrected locally (prior to widespread system release) that were not anticipated by the vendor of the EMR, with a

resultant high level of user uptake of the clinical guidelines (as determined from a subsequent full scale trial that was conducted) [4].

4. Discussion

From our work we have found that many usability problems and errors that are encountered in real clinical contexts are not detected or corrected by usability testing conducted at centralized vendor usability laboratories prior to system release (or at only selected beta test site healthcare organizations). We do feel that vendor-based testing (including vendor usability laboratory testing, as well as regional centralized conformance testing of vendor products) is necessary. However, it has been argued in this paper that centralized private usability testing (such as that conducted by major EHR vendors) needs to be complemented by "public" in-situ testing to ensure system usability and safety. Current issues and challenges include getting permission to conduct studies in a real environment and also obtaining rooms and locations after hours for conducting in-situ usability testing. Furthermore, there is a need for improved communication between healthcare institutions and vendors in order to allow for the most serious usability and safety problems identified at the local level to be fed back for software improvement at the vendor level. It is argued that if we are to ensure that the systems we implement are both usable and safe, then these additional types of studies (conducted in-situ at local healthcare organizations) are necessary and that they can be carried out in a cost-effective and beneficial way to improve the safety and efficiency of healthcare IT.

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Integrating Human Factors in an International Research Project: Lessons Learned from the PSIP Project

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Abstract. This paper presents how a Human Factors (HF) engineering approach has been applied to a European Project aiming at preventing Adverse Drug Events. Methods used by HF experts and their main contributions are depicted. Main lessons learned from HF involvement in this project are proposed in terms of methods for ADE prevention interventions and project management.

Keywords: user-centered design, human engineering, adverse drug event, CDSS

Introduction

Human Factors (HF) activities are increasingly applied during the design of Health Information Technology devices/software. Those activities consist in applying HF expertise and methods all along the project and in involving representative end-users at every step. Applying those methods supports a better consideration of HF issues in the design, development and evaluation of devices. Ultimately it has a positive impact on the acceptance of the product [1] and on the effectiveness of the product [2]. The HF strategy is even recommended to comply with the European Medical Device Directive [3] specifically to prevent the risk of use errors related to ergonomics features [4].

One of the most common HF strategies is the User-Centered Design process (UCD) [5]. As described in Figure 1, this process includes four iterative HF activities ranging from the analysis of the context of use and the specification of the users' requirements to the design itself, the iterative evaluation of the solutions to ensure that it meets users' requirements and a long-term post-implementation monitoring. Besides, to improve the performance of the user-centered part of the system development (*e.g.* improving UCD process efficiency), a "process for usability" application is also proposed [6]. This process is composed of 7 activities (Figure 2) starting with the overall consideration of UCD process in the lifecycle (#1), then ensuring the management of the UCD all along the process (#2), achieving all UCD tasks (#3 to #6) and finally supporting the implementation of the product (#7).

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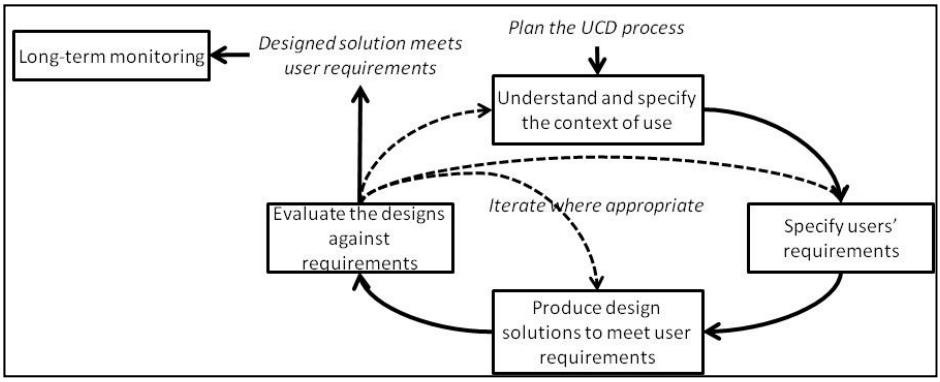

Figure 1. The User-Centered Design process adapted from the ISO 9241-210 [5].

The paper at hand presents how the HF strategy, inspired by the HCL, has been planned and conducted during a European Union project. Lessons learned from this experience are presented.

1. Background: HF engineering in the PSIP project

The European Union project entitled "PSIP - Patient Safety through Intelligent Procedures in Medication" aimed to (a) innovatively produce new knowledge on Adverse Drug Events (ADE) (by data/semantic mining methods) and (b) investigate different possibilities for reducing ADE (*e.g.* developing knowledge to be integrated into Computerized clinical Decision Support System (CDSS) and solutions supporting patients' compliance) [7]. The entire project was considered as a patient-safety intervention aiming at identifying the current barriers against ADE existing in hospital settings and at reinforcing them through innovative technologies [8].

Table 1 describes the compliance of the PSIP project with HCL. Following the requirements of the UCD process, HF experts worked tightly with researchers and industrials in the shaping of the produced knowledge and in the design of the applications displaying this knowledge to clinicians and patients.

Three teams of HF experts from three countries (Italy, Denmark, and France) characterized by different background expertise worked together on the project in cooperation with a Danish patient-safety unit.

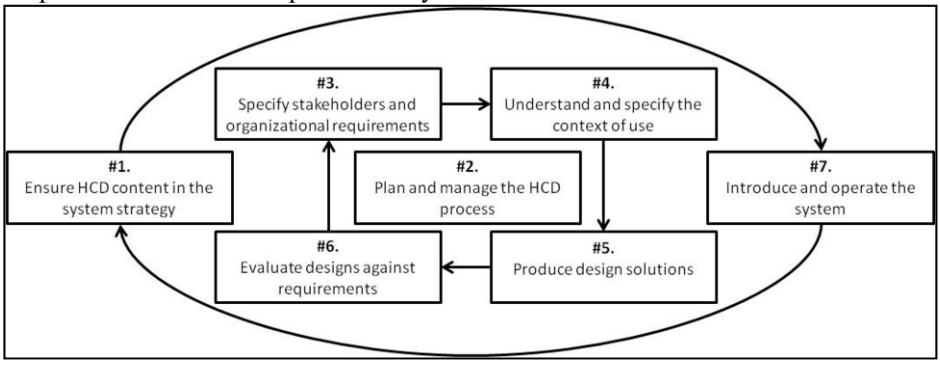

Figure 2. Human-Centered Lifecycle (HCL) process description adapted from the ISO 18529 [6].

Table 1. Human-centered lifecycle process activities applied to the PSIP project.

HCL activities	Corresponding activities in PSIP
#1	UCD process was explicitly integrating in the project as accepted and funded by the EU
#2	Human-centered activities were defined beforehand in the project plan and HF representatives participated in the management board.
#3 #4 #5 #6	A UCD process has been followed to design the applications developed during the project.
#7	Within the duration of the project (40 months), the most advanced application (ADE-scorecards) has been installed in a hospital and a one-year monitoring has been performed.

2. Methods

Main contributions of each HF team are presented in **Table 2**. Those methods were applied all along the project for the HF patient-safety intervention and for the development of innovative ADE prevention tools. Therefore representative end-users and industrials have often been engaged (*e.g.* through focus groups, tests) all along the project to optimize the intervention and the design process. Finally, HF experts worked on a list of HF recommendations for the design of medication-related CDSS. Those principles were proposed to industrials partners to assess their appropriateness and technical feasibility.

3. Results - Lessons learned

Integrating HF expertise all along the project and at every level proved to be an efficient approach. Participation in the management board is essential for the HF approach and results to be actually integrated in the decision and development process.

3.1. ADE prevention requires complementary tools for the whole healthcare team

The multi-perspective approach allowed identifying that ADE prevention requires more than a single tool addressed to a single healthcare professional. On the contrary, a set of functions reinforcing the existing effective barriers developed by every professional is necessary.

Table 2. Expertise fields and main contributions of each HF team. Tasks were often carried out in cooperation.

HF teams	Expertise	Main contributions
Italy	Italian's expertise was oriented toward the error prevention through barriers analysis and came from the aviation domain.	Analysis of the existing barriers of prevention against ADE in hospital setting based on taxonomy of errors and work systems analysis [9].
Denmark	Danish expertise was related to co-design and user-driven design methods applied to medical devices and to the evaluation within a full-scale simulator.	Design support and product evaluation based respectfully on co-design process [10] (*e.g.* focus groups, prototyping) and simulation in a medical full-scale simulator [11].
	Patient safety unit	Validation of knowledge and of the interventions in terms of patient safety risk.
France	French team's skills dealt with usability, UCD process and cognitive ergonomics.	UCD process based on work system analysis, end-users involvement, usability inspection and test supported by usability goals [12].

Table 3. Functions required to reinforce the existing barriers and corresponding developed tools.

Required functions	Developed tools
Raise the ADE awareness of every involved clinician (physicians, pharmacists and nurses)	ADE-scorecards tool that allows clinicians getting an overview of the incidence and quality of ADE in their own wards.
Provide them with information at the point of care	CDSS integrated in Clinical Information System (CIS) or Computerized Prescription Order Entry (CPOE) informing clinicians in real time of the risk of ADE related to ordered meds.
Allow clinicians testing orders apart from their workflow	Standalone Intranet CDSS available to every clinicians apart from their workflow to simulate an order
Provide patients with medical information to support their compliance	Mobile patient component participating with clinicians to patients' awareness of ADE risks due to their medications.

This set is described in Table 3. Therefore, to optimally support ADE prevention, designed tools should be clinicians' partners, *i.e.* interacting with clinicians taking into account their actions, and also team players, *i.e.* supporting the cooperation between every healthcare professional involved.

Confronted to industrials' technical proposals, those functions were developed through four kinds of tools (Table 3). This set of tools was designed for every healthcare professional involved in the medication use process (physicians, pharmacist, nurses etc.). Hence, they are not workflow-dependent and may be implemented in different kinds of work organizations.

3.2. Safety oriented UCD process is useful to make release decisions

Following a safety-oriented UCD process allows assessing the usability level of the different tools and whether their usability features may cause use errors. Therefore sufficiently usable tools without usability flaws that may cause use errors can be identified and released.

During the project, the different tools did not achieve the same usability maturity. At the end of the project, the patient component still faced remaining usability flaws along with knowledge display issues. Those problems may have caused use errors. Therefore, this tool was not released and researches about how to provide patients with medical information had to go on. As for the integrated tools, they were more difficult to evaluate than the standalone ones because integrated CDS functions inherit the usability features from CPOE/CIS. Thus it was not obvious distinguishing the proper CDSS usability features from the main system ones. At the end of the project, improvements still had to be done on them to ensure that no usability flaws would cause use errors. Finally, the standalone CDSS and the ADE-scorecards were assessed as sufficiently usable and use error-prone-free and were released. The ADE-scorecards were even installed in test wards of a northern France hospital for an impact study [13].

3.3. Industrials-HF experts collaboration is a win-win cooperation

The tight cooperation between HF experts and industrials (knowledge and CIS/CPOE vendors) in shaping of the knowledge and designing the tools convinced the industrials of the usefulness of the HF approach: they are still working with PSIP HF experts for the PSIP follow-up and they integrate now HF engineering in their technological innovations projects. From the HF perspective, based on industrials' collaboration, the

appropriateness and the feasibility of formulated principles for the design of CDSS were validated [14] improving their usefulness.

4. Conclusion

The PSIP project ended-up successfully one year ago. The positive dynamic it created amongst participants (industrials and health institutions) still continues. The ADE-scorecards tool is well-received by users and health institutions. It is still installed in the test wards to continue the impact evaluation in terms of patient safety on a longer duration. Several hospitals are asking for roll out.

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Usability Inspection to Improve an Electronic Provincial Medication Repository

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Abstract: *Background:* Medication errors are a significant source of actual and potential harm for patients. Community medication records have the potential to reduce medication errors, but they can also introduce unintended consequences when there is low fit to task (low cognitive fit). PharmaNet is a provincially managed electronic repository that contains the records for community-based pharmacy-dispensed medications in British Columbia. This research explores the usability of PharmaNet, as a representative community-based medication repository. *Methods:* We completed usability inspections of PharmaNet through vendor applications. Vendor participants were asked to complete activity-driven scenarios, which highlighted aspects of medication management workflow. Screen recording was later reviewed. Heuristics were applied to explore usability issues and improvement opportunities. *Results and Discussion:* Usability inspection was conducted with four PharmaNet applications. Ninety-six usability issues were identified; half of these had potential implications for patient safety. These were primarily related to login and logout procedures; display of patient name; display of medications; update and display of alert information; and the changing or discontinuation of medications. *Recommendations:* PharmaNet was designed primarily to support medication dispensing and billing activities by community pharmacies, but is also used to support care providers with monitoring and prescribing activities. As such, some of the features do not have a strong fit for other clinical activities. To improve fit, we recommend: having a Current Medications List and Displaying Medication Utilization Charts.

Keywords Drug Information System; Usability; Medication Management; Improvement

Background

Medication errors are a significant source of actual and potential harm to patients [1]. Medication errors can include the wrong dose, frequency, route, and allergy details [2], duplicate dosing [3], and other unintended interactions [4]. Community medication records have the potential to reduce medication errors throughout the medication management workflow [5, 6], such as: providing medication information at the point of prescribing and dispensing [7], and supporting medication reconciliation [8]. However,

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using information systems may also inadvertently introduce unintended consequence [9]. They can introduce new types of errors, depending how the information system was designed and its usability [3]. This can be the case when the tool has a low cognitive fit to the task. Cognitive fit refers to match between the problem-solving task (e.g. reviewing a patient's medication history) and the problem representation (e.g. electronic dispensing record) [10]. Higher cognitive fit improves performance, as has been seen in medication administration records [11]. The purpose of this research was to inspect the usability of a representative community based medication repository, and explore the fit of a dispensing record for common clinical tasks at the point of care. We then drew out recommendations to improve design of medication repositories / dispensing records, with a focus on patient safety and improving cognitive fit.

Methods

PharmaNet is a provincially managed electronic repository that contains the records for community-based pharmacy-dispensed medications in British Columbia. PharmaNet is accessed by community pharmacists and physicians through certified 3rd party vendor applications [12]. PharmaNet vendors were sent an invitation letter via email. Vendors who agreed to participate completed activity-driven scenarios using five existing test patients from the PharmaNet training environment (not real patient data). We developed standardized user activities to highlight aspects of medication management workflow that were covered by PharmaNet's features (determined by reviewing the PharmaNet conformance specifications and mapping these to medication management workflow). (e.g., Figure 1, all annotated walkthroughs are available freely at ehealth.uvic.ca).

We completed usability inspections remotely via screen sharing, which permitted us to view the vendors' screens on our local computers. We facilitated inspection sessions while the vendors walked through the scenarios. We took extensive notes, and the screen was recorded for analysis. Three analysts attended the walkthroughs. One analyst reviewed the sessions in detail using Jakob Nielsen's ten usability heuristics [13]. A severity scale was not used; rather specific issues were mapped to focus on broader design issues and improvements. The other team members reviewed the inspection report to ensure accuracy and completeness. Confidential usability reports were provided back to the participants to inform potential product improvements. Aggregate findings related to usability issues that had potential safety issues were collected and summarized. We compared these findings with the conformance specifications.

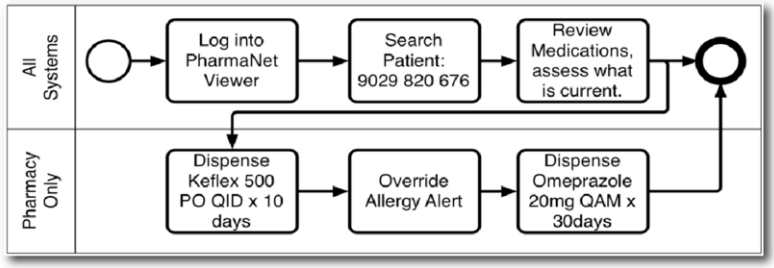

Figure 1: Example walkthrough for usability inspection. Simulated patient with allergy to penicillins.

Results

Seven PharmaNet vendors, selling one or more PharmaNet applications, were invited to participate; two consented. Usability inspection was conducted for four PharmaNet applications (all participating vendor products). Inspection occurred in March 2011.

Ninety-six usability issues were identified across the four applications. The largest proportion of observed usability issues (44%) was related to error prevention (conditions that could lead to errors, e.g., being unable to confirm an action before proceeding). Half (49%) of the observed usability issues had potential implications for patient safety as determined by the analysts. Usability issues with implications for safety were primarily related to: login and logout procedures (e.g., unclear procedures; user name not clearly displayed); the display of patient name (e.g., patient name lost in scrolling or covered by popup windows); the display of medications (e.g., no current medication list, current medications not labeled, potential truncation of medication administration directions, difficult to locate dose changes); the update and display of alert information (e.g., timing of alerts, adverse reactions linked to a specific drug code not the active ingredient or class); and the changing or discontinuation of medications (e.g., unclear dosage selections, lengthy or incomplete picklists).

Discussion

For *login and logout procedures*, it is important to ensure that the correct authorized user is accessing the system at any given time. A poorly visible login feature can increase reliance on the previous user to logout; similarly, a poorly displayed logout function can make it difficult for users to remember to logout [3]. We observed ways to mitigate these challenges, including: clear login and logout buttons that do not scroll off screen; straightforward, logical login and logout procedures; and screen timeout.

The *display of patient name* should be constant and consistent to help reduce the likelihood that the wrong patient is being reviewed [3, 14]. There can be many interruptions in practice; therefore, the patient name should never be obscured on screen. We observed the patient name lost in scrolling, overlapping boxes, or not appearing on each screen. It should be consistently and clearly displayed along with key identifiers to ensure the right patient is being accessed at all times [15].

One of the key functions of a medication repository is to *display medications* to a provider. A chronologic dispensing record can be very helpful to providers [16]; however, for many of the common medication related activities, it requires the user to perform excess cognitive tasks. For example, to determine an expected list of current medications from a dispensing record, the user must review each dispensing item and calculate an expected end date and then compare it to today's date. Similar mental calculations must be made for medication use rates. Dose changes can be difficult to locate in a long dispensing list. The user must remember current dose and then find previous dispensings and mentally compare prescribing instructions.

In terms of the *update and display of* alerts, we found good instances of clearly displayed alerts provided at the appropriate points. However, the reverse was also identified, for instance, drug allergies appearing after the user dispensed the medication. It appeared that adverse reactions are linked to a Drug Identification Number and did not appear to be linked to the active ingredient or drug class. Identical alerts could be duplicated when the vendor's own pharmacy information system provided drug-to-drug

interactions and maintained its own medication list in parallel to PharmaNet (all pharmacy information systems are required to do this). This could lead to user alert fatigue and alerts may be overlooked [17].

The patient's medication profile should be up-to-date by ensuring *medication updates* (changes or discontinuations) are in the system. This helps inform medication decision-making and to generate the appropriate alerts (e.g., drug-to-drug interactions). Limits on who can update a dispensing repository can impact accuracy of the data. These features should fit the workflow of appropriate members of the care team. For example, physicians often will cancel or change a medication dose without requiring a new dispensing (e.g. "use the medication you have already, just take half a tablet instead of a whole one"). In a dispensing repository like PharmaNet, only those who dispensed a medication could "correct" that dispensing record. Prescribers and others could not go in and change a previous dispense record to reflect the current activities of the patient; this does not fit well with the task of reviewing and updating medications.

Recommendations

Systems may be designed to support primary medication activities (e.g., dispensing, billing), but may subsequently be used to support other medication activities not originally intended (e.g., monitoring, prescribing). As such, some of the features do not have a strong fit for other clinical activities. These types of usability issues likely extend beyond PharmaNet to other dispensing records that provide medication information for clinical decision-making. At the core of these challenges is providing useful (accurate) and easy to use information to the care provider, at a time that it makes sense in the workflow [3]. Pharmacy information systems that do not support the existing workflow can lead to unintended consequences, including medication errors [14]. To improve the fit of a dispensing record to the work of reviewing medication use, we present two recommendations: displaying (and maintaining) a Current Medications List and Displaying a Medication Utilization Chart.

A *current medications list* would help a provider separate historical from current medications in a dispensing record and focus on the most recent interventions [18]. Being able to separate current from previously taken medications is an important step to informing treatment decisions. Reviewing a reverse-chronologic dispensing record requires the provider to sift through dispensing details, manually calculating and extrapolating current medications. This can be a tedious and time-consuming task that one could assume would increase chance of error. A current medications list, however, is a better fit for the task of reviewing medications and, with a better fit, reduces the cognitive load of the provider [10]. This would theoretically improve usability and reduce error, sparing the provider from mentally completing this task for each item by displaying a list of current medications within the system (Figure 2). Having current medications clearly highlighted is an important step towards gaining a picture of the patient's medication story without being overwhelmed with extraneous information.

Current Medications

Medication Details	Last Prescriber	Last Dispensed	Amount	Expected End
hydrochlorothiazide - 25 mg - tablet - oral - each morning	A. Jones	29-Mar-2012	56 tablets	23-May-2012
metronidazole - FLAGYL - **500 mg** - tablet - oral - twice a day	A. Jones	29-Mar-2012	20 tablets	07-Apr-2012
oxycodone - OXYCONTIN - **10 mg** - modified release tablet - oral - every twelve hours	A. Jones	29-Mar-2012	56 tablets	25-Apr-2012

Figure 2: Example illustration of a potential current medication list, key information such as which medications are current and when the current dispensed medications are expected to end are provided in one list.

A medication utilization chart supports a review of medication utilization by providing a visual summary of a specific dispensed medication over time. When reviewing a dispensing record, it can be difficult to draw out key information [18] like dosage changes and adherence rates (e.g., pickup frequency from the pharmacy) for a single medication over time, especially when each dispensing is represented separately and mixed with all other medications. Figure 3 illustrates an example medication utilization chart demonstrating how it can track medication usage over time (in this case, daily dispensings of methadone). Again, this tool provides a better cognitive fit to the task of reviewing medication utilization than the simple reverse-chronologic dispensing record. In this chart, the provider can see at a glance the frequency of dispensings, dosage changes, and adherence. This provides the user with an informative snapshot to inform clinical decision-making and reduces cognitive load in an already busy patient encounter. We observed one example of this in our inspections.

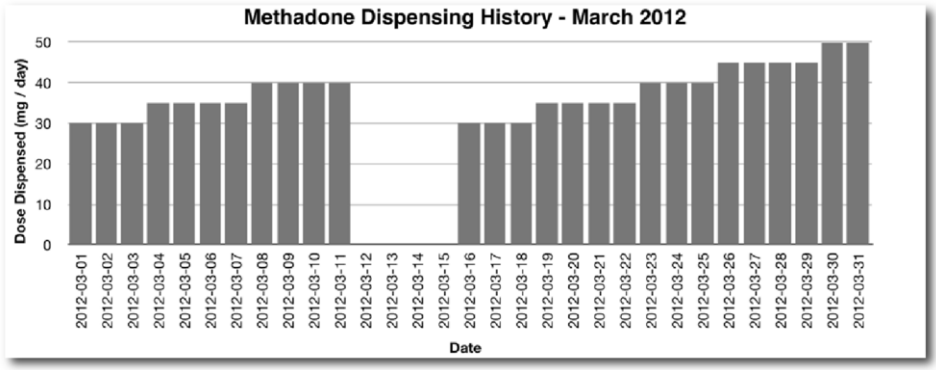

Figure 3: Example of a medication utilization chart using daily-dispensed methadone as an example. Note it is very easy to see that the patient did not get any methadone dispensed for 4 days in a row in March.

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The Long and Twisting Path: An Efficiency Evaluation of an Electronic Whiteboard System

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Abstract. Electronic whiteboard systems are becoming increasingly popular as replacements for the dry-erase whiteboards previously used for communication and workflow coordination at Emergency Departments. With this it also becomes increasingly important that these systems do not disrupt or delay the working practices of the departments where they are taken into use. Usability evaluations should therefore be employed as part of developing and implementing these systems. We report on a subset of the results from a larger usability study of a electronic whiteboard and find that there are inefficiencies, which could be mitigated by a relatively simple redesign and thus improve the usability of the system.

Keywords. electronic whiteboards, usability evaluation, efficiency, GOMS-KLM

Introduction

Electronic whiteboard systems (EW) are becoming increasingly popular as replacements for the ubiquitous dry-erase whiteboards used for communication and workflow coordination in emergency departments (ED) [1]. However, with this increase in popularity it becomes ever more important that these EWs do not disrupt or delay the working practices of the EDs where they are taken into use. Usability evaluations should therefore be conducted as part of developing and implementing these systems to uncover any potential usability issues. In this paper we report on a subset of the results from a larger usability study performed as part of an evaluation of a specific EW system at two Danish EDs. The focus of this paper will be on efficiency, which refers to the number of resources needed to complete tasks with a system and which constitutes a key aspect of usability [2]. For example, high efficiency occurs when minimal steps are required to complete a task using a system such as an EW. In this paper we explore the analysis of data collected from real users working with an EW system over time in order to determine if inefficiencies can be identified leading to proposed redesigns developed based on the analysis.

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Figure 1. Screen shot cutout of the EW system's user interface

1. Methods

The usability study was performed as a longitudinal and naturalistic study of the ED clinicians' interactions with the EW system. The study involved continuous and long-term screen recordings of the clinicians' interactions with the EW system throughout multiple five-hour periods during dayshifts at two EDs. The healthcare region and ED management approved the study prior to it being conducted. Also, because the study involved collection of live patient data the study had to be registered and approved by the Danish Data Protection Agency. Clinicians on duty during the study were briefed during morning meetings and throughout the study if questions or concerns arose.

1.1. The Electronic Whiteboard

The EW system is a web-based application installed on a central server and is accessible from all web-enabled devices connected to the same network as the server, e.g. laptops, workstations and wide screen displays. The system displays patient related information relevant for coordinating workflow and patient care e.g. name, age, medical problem, triage levels, attending nurse and physician, lab results, etc. Figure 1 presents the general information structure using a matrix with rows for patients and columns for patient data.

1.2. Procedure and Materials

User interactions with the EW were captured using the HyperCam 2 screen capture software installed on 4 Gb flash drives. The resulting video files were stored on either an external 2 Tb hard drive or a 16 Gb flash drive. User interactions were captured over a period of five days between 10 AM and 4 PM each day at two EDs. This period was specifically chosen because experience proved this was often the busiest time of the day and should therefore produce the highest number of interactions with the EW.

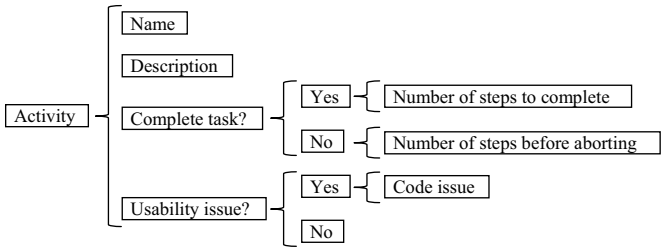

Figure 2. The coding scheme used for logging on-screen activities

The recordings rotated between different workstations throughout the departments and the wide-screen displays located in the ED command rooms. Finally, the first-author was present at the departments during the study to carry out concurrent observations and in-situ interviews with users of the EW system and to administer the recordings.

1.3. Data Analysis

Each video file was viewed and logged by the first-author using a predefined coding scheme developed by both authors – see Figure 2. The initial viewing and logging was carried out solely by the first-author due to restrictions imposed by the Danish Data Protection Agency's directives. Using the coding scheme, on-screen activity was recorded and entered as entries in separate log files. Each entry contains a timestamp, an activity indicator, a name for the activity and a description of the activity. In instances of task oriented activity the entries indicate whether or not the task was completed and the number of steps taken before completing or aborting the task. When usability issues were discovered we marked them with an indicator and coded the issues using one of the following categories: System bugs, efficiency problems, error messages and work patterns. We also provided a description of the issue including whether or not the user solved the issue.

Following the logging process both authors perused each log file and coded activities of interest for further analysis. All codings were discussed to mitigate biases in the analysis. The initial coding of the data was used to locate particular interactions of interest that were further analyzed to identify efficiency issues. In this paper we focus on the analysis of potential inefficiencies. This involved using the GOMS-KLM method [3] to calculate how much time a theoretical expert user would spend on completing a task with the EW system following a specific pathway determined by the original system design.

Based on these analyses, our approach then involves proposing a redesign aimed at improving the efficiency for that task, calculating how much time an expert user would spend using this design before finally comparing this with the GOM-KLM calculations for the original design.

2. Results and Discussion

We logged a total of 2863 entries and recorded 13 unique usability issues: 4 system bugs (55 instances), 4 efficiency issues (141 instances), 3 error messages (38 instances) and 2 inefficient working patterns (229 instances). The most common efficiency issues found in the results concerned complicated and long pathways, which the EW system forces the users to follow when using the system for specific tasks. This issue occurred a total of 63 times (44.68 % of all instances of efficiency issues) in the results. The complicated and long pathways become very apparent when new patients are added to the EW or when certain information fields are updated. In logging the video files we found that adding a new patient on average took 12.3 steps to complete. When users completed this task error free e.g. without mistakes or interruptions and provide the maximum amount of information the task required 19 steps to complete. These steps are the following: **1)** Open "Add row" dialog box **2)** Open "SSN" dialog box **3)** Input SSN **4)** Close "SSN" dialog box **5)** Open "Note" dialog box **6)** Type note **7)** Close

"Note" dialog box **8)** Open "Problem" dialog box **9)** Open problem selection dialog box **10)** Search/select problem **11)** Close selection dialog box **12)** Close "Problem" dialog box **13)** Open "Waiting for" dialog box **14)** Select waiting for option **15)** Close "Waiting for" dialog box **16)** Open "Location" dialog box" **17)** Select location option **18)** Close "Location" dialog box **19)** Close "Add row" dialog box. As this indicates the current design of the EW is based on individual dialog boxes for input into each information field. In the following, we will use the add-patient task as an example to demonstrate how the efficiency of the EW design could be improved via a simple redesign. Using the GOMS-KLM method [3] we are able to calculate how much time a theoretical expert user of the EW system would spend on completing the add-patient task (see Eq. (1) where H = moving hands between mouse and keyboard, P = pointing to a position on the display, K = tapping a key or button, M = mentally preparing for next step – see [3] for definitions of the GOMS-KLM operators). Assuming that the user starts the task with hands off the keyboard, that there is no system response time and that the user inputs a 10-digit SSN and a 30-character note the calculations will be as follows:

$$H + M + P + K + M + P + K + H + M + (K * 10) + H + M + P + K + P + K + H + M + (K * 30) + H + M + P + K + M + P + K + M + P + K + M + P + K + M + P + K + M + P + K + M + P + K + M + P + K + M + P + K + M + P + K + M + P + K + M + P + K + M + P + K + M + P + K = time\ spent\ in\ seconds \quad (1)$$

When replacing the operators in Eq. (1) with the times they represent (H= 0.4 seconds, P = 1.1 seconds, K = 0.2 seconds and M = 1.35 seconds) we find that a theoretical expert user would spend 56.4 seconds on completing the add-patient task when following the pathway that the system currently enforces. The amount of input information needed to complete the task is independent of the pathway followed and therefore cannot be reduced by redesigning the interface. However, by reducing the number of steps needed to complete the task it is possible to make the interface more efficient than the current. We will demonstrate this by proposing a theoretical interface design where the input information is entered directly in text fields or by selection via drop-down menus instead of opening new dialog boxes for each individual input. Once again we assume that the user starts the task with their hands off the keyboard and mouse, that there is no system response time and that the user inputs a 10-digit SSN and a 30-character note. In this case we have the following steps for the task: **1)** Open "Add row" dialog box **2)** Select "SSN" input field **3)** Input SSN **4)** Select "Note" input field **5)** Input note **6)** Select "Problem" option from drop-down menu **7)** Select "Waiting for" option from drop-down menu **8)** Select "Location" option from drop-down menu **9)** Close "Add row" dialog box. When applying the GOMS-KLM calculations to the proposed redesign we arrive at Eq. (2):

$$\mathrm{H + M + P + K + M + P + K + H + M + (K * 10) + H + M + P + K + H + M + (K * 30) + H + M + P + K + M + P + K + M + P + K + M + P + K = 31.25\ seconds} \quad (2)$$

Thus, it would take an expert user of the EW system 31.25 seconds to complete the task of adding a new patient when using the proposed redesign of the systems interface. This simple redesign of the EW interface thereby presents a reduction of the theoretical task completion time by 25.15 seconds (44.6 %). Taking into consideration that each ED receives approximately 40.000 – 45.000 patients each year a redesign of this pathway could prove to be a significant time saving improvement over the current

design. In a conservative estimate the clinicians provide the maximum amount of information for a new patient for every second patient admitted to the EDs and added to the EW. This leads to a time saving of 157.2 hours each year for this task alone. In cases where the clinicians do not provide the maximum amount of information this time saving will be smaller but still noticeable. Furthermore, since adding patients to the EW is not the only task where the system enforces longer than necessary pathways, a redesign of the input method used throughout the EW system's interface could even further increase the amount of time saved when using the system.

Whether or not the proposed redesign would in fact translate to actual time saving if taken into everyday use is of course a matter of further researcher and experimentation. However, previous evaluations using variations of GOMS methods have proven that these calculations are often precise [4] and therefore we feel assured that our proposed redesign would in fact provide the calculated time saving benefits.

3. Conclusions

Through our usability evaluation of the EW system we found a wide range of usability issues in the EW system. In this paper we chose to focus on long and complicated pathways within the EW system. Using the GOMS-KLM we illustrated with an example how the system could be redesigned to increase its efficiency. We found that our proposed redesign could reduce the time needed to enter a new patient to the EW by roughly 45 % and with the reservation that the clinicians do not always provide the maximum amount of information we found that this could provide a time saving of 157.2 hours pr. year. Also, since the EW system can be accessed via multiple devices the potential increase in efficiency could be far ranged and have a positive impact upon the work practices at the ED. Furthermore, we argued that this redesign could have an even greater impact than our results show since it could potentially affect a larger part of the EW than we studied here. In conclusion we call for more and earlier usability evaluations of healthcare information systems such as the EW studied here to ensure a higher quality of the systems used by healthcare professionals.

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Applying Usability Methods to Identify Health Literacy Issues: An Example Using a Personal Health Record

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Abstract. The prevalence of consumer health information systems is increasing. However, usability and health literacy impact both the value and adoption of these systems. Health literacy and usability are closely related in that systems may not be used accurately if users cannot understand the information therein. Thus, it is imperative to focus on mitigating the demands on health literacy in consumer health information systems. This study modified two usability evaluation methods (heuristic evaluation and usability testing) to incorporate the identification of potential health literacy issues in a Personal Health Record (PHR). Heuristic evaluation is an analysis of a system performed by a usability specialist who evaluates how well the system abides by usability principles. In contrast, a usability test involves a post hoc analysis of a representative user interacting with the system. These two methods revealed several health literacy issues and suggestions to ameliorate them were made. Thus, it was demonstrated that usability methods could be successfully augmented for the purpose of investigating health literacy issues. To improve users' health knowledge, the adoption of consumer health information systems, and the accuracy of the information contained therein, it is encouraged that usability methods be applied with an added focus on health literacy.

Keywords. usability testing, heuristic evaluation, health literacy, Personal Health Record (PHR)

Introduction

Personal Health Records (PHRs) have been lauded for their potential to engage health consumers and provide them with governance over their own health information [1]. PHRs are used to access, manage and share personal health information, privately and securely [2]. Moreover, if they are interoperable, PHRs may contain data from different sources (e.g., pharmacies, labs, EHRs) [1]. However, health consumers act as curators of their PHRs and thus, decide what health information is and is not included. Ideally, PHRs provide comprehensive, longitudinal depictions of both static (e.g., allergies) and dynamic (e.g., blood pressure, cholesterol levels) health data. In addition to serving as a data repository, some PHRs offer interactive tools to foster self-management, education and decision-making.

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PHRs are unique in that they are healthcare applications designed for consumers who have limited or no healthcare expertise [3]. For PHRs to facilitate self-management, it is imperative that they are designed to accommodate consumers with limited health literacy to ensure users' comprehension of the information [4]. Ratzan and Parker [5] define health literacy as "the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions" (pg. iv). Health literacy extends beyond reading and writing and encompasses a variety of other skills (e.g., listening, speaking, arithmetic, problem-solving and decision-making), and is also influenced by culture and society [6]. Health literacy skills are associated with a broad range of benefits from increased health knowledge, improved self-reported health status, and reduced healthcare costs (e.g., shorter hospitalizations, less frequent use of health care services) [7].

Consumer health information (e.g., PHRs) systems can undoubtedly benefit from the application user-centered design methods [8]. It is argued here that there is a close interaction between usability and health literacy, particularly when we consider the effectiveness, efficiency and satisfaction of end users (i.e., patients and lay people) with PHRs. Specifically, the PHR user's capacity for obtaining, processing and understanding basic (as well as their own) health information will influence how usable such systems are.

Health literacy levels and usability both have the potential to impact data accuracy, quantity and quality of the information users enter into their PHRs. For example, medical terms and definitions not understood by PHR users could result in data entry errors or omissions. Whereas, if PHRs are challenging to use, health consumers are less likely to consistently monitor symptoms, vitals and other statistics into their PHRs. Thus, to optimize the value of PHRs, it is imperative that they are usable and designed to mitigate the demands on health literacy, as well as develop health literacy skills.

Currently, there is a dearth of research on methods for identifying and ameliorating health literacy issues in consumer health information systems. Given the relationship between usability and health literacy, usability evaluation methods may prove to be effective in detecting potential health literacy issues in consumer health information systems.

Three studies inadvertently identified health literacy issues during investigating of PHRs for other purposes. Kim and Johnson [9] compared the utility and functionality of 11 web-based PHRs and revealed a barrier to use that stemmed from a health literacy issue. These authors reported the PHRs failed to provide guidance or explanation to facilitate user data entry. Specifically, these authors found no resources to help users interpret prescription labels or test results to increase the likelihood that they were entered into the PHRs accurately. Cimino, Patel, and Kushniruk [10] reported that although patients wanted to know their lab results, some had challenges understanding and interpreting them. Segall and colleagues' [3] also found that many participants could not understand the content of their medical reports. Additionally, these authors also suggested replacing jargon with the vernacular and expanding acronyms. For example, Segall and colleagues proposed using "as needed" rather "prn" and "by mouth" instead of "orally" (pg. 1239) and suggested other changes to.

In the previous studies, health literacy issues were revealed without an apriori objective of their identification. The present study will demonstrate how usability methods can be extended with to identify both usability and health literacy issues.

1. Methods

At the time of testing, the PHR used in this study was Canadian based and offered at select clinics as a tethered solution. The PHR allowed the storage of a variety of personal health information (e.g., allergies, medications, health conditions). Additionally, several tools were provided by the PHR to manage (e.g., Appointments, Journal, Care Plan) and monitor (i.e., body dimensions, cardio, blood glucose, peak flow) health, with specific modules (i.e., Asthma, Cardio, Diabetes) focused on chronic illnesses.

1.1. Heuristic Evaluation

A heuristic evaluation is a method of investigation whereby a small group of usability experts (one to three) judges how well the system complies with usability principles [11]; issues that arise while using the system are categorized according to the heuristics used. A total of eleven heuristics were used for this evaluation from Nielsen's list of heuristics [12]. Nielsen's heuristics were supplemented with a new "Health Literacy" heuristic proposed by the authors of this paper. This heuristic is used to identify and categorize when clinical information (contained in the PHR) would be judged to be unlikely to be understood by a layperson who does not have a healthcare background or education. Each issue identified was assigned a severity rating to assess how detrimental these violations are to the usability of the system, and how urgently the issue should be solved [11].

The usability specialist for this heuristic evaluation selected four common PHR tasks. The four tasks were evaluated using PHR were: 1) Enter a Lab Result; 2) Enter a Medication; 3) Check and Edit An Allergy; and 4) Input and Check Blood Pressure. The investigator completed these four tasks using the PHR. Issues that arose while attempting to do the task were assigned a heuristic and evaluated for severity. In addition to usability issues, areas where the PHR demonstrated good design were also identified. Screen shots were taken to illustrate system issues and recommendations for improvements were suggested.

1.2. Usability Testing

In order to compare the results from the heuristic evaluation to the usability testing method (and to explore the utility of this method to reveal health literacy problems) one participant was used for pilot usability testing purposes. To do this, the PHR account was pre-populated with health information to give the impression of an existing record. A MacBook Pro laptop was used for this experiment. QuickTime Player version 10.1 was used to simultaneously record the audio and the events that occurred on-screen.

After the participant was seated in front of the laptop computer with the web browser on the PHR login page, the audio and screen recording began. Once QuickTime Player was running, the experimenter read the instructions to the task. The participant was asked to "think aloud" or verbalize his thoughts as he attempted to complete each task [8]. The participant completed the following three tasks sequentially: 1) Enter a medication; 2) Interpret vital sign data; and 3) Determine allergy documentation. After completing each task, the participant was asked to evaluate and comment on various aspects of the screens they encountered during the

previous task. Finally, when the participant completed all three tasks, he was asked to make general comments about the PHR in a brief post-task interview.

2. Results

2.1. Heuristic Evaluation

A total of 15 usability issues were revealed during this investigation of four tasks. The heuristic that was violated most frequently was Health Literacy, followed by Recognition rather than Recall, and Flexibility and Efficiency of Use (See Figure 1). All of the Health Literacy violations occurred during the Medication and Allergy tasks. As indexed by no violations for heuristic Error Prevention, the PHR was well designed from this perspective. For example, the PHR clearly described any errors that occurred while inputting data and the steps necessary to complete the data entry successfully. Also, any data that was entered could be subsequently edited or deleted very easily. The PHR was well organized; the categories and sub-sections were logically grouped and all of the groups of items were kept within reasonable memory limits.

One Health Literacy violation was rated as catastrophic and occurred in the Allergies section. When adding a new allergy, the drop-down menu was confusing, inconsistent and failed to list many common allergies (e.g., penicillin, peanut). For example, "Penicillamine allergy", "Penicillinase-resistant penicillins allergy" and "Penicillinase-sensitive penicillins allergy" are allergy entries listed. The complexity of these words and the nuances between the latter two options were unlikely to be understood by a layperson without a healthcare background and users may be more likely to select the incorrect option if they were trying to report a "Penicillin allergy". As an example of the list's inconsistency, this menu listed pollen as a food allergy rather than environmental. In order to remedy this issue, a detailed investigation of the contents of the allergy options should be conducted. It is imperative that allergies can be reported as simply as possible. If adding allergies is challenging, the probability that errors in data entry will occur are increased and could have critical consequences in an emergency situation.

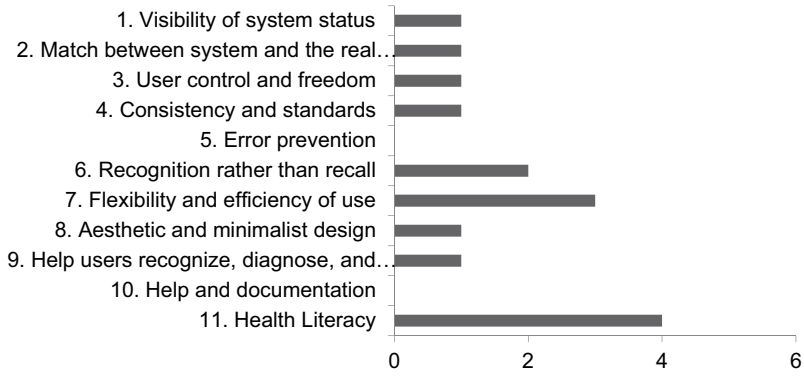

Figure 1. Frequency of PHR Heuristic Violations

2.2. Usability Testing

The video of the participant interacting with the PHR was transcribed and annotated in full, and then coded for usability issues. Of the three tasks completed by the participant, the most usability problems (12) occurred when the participant was trying to enter a medication. The PHR failed to facilitate entering a medication. For example, the participant did not know what the strength and dosage of a medication values were and repeatedly received error messages.

After completing all three tasks, the participant indicated that design changes could improve the usability of the system. Specifically, the participant felt that the all of the content font size should be adjustable, so it could be increased for easier reading. Further, he expressed it would be helpful to have a link to more information on medications and medication interactions. Lastly, the participant also wanted titles on the blood pressure graphs and increased visibility of outlier values (e.g., red data points).

A health literacy issue that was identified in both the heuristic evaluation and the usability test was the medication entry dialogue box. This box was overly complex and had fields for a lot of detailed information that users may not know. Further, many of the categories of information may not be clear to users who do not have medical expertise. The participant experienced difficulty differentiating between strength and dosage. The PHR should facilitate understanding by adopting simpler terms and providing examples. An approach to making prescription labels more understandable and informative was found on the Women's Health website (http://www.womenshealth.gov/aging/drugs-alternative-medicine/how-to-read-drug-labels.cfm). This website decomposed an image of a prescription to describe its constituent parts with simple, easy to understand language. Making this information available to users of PHRs is beneficial because the user has the opportunity to improve their understanding of their prescription. Further, this strategy may also increase the accuracy of the information entered into the PHR, which may be critical in the case of an emergency. Thus, it is strongly recommended that the PHR adopts strategies like this that increase user knowledge and simultaneously make information easier to enter and more likely to be accurate.

3. Discussion

The heuristic evaluation and usability study proved to be complementary methods of investigating both the usability and health literacy of the PHR. Some issues were only revealed using one technique and thus may have gone unnoticed if only one method was applied. Although the focus of the work described in this paper has been on extending heuristic evaluation with health literacy considerations, we found that the results of this study were more extensive as a result of using both heuristic evaluation and usability testing. Whenever feasible, it is encouraged that these methods are applied in conjunction to collect the most comprehensive data set possible. Although one pilot participant demonstrated the utility of usability testing to identify health literacy problems (for comparison purposes with the heuristic evaluation method), more participants should be used in practice. Along these lines we are currently planning on carrying out a follow-up study that will include usability testing with users of varying levels of health literacy as subjects. Ameliorating the issues

identified in this study through design changes, will result in a more usable PHR. Moreover, modifying the content to accommodate its layperson user population will increase the accuracy of the information entered and the PHR could serve as a useful resource for health consumers.

Given the exploratory nature of this study, only a single usability specialist conducted the heuristic evaluation. However, multiple evaluators have been shown to reveal more usability issues than a single evaluator [12]. Thus, it is recommended that for more detailed analysis, several evaluators should be included to identify a comprehensive list of heuristic violations.

Some health literacy issues in PHRs may arise as a consequence of designers adopting functional components from electronic health records (EHRs), which are used by providers. Although this is not problematic for many areas, previous research and the current study demonstrated that some health topics (e.g., medications, lab results, allergies) require extra attention devoted to designing with health literacy considerations in mind.

The utility of applying and extending usability methods to detect health literacy issues in consumer health information systems was demonstrated in this study. Health consumers might have limited medical knowledge, and design strategies should be developed to assist users in understanding health information and inputting data accurately. Some examples of techniques that could be adopted by consumer health information systems to help improve the health literacy of their applications are: using multi-modal (e.g., illustrations, movies) descriptions; linking to other resources; and integrating definitions of term. To improve users' health knowledge, the accuracy of the information, and the adoption of consumer health information systems, it is encouraged that usability methods be applied with an added focus on health literacy.

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Clinician Variations in Data Trust and Use

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Abstract. This study examined how variations in the source and type of patient health data affected health care providers' perceptions of the trustworthiness and usefulness of the data. Overall, respondents (n=107) reported moderate to high levels of trust and usefulness of health status data from all sources. Technology sources were rated as more trustworthy than traditional, non-technology sources (paired t = -2.84, p <0.006). However, there was no significant difference between technology sources and non-technology sources (paired t = -1.63, p <0.108) in perceived usefulness for clinical decision making.

Keywords. Technology Assessment, Biomedical; Decision Making; Trust

Introduction

Little is known about how health care providers value and subsequently use external or remotely acquired data in their clinical decision making. Existing literature has focused on the process of exchanging information across care settings, with little attention to the perceived value of sharing data or the perceived value of data acquired from remote sources [1]. Recent models in data provenance suggest that the lineage or tracing of the source of the data reflects on the quality and trustworthiness of the data [2]. Indeed, Simborg [3] notes that health care providers need to consider the source of the data in order to evaluate its validity. While data quality can vary in any given instance [4, 5], clinician values or generalized attitudes toward remotely acquired data could be just as important as actual quality variance. Negative attitudes may lead clinicians to disregard or discount non-traditional sources or unique types of health data.

With the dramatic expansion of technology use in health care, clinicians are bombarded with clinical data, some of which may be perceived to be of limited or unknown value and therefore contributing to the "noise" of clinical decision making [6]. Despite this overabundance, clinicians may decline to utilize a system that fails to provide the "right" data [7]. New technological applications outside of traditional health care settings are delivering novel types of data. Though these data are intriguing and promising, neither researchers nor clinicians yet know their clinical value. For example, motion sensor data gathered at TigerPlace, a smart home-enabled assistive living facility, are being used to create activity density maps for residents [8]. While the comparison of activity density maps with known clinical changes are intriguing, the clinical utility of such data is still unknown.[8]. Uncertainty in intended use and lack of experience with these new sources and types of data may heavily influence the

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perceived value and subsequent adoption of novel data.[9]. Without understanding the attitudes and behaviors of clinicians, we may design and implement clinical data collection systems that health care providers neither trust nor use. In this study we examined how variations in the source and type of data and prior experience with health information technology affected health care providers' perceptions of the trustworthiness and usefulness of patient data.

1. Methods

1.1. Data Collection

Following Institutional Review Board approval (PRO07080326), the Quality of Life Technology Engineering Research Center conducted the Health Care Provider Data Trustworthiness Survey. The self-administered survey was distributed to health care providers attending a geriatric care conference. Approximately 469 clinicians attended the conference. Among the 107 respondents (22.8% response rate), 39 were physicians, 32 were registered nurses, 22 were nurse practitioners or physician assistants, 12 were other care providers and 2 did not indicate their professional background. This survey required five to ten minutes to complete.

The survey consisted of two main sections of potential data sources. The first section explored traditional sources of data, including primary care providers, specialists, home health agencies, nursing home or assisted living facilities, community health screenings, patients, and family members of patients. The second section of the survey focused on information technology-mediated data sources, including telehealth monitors, wearable monitors, environmental monitors and other monitors. Other monitor data sources were defined as "technologies that may not have traditionally been thought of as health sensors but could generate and share information that may be relevant for health care providers. An example might be longitudinal performance on the Wii™ balance board."

For each traditional data source there were three to six specified types of data such as vital signs, physical assessment, psychological assessment, images or pathology reports, diagnoses, and treatment plans. For each health technology monitor, the specified data types varied depending on their monitoring characteristics. For example, the data captured by wearable monitors included emergency signals, vital signs or electrocardiograms, and activity or exercise. Additionally, respondents were asked if they had ever received data from each of these technology sources.

For each data source /data type combination respondents rated the trustworthiness and usefulness of the data and indicated whether they had experience with such data. Respondents were asked "**In general, how trustworthy are data from these sources?"** The trustworthiness scores ranged from 1 to 10, with "1" for "completely untrustworthy" and "10" for "completely trustworthy." To capture perceived usefulness, clinicians were asked of each data source "**How useful are these data in your clinical decision making?"** The four-point likert scale of response options included Not at all (coded as 1); A little (coded as 2); Moderately (coded as 3); and Very Much (coded as 4). The survey instrument is available upon request.

1.2. Data Analysis

Survey data were analyzed using SPSS Statistics 17.0. There was high internal consistency across specific types of data (e.g. vital signs, psychological assessment, treatment plans, etc….) within each source, and thus these were combined for analysis. Internal data consistency within each data source and between data sources was measured by Cronbach's alpha and ranged from 0.80 to 0.96. We examined trustworthiness and usefulness ratings for both individual data sources and for broader combined categories of sources (e.g., technology vs. non-technology sources). Descriptive statistics were used to compute mean trustworthiness and usefulness scores. Paired t-tests were used to compare trustworthiness and usefulness between data sources, specifically between non-technology sources and technology sources in general and within each specific technology source. All significance tests were evaluated at $\rho < 0.05$ with two-sided tests. Non-technology sources were aggregated into the following pairings based on high correlations among perceived trustworthiness (r between 0.649 and 0.857, $p < 0.000$): primary care providers and specialists; home health and nursing home or assisted living facilities; and patients and family members.

2. Results

2.1. Technology Exposure vs. Non-Exposure

Exposure to individual types of data across data sources varied widely, ranging from 9.5% for exercise or social contact data from other monitor sources to 40.4% for physiologic data captured by telehealth monitor sources. If a respondent indicated having received any type of data within a technology data source in the past, we considered the respondent to have prior exposure to that particular data source. In our sample, 57.9% had been exposed to at least one type of data from any technology. Prior exposure varied by data source. Overall, more respondents reported exposure to data from telehealth monitor sources (38.3%) and wearable monitor sources (37.4%) than other monitors (22.4%) or environmental monitors (18.7%). Prior exposure to a particular technology source did not significantly influence respondents' perceptions of trustworthiness or clinical decision making usefulness of data from that source.

2.2. Trustworthiness

Respondents indicated a moderate to high level of trust in data from varying sources (range M = 6.22-8.39). Among the traditional, non-technology data sources, the specialist data source (M = 8.34 ± 1.41 SD) had the highest trustworthiness rating and the wearable monitor data source (M = 8.39 ± 1.34 SD) had the highest trustworthiness rating among the technology sources and overall. The community health screening data source (M = 6.22 ± 1.93 SD) ranked lowest for trustworthiness overall and among the non-technology sources. Among technology sources, other monitor data sources (M = 7.08 ± 1.81 SD) held the lowest rating for trustworthiness. When data sources were aggregated into two broad categories, technology sources (M = 7.75 ± 1.38 SD) were rated as significantly more trustworthy than traditional, non-technology sources (M =7.37 ± 1.24 SD) (paired $t = -2.84$, $p < 0.006$), although the absolute difference in ratings was relatively small. To explore whether this finding was still true without the influence of community health screening data sources (the lowest rated source) on the non-technology data sources, we compared technology sources against each of the

three broad pairings (primary care provider-specialist, home health- nursing home, and patient-family member). Technology sources were rated as more trustworthy than the data sources in the home health-nursing home comparison (M =7.08 ± 1.54 SD) (paired t = -4.25, p <0.000), the patient-family member comparison (M =7.41 ± 1.54 SD) (paired t = -2.09, p <0.039) but not the primary care provider- specialist comparison (M =8.22 ± 1.30 SD) (paired t = 2.99, p <0.004).

2.3. Usefulness

With few exceptions, respondents considered data collected by various sources to be at least "moderately" useful in clinical decision making (range M = 2.45-3.49). For non-technology sources, only nursing homes (M = 2.91± 0.75 SD) and community health screenings were rated (M = 2.45 ± 0.87 SD) between "a little" to "moderately" useful." For technology sources, only other monitors received a mean rating (M = 2.81 ± 0.81SD) that suggested they were less than moderately useful in clinical decision making. When aggregated into broad categories, there was no significant difference between technology sources (M = 3.13 ± 0.62 SD) and traditional, non-technology sources (M =3.02 ± 0.50 SD) (paired t = -1.63, p <0.108) in perceived usefulness in clinical decision making. As with the trustworthiness data, we examined technology sources against each of the three broad comparison groups (primary care provider-specialist, home health-nursing home, and patient-family member). Technology sources were rated significantly more useful in clinical decision making than the data obtained from home health-nursing home (M = 2.92 ± 0.65 SD) (paired t = -2.71, p<0.008), but significantly less useful than data from primary care provider- specialist sources (M = 3.42 ± 0.59 SD) (paired t = 5.25, p <0.000). No significant difference was found between technology sources and the patient-family member pairing (M = 3.22 ± 0.59 SD) (paired t = -1.45, p <0.152).

2.4. Relationship between Perceived Trustworthiness and Perceived Usefulness inClinical Decision Making

With one exception, there was a significant, moderate positive relationship between perceived trustworthiness of the data and perceived usefulness of the data in clinical decision making across data sources (r = 0.363 – 0.646, p < 0.001). The weakest association between perceived trustworthiness and perceived clinical decision usefulness was for specialist-sourced data; whereas the strongest was for community health screening-sourced data. A positive, moderate association was found between perceived trustworthiness and usefulness when traditional, non-technology data sources were aggregated (r = 0.494, p < 0.000). This association was considerably higher when technology sources were aggregated (r = 0.702, p < 0.000).

3. Discussion

Of concern to engineers, informaticists and clinicians alike are factors that influence the adoption and continued use of optimal health information technologies by health care providers. Although anecdotal evidence has suggested that the provenance (data source and process used to create the data) of health data might affect the clinician's perception of it, no studies to date have directly assessed clinicians' perceptions of the

trustworthiness and usefulness of data by source and type. As expected, we found that perceived trustworthiness and usefulness are moderately correlated. Since our study was conducted, other work has been published that also supports the relationship between perceived usefulness and perceived information quality. [10]. More importantly, our findings show that technology data sources were perceived at least as favorably as data from traditional, non-technology, sources. This finding supports the movement in health care towards more technology based sources of data. Ironically this technology trend also includes data from outside traditional health care facilities and may rely heavily on patients or family members as primary data providers.

This trend will ultimately raise other challenges. Some challenges may be cultural such as how to integrate technology data into practitioner workflow. Other challenges may be more technological in nature such as how to integrate new data sources into existing health information systems. Inclusion of data provenance metadata alone within electronic health records will require careful consideration of affected terminologies and standards.

When developing the study, our team was concerned that clinicians may have had little prior exposure to data from the technology sources. As a result, we added an exposure question for each technology data source. Our results showed that prior exposure to any of the technology data sources did not affect perceptions of trustworthiness or clinical utility. Further research should attempt a more fine grained assessment of prior experience. This study was limited by its small, non-representative sample of health care providers. Some of the respondents may have also been pre-disposed with positive attitudes towards technology in general as they were attending a geriatric medicine update conference with an optional concurrent technology workshop.

This investigation is a critical first step in identifying differences that exist in clinicians' perceptions of data based on source. Understanding how information technology as the delivery mechanism may change the perceived trustworthiness or clinical decision making utility merits further inquiry.

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Design and Implementation of Synoptic Operative Report Template Using Interoperable Standards

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Abstract. The increasing use of synoptic operative reports in clinical settings represents a major milestone in the advancement of health information technology. Synoptic operative report templates enable clinicians to capture and display succinct clinical information in a standardized and logical manner. Synoptic operative report templates also provide the optimum goal of enriching personalized health information of a given patient at the point of care so as to support the exchange of clinical information across the continuum of multiple healthcare providers. However, most of the available synoptic operative report templates in many clinical settings do not incorporate interoperable standards in their design and implementation. This paper proposes a novice template (i.e., eSOR-SCI) that uses interoperable standards for its design and implementation.

Keywords. Synoptic operative report, interoperable standards, HL7 V3 CDA, HL7 V3 CCD, SNOMED-CT, LOINC

Introduction

Synoptic operative reports are simply structured or discrete medical reports that provide a snapshot of patient encounter with a clinician at the point of care. Specifically, synoptic operative reports often have a direct and critical role in patient care by providing the necessary information needed to understand, interpret, and communicate a patient's surgical history [1]. Synoptic operative reports have emerged as the gold standard for capturing and displaying structured surgical data in clinical settings [1-5]. Citing the work of Temple et al. [6], Paterson, Swain, Christie, Thibault-Halman, and Behzadi [7] noted that the replacement of traditional narrative with a synoptic operative report has proven to be an effective strategy in improving surgical data for the knowledge transfer process. This approach enables the capture of discrete data items and transforms a narrative operative report that is qualitative in nature to a quantitative one that can be aggregated to generate information and knowledge [2].

Electronic synoptic operative reports have replaced dictated reports at many healthcare institutions because users could demonstrate improvements in reliability,

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completeness, and timeliness with this alternative. Electronic synoptic operative reports use "computer-based forms to describe the findings and important steps of an operation, based on predefined templates for individual procedures" [1, p. 308]. In other words, electronic synoptic operative reports are dependent upon predefined templates for individual procedures. Such templates are based on synoptic methodology, which on its own refers to the creation of a library of keywords and phrases to show a preferred way to communicate a clinical concept in an operative report.

Electronic synoptic operative templates support the creation of clinical documents that are of higher quality than those produced by the same individual using dictated narrative reporting method [8]. The template serves as a prompt for pertinent information, which could be reused to support the information needs of researchers and administrators. In accordance with the clinical documentation standards set by the Joint Commission Accreditation of Healthcare Organizations (JCAHO) and Accreditation Association for Ambulatory Health Care (AAAHC), synoptic operative report templates contain sufficient information to: identify the patient; support the diagnosis; justify the treatment; document the postoperative course and results; and promote continuity of care [1,9]. Thus, the continuing use of electronic templates in medical practice promotes health policy informatics and secondary data use.

1. Related Studies

Several synoptic operative templates have been proposed and used by many vendors and researchers in the healthcare domain. Noticeable amongst them is the *WebSMR* template proposed and developed by the Alberta Cancer Surgery Working Group. The Working Group developed and implemented a web-based synoptic surgical medical record, known as the Alberta *WebSMR*, for rectal cancer resection [1]. Edhemovic, Temple, de Gara, and Stuart [3] reported that following the implementation of a rectal cancer template, the synoptic report captured 99% of the required data elements versus 45.9% captured via a dictated narrative report. This showed that the science of surgical technique could be better measured using a synoptic reporting method. The synoptic checklist approach has consistently shown superior results to narrative reports for completeness [4]. The *WebSMR* did not, however, incorporate major interoperable standards in the system design.

In a related study, Paterson and Soroka [10] developed and implemented Health Level Seven (HL7) Version 3 Clinical Document Architecture (CDA) Release Two (R2) template for capturing discharge summaries for chronic kidney disease patients. The template was designed using Microsoft InfoPath and HL7 V3 CDA R2 specifications. Even though the study by Paterson and Soroka [10] utilized interoperable standards in the system design and implementation, they did not focus on synoptic operative reports. The proposed **e**lectronic **S**ynoptic **O**perative **R**eport-**S**pinal **C**ord **I**njury (eSOR-SCI) template not only focuses on synoptic operative report but also uses interoperable standards in its design and implementation.

2. Methods

The methods were primarily based on the principles of health interoperability using HL7 V3 CDA R2, Systematized NOmenclature of MEDicine - Clinical Terms

(SNOMED-CT), and Logical Observation Identifiers Names and Codes (LOINC) [12]. Drawing upon the work of Rector, Qamar, and Marley [11], Benson [12] asserted that electronic information systems operate at two different levels: *Model of Use* and *Model of Meaning*. Whereas *Model of Use* is defined as the human interface that describes how the system is actually used, *Model of Meaning* is defined as the representation for reporting and analysis that supports data processing and reasoning [12]. These two distinct levels of system operation are necessary because each "model of use needs to be convertible into a model of meaning to make it computable" [12, p. 221]. This study extended the work of Rector et al. [11] by adding another level (i.e., *Model of Design*) to the methodology to describe how electronic information systems are designed.

The methodology, therefore, involved the design and use of HL7 V3 CDA R2 and SNOMED-CT together in the context of synoptic operative report for patients with spinal cord injury. The eSOR-SCI template is the model of use in that it enables data to be captured and displayed by clinicians after the completion of each surgical procedure. The eSOR-SCI template was implemented using a model of meaning methodology to ensure that data can be aggregated and analyzed for research purposes. The binding of the SNOMED-CT with the HL7 V3 CDA R2 template structure depicts how the model of meaning was achieved. In the case of the eSOR-SCI template, the clinical document is the synoptic operative report generated by the system.

3. Results

The implementation of the eSOR-SCI template followed three processes: Model of Design, Model of Use, and Model of Meaning.

3.1. Model of Design

The model of design represents the design architecture of the eSOR-SCI template. The design architecture components of the eSOR-SCI template consisted of a template based on the Rick Hansen Spinal Cord Injury Registry (RHSCIR) Forms, Interoperable Standards; and Microsoft Infopath.

3.1.1. RHSCIR Forms

The RHSCIR forms for diagnoses and procedures provided the minimum core data elements for the eSOR-SCI template. Both the diagnoses and procedures forms were the source of the template sections. Based on secondary data use requirements, the data elements provided the content to populate the diagnoses and the procedures as per RHSCIR diagnosis and procedure forms. These data elements were represented using HL7 V3 CDA R2 specifications to bind to the template hosted on the InfoPath platform.

3.1.2. Interoperable Standards

The eSOR-SCI template used a congruence of interoperable standards including HL7 V3 CDA R2, HL7 V3 Continuity of Care Document (CCD), SNOMED-CT, and LOINC in its design and implementation [12]. These standards support the exchange of clinical information across the continuum of multiple providers. The implementation of

these standards was facilitated by the use of published implementation guides. In the context of eSOR-SCI template, the interoperable standards were used to capture, represent, and store the minimum core datasets for the template and made available in XML format that could be uploaded to proprietary document management systems. The use of the interoperable standards was necessary to improve the data quality of the template thereby facilitating secondary data use [13].

3.1.3. Microsoft InfoPath

Microsoft InfoPath was used to build the eSOR-SCI template. The InfoPath platform enables users of the system to enter patient's surgical information and then view and print the resulting report from the interface. The InfoPath platform also supported the binding of the template with the modified XML schemas from the HL7 V3 CDA R2 specifications. InfoPath is ubiquitous and is already installed in many computers used by the clinicians at Capital District Health Authority (CDHA) in Halifax, Nova Scotia.

3.2. Model of Use

The model of use comprises of the way that data are captured and displayed in the eSOR-SCI template. The human interface of the template is made up of two views: data entry view and report view. The template also consists of several sections including Patient Information, Surgeon and Anaesthesiologist Information, Procedure Date and Time, Pre-operative Diagnosis, Indications, Pre-operative Clinical Status (i.e., ASIA Scale, ASA Grade, and Glasgow Coma Scale), Co-morbidities, Post-operative Diagnosis, Anaesthesia Information, Surgical Procedures, Implants, Surgery Descriptions/Findings, Surgical Drains, Bone Graft, Fluid Intake/Output, Discharge Disposition, and Author of Operative Report. A user manual has been developed to assist clinicians and residents in understanding the appropriate use of the template.

3.3. Model of Meaning

In facilitating the model of meaning of the eSOR-SCI template, several concepts and terminologies, utilized by the template, were encoded to SNOMED-CT expressions with the uttermost goal of making the stored data reusable to support information needs of researchers and administrators. Consequently, 391 out of the 402 clinical data elements presented in the electronic template were encoded to SNOMED CT expressions, representing 97.26% of all clinical data elements presented in the eSOR-SCI template. Approximately 2.74% of the clinical data elements were considered to be difficult to encode using the SNOMED-CT expressions. Table 1 shows the SNOMED-CT compositional grammar for sample three procedures (i.e., Decompression laminoplasty, Suboccipital craniectomy, and Facet Rhizotomy) adapted from the RHSCIR form for procedures.

Table 1. SNOMED-CT compositional grammar for three procedures adapted from the RHSCIR form for procedures.

Procedures	SNOMED-CT Compositional Grammar
Decompression laminoplasty	438374004|laminoplasty|+410756002|surgical decompression|
Suboccipital craniectomy	36910002|craniectomy|+260623005|suboccipital approach|
Facet Rhizotomy	19214009|incision of spinal nerve root|:363704007|procedure site| = 89836005 |entire zygapophyseal joint|

4. Conclusion

This research project aims to improve the quality of data for primary and secondary use through implementing an electronic template for synoptic operative reports for spinal cord injury patients. Success in this project would improve the quality of data, which is already collected for other research projects, such as the RHSCIR, as well as for the Canadian Institute for Health Information Discharge Abstract Database (CIHI DAD), which collects health information from institutions across the country. The eSOR-SCI template has been implemented and is being piloted by the residents at the Division of Neurosurgery, CDHA in Halifax, Nova Scotia. The pilot study will gather data on usefulness, usability, and use of the template for Neurosurgery operative reports.

It is expected that the synoptic reporting will enhance the transfer of information, which will lead to improvements in the clinical data captured on spinal cord injury operations for secondary data use (i.e., RHSCIR and CIHI DAD). Moreover, it is anticipated that the eSOR-SCI template would assist surgeons in quickly completing clinical documentation; improving data quality to support secondary data use; and generating standardized reports that are easier to read and interpret. Success is achieved if the implemented eSOR-SCI template is usable, useful, and used [14].

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Processing Medical Reports to Automatically Populate Ontologies

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Abstract Medical reports are, quite often, written and stored in computer systems in a non-structured free text form. As a consequence, the information contained in these reports is not easily available and it is not possible to take it into account by medical decision support systems. We propose a methodology to automatically process and analyze medical reports, identifying concepts and their instances, and populating a new ontology. This methodology is based in natural language processing techniques using linguistic and statistical information. The proposed system was applied successfully to a set of medical reports from the Veterinary Hospital of the University of Évora.

Keywords. Ontologies, Information Extraction, Natural Language Processing, Machine Learning, Semantic Web

Introduction

In the last years complex computational systems have been developed in the health domain. The integration of information is one of the major challenges in health informatics. Medical reports are often made at several institutions, which use proprietary vocabularies and, if this information is not properly prepared and presented, can cause important failures of interpretation. To solve this problem one can resort to the use of ontologies, which allow to design and model concepts and relations correctly [1]. Through the languages of the Semantic Web ontologies can be represented by adding semantic annotations. To facilitate the population of the ontology, automated processes or semi-automatic ones can be applied. Text mining techniques are applied, using several techniques, such as natural language processing and machine learning [2]. Thus, through the creation of ontologies and its population, it is possible to represent medical information, allowing institutions to improve patient health care systems.

The main objective of this work is to create an ontology that allows us to represent information expressed in medical reports and to create automatic mechanisms that extract information and carry out a population of this ontology. Therefore, we will obtain a medical knowledge base, making possible to access it through the use of inference engines and to develop more powerful health information systems.

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1. Methodology

The proposed work has four sequential phases.

1.1. Analysis of Documents

In the context of this work, we used a set of 590 histopathological reports, which were supplied by the Veterinary Hospital of the University of Évora. The reports were analyzed and all the relevant fields identified.

1.2. Creation of Ontology

From the analysis of documents it was possible to create an ontology covering the domain of histopathological reports. Among the various existing languages to represent ontologies, the OWL language was chosen because it is more efficient on the Web than XML, RDF and RDFS, it is a W3C recommendation and, also, because it has a formal semantics definition.

As methodology to create the ontology we followed the proposal of Noy and McGuiness [3], from the Stanford University, which defines the sequence of steps needed to create the ontology and to model the knowledge.

The ontology was built from scratch due to the shortage of work developed in this area, most likely due to the great complexity of the domain and the fact that Semantic Web languages are a relatively new area. First, we analyzed all medical reports and extracted all terms. Then, with the help of the health professionals classes, their properties and restrictions were created. We normalized all concepts and, when possible, we used the UMLS terminology (http://www.nlm.nih.gov/research/umls/), aiming to facilitate the interoperability of the system. The ontology was developed using the Protege tool (http://protege.stanford.edu/). The overall scheme of the domain is composed of twelve classes related to each other, as shown in Figure 1.

1.3. Automatic Labeling of the Reports

In this phase of work we used Minorthird (http://minorthird.sourceforge.net), software that was developed in Java and includes some machine learning and information extraction algorithms, and allows labeling text automatically [4]. To automatically label the reports it is necessary to have first a set of reports manually labeled. These will serve as the training set for the machine learning algorithms. From the analysis of the ontology we identified 29 major concepts, varying from simple entities, such as “date of the exam”, to complex ones, such as “description of the exam”.

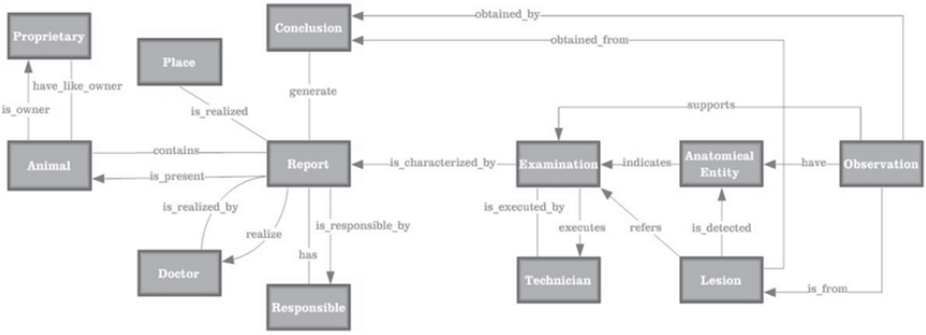

Figure 1. Modeling of the Global Schema Domain

Seventy-four reports were labeled with the help of health professionals (approximately 12.5% of the size of the corpus), value that we found enough to get good results. After analyzing the final results, we verified that the algorithm that produces better results is the SVM- CMMLearner, a probabilistic support vector machine to learn conditional Markov models. The results obtained by this algorithm are quite satisfactory: for 21 of 29 labels the algorithm identified and extracted above 90% of the information. For some text labels the results were not so good, presenting, however, percentages above 75%. From these results we created a classifier SVMCMMLearner for each label of the training set, allowing all reports to be automatically labeled by Minorthird in XML format.

1.4. Ontology Population

The last phase of the work concerns the extraction of information from the XML labeled medical reports, creating class instances in the ontology. For such, we developed a Java application that extracts information from reports using the DOM parser xml (http://www.w3schools.com/dom/dom_parser.asp), processing the information contained in labels and creating the instances in the ontology using the Jena *framework (*http://jena.sourceforge.net). All the information extracted from "simple" fields, such as, "Report", "Place", "Technician", "Responsible", "Doctor", "Proprietary" and "Animal", could be directly instantiated in the ontology. Regarding the content of examinations and of the conclusion, the information needs to be processed because it corresponds to a text with a set of anatomical entities, lesions and observations related to each other. Thus, the text of each label is extracted and created a vector.

For example, for the text *"Foi enviado para ana´ lise um fragmento cuta^ neo com um no´ dulo cuta^ neo ulcerado. Ao corte apresentava colorac¸a˜ o acinzentada./It was sent to be analysed a cutaneous fragment with an ulcerated cutaneous nodule. When cutting it showed a grayish colour", w*e obtain the vector represented by Figure 2.

We developed a 4-step algorithm that processes this initial vector and transforms it: 1) remove tags within tags; 2) create anatomical entity(ies) that will eliminate some labels of the vector simplifying it; 3) create lesion(s) that will eliminate other labels of the vector ("lesionName", "type", "size", "color", "degreeMalignancy") simplifying it; and 4) create relations between anatomical entities, lesions and observations.

The first phase of the transformation of the vector is fundamental because it is important that instances with labels don't appear in the ontology. For the previous

vector, the label ”type” within the label “lesionName” is removed adding a new position of the vector, as shown in Figure 3.

Figure 2. Vector with the labels of the text of the paragraph

Figure 3. Vector after Removing Labels within Labels

The second and third phase of the proposed transformation of the vector is mainly to facilitate, in first place the relationship between the labels occurring in the fourth phase, and later the creation of instances in the ontology. Figure 4 corresponds to the application of these two phases to the previous vector.

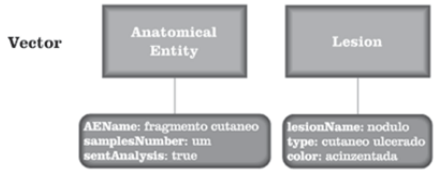

Figure 4. Vector after creating Anatomical Entity and Lesion Labels

Finally, the last phase of transformation of the vector is to create relations between tags. Figure 5 represents the final processing stage for the previous vector.

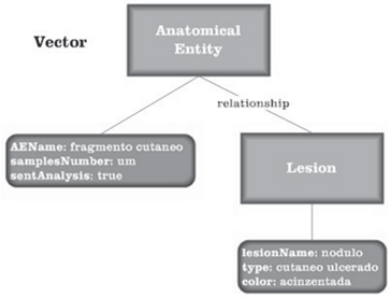

Figure 5. Vector after creating Relations between Labels

With this approach it is possible to create the instances of the ontology corresponding to the

information extracted from the medical reports.

2. Results and Application of Ontology

After the creation of instances in the ontology, we used once again the Protege´ framework to evaluate the results and perform some tests. In total, for all reports of the corpus, 7824 instances were created in the ontology. These are correctly structured according with the texts. We also observed that all information labeled by Minorthird is instantiated in the ontology and errors were not detected. The results are very positive and achieve the objectives originally proposed.
Using the Minorthird plugin DL Query, it is possible to make queries and obtain results directly from the created medical knowledge base. For instance, applying the query "*Which are the medical reports that have exams that have the lesion with the name 'Furunculosis'?"*, the system quickly provides the resulting instances, saving the time from a manual search and allowing the results to be used in new searches.

3. Conclusion

This work aims to create and to populate ontologies as a way to acquire knowledge from medical reports. We have used histopathological reports, written in a semi-structured form and having textual fields. An ontology was created for this domain of histopathological reports and heuristic and machine learning techniques were applied, allowing to initially automatically label the reports and, at a later stage, to relate entities and automatically populate the ontology. The results show that this is a promising approach, allowing the automatic extraction of relevant information.

The use of information systems in the health domain is nowadays indispensable, aiming to help professionals in health or patient care. Our work helps to support the claim that the use of ontologies in medical reports can represent an important step in this area, providing new and more powerful tools and supporting either investigators or health professionals in their work.

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Health Modeling

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A Complex Adaptive Systems Perspective of Health Information Technology Implementation

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Abstract. Implementing health information technology (HIT) is a challenge because of the complexity and multiple interactions that define HIT implementation. Much of the research on HIT implementation is descriptive in nature and has focused on distinct processes such as order entry or decision support. These studies fail to take into account the underlying complexity of the processes, people and settings that are typical of HIT implementations. Complex adaptive systems (CAS) is a promising field that could elucidate the complexity and non-linear interacting issues that are typical in HIT implementation. Initially we sought new models that would enable us to better understand the complex nature of HIT implementation, to proactively identify problem issues that could be a precursor to unintended consequences and to develop new models and new approaches to successful HIT implementations. Our investigation demonstrates that CAS does not provide prediction, but forces us to rethink our HIT implementation paradigms and question what we think we know. CAS provides new ways to conceptualize HIT implementation and suggests new approaches to increasing HIT implementation successes.

Keywords. Complex adaptive systems, interoperability, HIT implementation, process redesign, simulation modeling.

Introduction

There is increasing investment in information technology for health care to enhance healthcare delivery in North America and elsewhere [1]. To date the introduction of health information technology (HIT) into clinical settings has been problematic because of changes to care delivery workflows and unintended consequences. Several studies have examined the role and nature of these consequences from the perspective of HIT implementation [2-4]. Much of the current research on these consequences has focused on the negative aspects of HIT implementation including technology-induced errors [5], workarounds [4], power issues, workflow disruptions [2-5] and patient safety concerns [4,6].

The existence of these so-called unintended consequences emphasizes that we cannot look at HIT implementation as process centric (i.e. order entry or decision support) in isolation from other processes. Rather we need to look at the overall system that HIT is automating. Safe use of HIT requires a continuous monitoring of

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implementation over the continuum of providers who provide care, the patients who receive care, the organizational context in which care is provided, the tasks that are associated with a process, the environment within which the organization exists and other relevant processes and constraints [7].

Complex adaptive systems (CAS) are a means of looking at the complexity and interacting issues that define HIT implementation [8]. CAS can help reframe the thinking about HIT implementation and acknowledge the non-linearity of processes and how behaviors and tasks emerge as a result of non-linearity [9].

Surprisingly, a search for complexity theory and CAS within the health informatics literature yields a paucity of articles [8,9]. While these studies have suggested that HIT implementation issues are characteristic of CAS, they have not specifically looked at HIT implementation through the CAS lens.

The medication prescribing, dispensing and administration process is one of the most common sources of medical errors due to the complexity of the process and the significant potential for harm from potent medical interventions [11, 12]. Therefore it is an excellent process to study from the perspective of CAS. In this paper we analyze and link the prescribing process to CAS theory. This allows us to leverage the prolific research being done in other disciplines for gaining insight into developing a framework for HIT implementations.

1. Methods

We developed and used a use case of prescribing and dispensing in the community to identify CAS elements. Figure 1 displays the use case.

We analyzed the prescribing and dispensing process using the lens of CAS. We listed the features of CAS and identified instances of prescribing and dispensing which fit those features. Our goal was to identify a mechanism or method to predict unintended consequences and to predict areas of higher risk in HIT implementation.

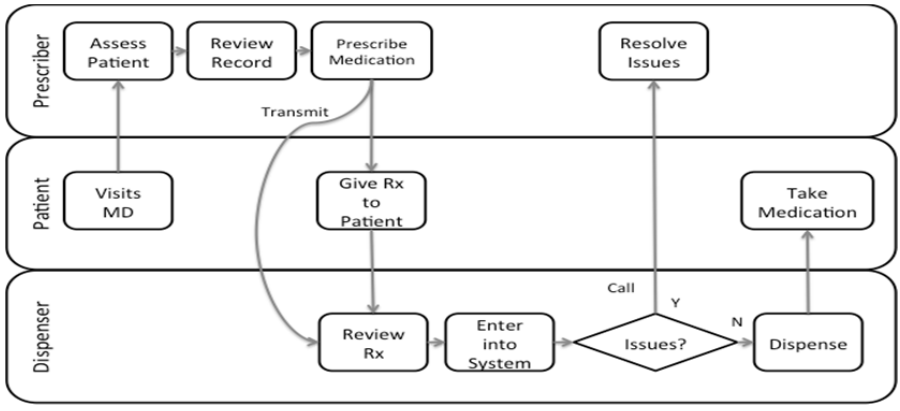

Figure 1. Simplified medication prescribing, dispensing and administration process in the outpatient setting

2. Results

Table 1 maps features of the medication prescribing process to features of CAS.

Table 1. Features of CAS and Medication Prescribing

Features of Complex Adaptive Systems	Corresponding Features of Medication Prescribing Process
Non-linear processes	Changes in one area affect things in another area, but in non-linear and non-intuitive ways. E.g., decreasing drug-drug interactions leads to increased work for physicians. Some errors in prescribing are easily solved by pharmacists; others require a phone call.
Emergent behavior	Unintended consequences of HIT [2,3]. Workload shifts from pharmacist to physician when e-prescribing is implemented.
Feedback loops	Pharmacists phone physicians to confirm information. Physicians monitor drug effects and side effects. Patients revert to their physician or pharmacist if they face any issue with their medication.
Co-evolution	When physicians start printing prescriptions, patients experience a decrease in dispensing errors due to illegibility and pharmacists have to make fewer calls back to physicians to clarify the prescription. Overall, this leads to fewer phone-calls between providers.
Requisite Variety	Each network of prescribers, dispensers and patients has its own unique characteristics. There are no uniform methods for prescribing and dispensing. Changes that work in one network do not work in other networks.
Connectivity	Relationships and communication between physicians, patients and pharmacists is very important to ensure patient safety. The prescription is an important tool for communicating between prescribers and dispensers.
Simple Rules	Prescriptions have a very small number of elements, yet they can have far-reaching implications. The act of prescribing is made of several simple rules (the contents and process of a prescription) but the end-result is an information-rich document with far more complex interpretations and implications for patient health.
Self-organization	Pharmacists can monitor prescription problems and work with patients and physicians to correct them. E.g., during the recent large scale switching from one opioid to another in Ontario.
Non-discrete Boundaries	The prescribing process is regulated by licensing authorities and by legislation. These can have profound effects on prescribing and dispensing.

A review of Table 1 quickly demonstrates the futility of trying to predict the path and outcomes of an HIT implementation when there are large numbers of interacting variables with non-linear relationships between them. Even a downturn in the economy can cause a perturbation in an HIT implementation if strategic plans change because of financial issues.

The key insight to emerge from our analysis is that HIT implementations are inherently unpredictable and that unintended consequences are to be expected. Rather than trying to predict and control an implementation, CAS theory points to an approach that is more organic and iterative in nature: implement a small, minimally viable part of the HIT and observe the results (non-linear processes, feedback loops). Measure the impact of the implementation on key goals (i.e., develop new feedback mechanisms for the new system, watch out for emergent behaviours). Listen to nay-sayers and objectors, they may have useful advice to give and may be your best predictors of what could go wrong (self-organization, feedback loops). Make course corrections and adjustments (feedback, self-organization). Watch out for boundary issues such as regulations impinging on workflow (non-discrete boundaries). Don't expect that what worked in one setting will necessarily work in another (requisite variety). Develop new mechanisms for communication, especially for meta-communication (connectivity). Implement some more. This approach is reminiscent of quality improvement approaches such as the Plan-Do-Study-Act cycle which has been a successful model for generating change in complex clinical situations and is also reminiscent of the lean start-ups movement which promotes the idea of continuous quality improvement with small, incremental changes.

3. Discussion

In this paper we advocate for using complex adaptive systems theory to study HIT implementation issues and to make recommendations on how we can improve the HIT implementation process. The real strength in complex adaptive systems is in the word *system*. Healthcare processes are not disparate entities that exist in isolation. Rather they are complex systems with multiple actors and parts that are not linear but are defined by variation and dynamic evolution. Complex adaptive systems acknowledge that complexity exists in a system because of the range of actors and the multiple ways that they integrate with one another while engaging in system processes. Modeling healthcare processes from the perspective of this complexity allows us to understand the impact that implementing HIT will have a on a process such as how the burden of a task may shift from one provider to another or how the process may evolve over time.

The end point of our analysis is that CAS does not provide prediction, but forces us to rethink our HIT implementation paradigms and question what we think we know. CAS provides us new ways to conceptualize HIT implementation and suggests new approaches to increasing HIT implementation successes.

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A Systems Theory Classification of EMR Hazards: Preliminary Results

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Abstract. Jurisdictions in Canada, the US, the EU and Australia are struggling with regulation of ever evolving software in medicine. Recently this discussion has had a focus on electronic medical records (EMRs). There is a mountain of evidence that EMRs have actualized potential to lead to the injury of patients through the information they offer to facilitate care. We are undertaking a systematic review of relevant literature in the field to uncover some of the latent hazards. We hypothesize that this exploration, using a variation on Leveson's system theoretic accidents models and processes (STAMP) model as a classification tool, will provide two benefits. First, the model will be sufficient to capture the complexity of the domain and its hazards, thus providing a holistic perspective on the problem. Second, the classification process will provide insight as to what steps might be taken to mitigate the risk that medical errors associated with these software tools will arise in health care systems which employ them. In this continuation of our study we still have not been able to produce evidence which contradicts either hypothesis.

Keywords. electronic medical record, safety, systems safety

Introduction

We recently published a classification of electronic medical record (EMR) hazards based on a grounded theory approach [1] as part of a body of work in the area of EMR system's safety which also includes [2, 3]. This classification effort was undertaken with a systems theory perspective and a focus on human factors. The classification presented there is in many ways more complex than necessary. We present here preliminary results of our second iteration on this work. This study, at its completion, will extend the period of literature covered in the preliminary results and will also rely on a variation of the EMR STAMP model presented in [2, 3] rather than the grounded theory approach in [1]. In other words, in this study we begin with the hypothesis that all hazards described in the literature can be classified according to the EMR STAMP model. We then set about searching for counterexamples to disprove the hypothesis.

The rest of this paper is laid out as follows. In section one, we will discuss relevant background including an overview of our previous work and the work of others, an overview of Leveson's system theoretic accidents models and processes [4], and finally a number of definitions. In section two and three we will discuss the body or work which has been inspected so far, the process which was used to identify it, and the methodology

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and tools we used to extract the results we present in section four. In section five will provide our conclusions and a discussion of the work that remains.

1. Background

We have motivated this topic a number of times in our EMR hazards research [1, 2, 3].We will provide a cursory overview of Leveson's STAMP model, an overview of previous work, and we will review and revise a number of definitions.

1.1. System Theoretic Accidents Models and Processes

Leveson [4] describes a theory she calls the System Theoretic Accidents Models and Processes (STAMP). A fundamental underlying concept of this theory is that when accidents occur, it is not because of human error or even any single particular weakness in the system of participants and interactions from which that accident arose. Much like the "Swiss cheese" model for which Reason [5] advocates, Leveson proposes that instead, accidents occur as a consequence of the alignment of a number of weaknesses in the control structure that is intended to prevent them. That is to say that any system, whether it be the aeronautics industry, the nuclear power industry or the health care industry can be modeled as a web of control loops, and each loop and control node in that loop has its own weaknesses. Leveson describes this control web as being comprised of interactions and controllers that rely on process models to affect their control of processes in the system. Weaknesses in control structures can come in two primary forms, weak or missing controllers, or weak or missing control interactions.

1.2. Related Work

There are a number of notable authors who have provided critical perspectives on the benefits of EMRs. These tools are popularly touted as the cure to the ills of the health care system. The media has at times implied that with the use of EMRs medical error and economic waste in health care will be a thing of the past. Authors like Bates [7], Ash [8], Koppel [9], van der Sijs [10], Saleem [11] and others however have put this notion in doubt.

Saleem [11] identified a sense of resentment in professional practice against EMR tools. This resentment is a reaction to the failure of the studied tools to satisfy the workflow of their users. He describes how the elements of the EMR system operate in unison to provide care. The studied care providers used the EMR tools, but also used a variety of paper workarounds when the EMR tools did not support their workflow. In order to understand the safety of the EMR system which Saleem studied, one would need to understand all of its components and could not inspect the software in isolation. Safety is an emergent property.

In [1] we described the first iteration of the study we now present. In [3] we provide a STAMP-centric hazard analysis of an e-iatrogenesis case study by Horsky [6]. In [2] we provide a formal methods focused evaluation of that study.

1.3. Definitions

We provide here our definitions which will constrain our problem. We will define the term EMR and we will also contrast it to two other terms: EHR, and PHR. These are provided to clarify the inclusion and exclusion criteria which were used for the corpus selection. We will refine and refactor the definitions based on out work in [1]. Finally, we will refine the definition of e-iatrogenisis [6], to clarify our intended sense of the term safety.

- *Electronic Medical Record*: An EMR is a unit/suite of software that is used for collecting, storing, manipulating or making available clinical information about a patient's health care delivery process to facilitate the progression of that patient's care.
- *Electronic Health Record*: An EHR is a unit or suite of software that is designed or used for extracting data about a patient's process of care from an EMR for the purpose of maintaining an epidemiological understanding of a population.
- *Personal Health Record*: A PHR is much like an electronic medical record except for one fundamental difference. A PHR is used by the patient to record their health care process rather than by their physician.
- *E-Iatrogenesis*: E-Iatrogenesis can be defined as medical error which is caused (in part) by IT.

2. Corpus Identification

The corpus of work which has been inspected to date in this iteration of our literature review was extracted strictly from the Engineering Village indexing service. This service indexes a breadth of technical literature including IEEE and ACM, but does not cover medical literature. Upon completion of this study we intend on including PubMed as a source and seeking additional expertise in identifying other medical sources.

In order to capture the initial corpus of papers we executed the same query as in [1]. This initial query yielded 116 results of which 21 were finally included in the review. Inclusion and exclusion criteria were applied to determine acceptance in the study; however, as the degree of agreement between the authors as to how the criteria are to be applied remains low at this time, the criteria will only be summarized here. At the completion of this study it is the aim of the authors to include an analysis of the agreement on the application of the criteria including the use of a metric such as Cronbach's alpha [13]. Here, we will only state that the papers were filtered through three phases that inspected titles, abstracts and finally full papers. This filtering process will by the end of this study be supplemented by including papers that are highly cited in the primary corpus in a secondary corpus, and similarly a tertiary corpus will be included based on references in the primary and secondary corpora.

3. Data Extraction Methodology and Tooling

The Atlas.TI version 6.2.27[13] application was used to record observations about the papers in the corpus. This tool allows annotation and quotation of the text of pdfs. Dur-

ing the study, only when the information about the reported e-iatrogenesis hazards and or instances were sufficient to populate an error report template based on the nomenclature of Phillips and Gong [15] was information extracted. The information extraction template consists of two primary elements: an error state and a precipitating event.

The error state is comprised of three subcomponents: the error element, the error condition, and the error context. The error element describes the precise element which was in error. The error condition describes how the error element was in error. Finally, the error context describes how the error element fits into the broader context of the software system.

The precipitating event is comprised of three elements as well: the event agent, the event task, and the event context. Event agents are users who participated in the initiating or propagating the error state. The event task is the activity in which the event agent was engaged when they initiated or propagated the error state. A challenge of the methodology is that though much *could* be reported about context of e-iatrogenesis instances and hazard, typically little *is* reported.

4. Results

The initial query returned 116 results. Of those 116 results, 30 were duplicate listings, 5 referred to non-articles/books, and 1 had been retracted. 29 papers of the initial 116 were excluded based on title, 26 were excluded based abstract, and 5 papers were excluded based on full content. 21 papers remained for inclusion in the primary corpus. We uncovered 200 reported e-iatrogenesis instances or hazards. In order to classify these discoveries, we employed an EMR specific instance of the STAMP model. We present the annotated model in Figure 1. The annotations in this figure represent the number of reported e-iatrogenesis instances or hazard and. the number of parent concepts respectively. The arrows represent the control channels between controllers and processes.

In analyzing the distribution of hazards across the model we present in Figure 1, it is clear that two primary themes emerge: tool interaction issues and weaknesses in process control. The tool interaction weaknesses are expressed across the nodes and edges to which the EMR and physician process models are attached. Upon inspection of the hazard descriptions it becomes clear that these hazards can be broken down into two, non-exclusive subcategories: tool/work flow and display/control issues.

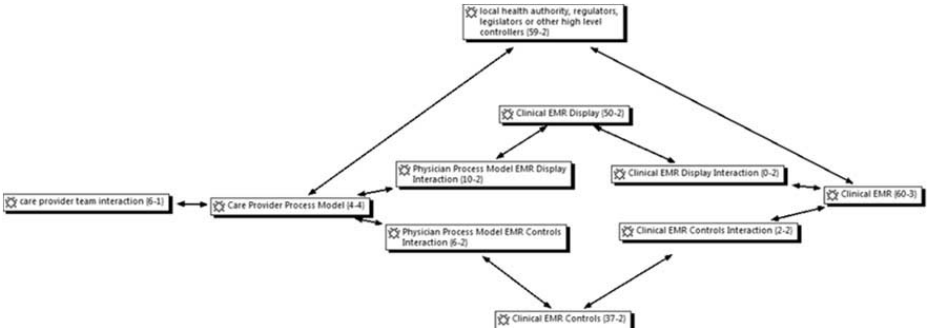

Figure 1. Representation of the STAMP model used to classify hazards and e-iatrogenesis instances.

Though these concepts, tool/workflow issues and display/control interaction issues are commonly understood to be of significance in the field, the systems focus taken in the evaluation of the corpus also strongly, and somewhat unexpectedly, highlighted the prevalence of the recognition of the role of systemic controls in the failures of EMRs. These systemic control failures extend from the highest levels where legislators and regulators act, to much lower levels where care providers, hospital administrators and software engineers hammer out product requirements for the EMRs which are to be created. Out of the 21 papers in the primary corpus, 10 papers reported a total of 103 interaction problems of either the tool/workflow mismatches type or the user interface/control type, and 12 papers reported on a total of 65 systemic control issues including difficulties in requirements gathering/specification or legislative/regulatory issues. Amongst the papers that discuss legislative and regulatory issues we cluster not only those that talk about jurisdictional legislation or regulation as might be imposed by a state, but also those issues of policy which arise within an organization.

5. Conclusions and Future Work

The most immediate conclusion which can be drawn from the results is that our hypotheses were not disproved. It is no surprise that the issues with tool/work flow mismatch and user interface issues were highlighted as major hazard and e-iatrogenesis sources. Experts in the field have been writing about these topics since the inception of the EMR. The third theme which arose from this study, the theme of problems with system controls, is more interesting in that it has been less explored in this domain.

If there were a single lesson to be learned from the preliminary results of this study, it would be that additional effort in quality assurance, both in its enforcement and execution may be key to reducing the frequency and severity of e-iatrogenesis. By employing quality assurance controls which are used in developing EMRs including user acceptance testing and usability assessment we may be able to simultaneously mitigate tool/workflow mismatch issues as well as user interface problems.

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Benefits of a Clinical Planning and Coordination Module: A Simulation Study

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Abstract. Digital Clinical Practice Guidelines are commonly used in Danish health care. Planning and decision support are particularly important to patients with chronic diseases, who often are in contact with General Practitioners, Community Nurses and hospitals. In the Capital Region of Denmark the potential benefits of a planning and coordination module has been assessed in a full-scale simulation test including 18 health care professionals. The results showed that health care professionals can benefit from such a module. Furthermore unexpected new possible benefits concerning communication and quality management emerged during the test and potential new groups of users were identified.

Keywords. Clinical simulation, eHealth, clinical practice guidelines, usefulness

Introduction

Clinical practice guidelines (CPG) have been used more frequently during the last years [1]. Continuity of care programs containing CPG aimed at planning and decision support for healthcare professionals are therefore being developed [2]. The Capital Region of Denmark is exploring the potential benefits of an information system supporting the planning and coordination of chronic patient across sectors [3]. Patients with Chronic Obstructive Pulmonary Disease (COPD) and Diabetes Mellitus Type 2 (DM2) are selected to establish a proof of concept project. Currently there are no information system supporting the coordination and planning across community nursing, general practitioners and hospitals in Denmark. The consequence is limited planning and reduced coordination across the three sectors followed by decreased **quality** and compliance of CPG. International experiences indicate that IT-systems can enhance compliance as well as quality of care [4;5].

The Capital Region in Denmark has launched a project: "Chronic 5" that aims to demonstrate the potential benefits of a Planning and Coordination Module (PCM). The project analyzes and specifies requirements for such a system and builds and tests a PCM prototype. Clinician end-users, clinical managers, quality managers, IT-architects and health informaticians performed the analysis and the specification.

The PCM is basically designed to establish and maintain a cross organizational overview and virtualized management of all health services in individual patient cases among all relevant health actors – including the patient. All health services in an individualized patient plan are mapped to relevant CPGs

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The purpose of PCM is to support the coordination across sectors, concerning the status and planning for patients with COPD and DM2 according to the CPG, and handling of derived activities and services. This digital support will be groundbreaking in Denmark, and will offer new opportunities for coherence and continuity in the care activities. Moreover it will possibly ensure a higher compliance to the existing continuity programs and CPG.

To realize the intended benefits of a PCM usability of the system is pivotal [6]. Usability may be defined as "extent to which a system, product or service can be used by specified users to achieve specified goals with effectiveness, efficiency and satisfaction in a specified context of use" [7]. When using simulation it is possible to assess the effect of an information system in different contexts as well as evaluating efficiency, satisfaction and effectiveness [8]. The objective of the simulation study was to assess the potential benefits of a PCM for health care professionals involved in planning and coordination of patients with COPD and DM2, primarily focusing on the efficiency of the PCM, and secondary on satisfaction. Efficacy and effectiveness has not been assessed.

This paper presents the test of the PCM-prototype and the results from the test, and discusses the potential benefits and concerns of a PCM. Furthermore the use of simulation as a method for testing potential use of clinical information systems is discussed.

1. Method

The test was conducted as a controlled full-scale simulation study. The concept of simulation has been used for training medical skills during the last 40 years [9] and has during the last decade been used to assess health information systems [10]. A simulation study makes it possible to assess the use of a prototype in a realistic environment [11], and is well suited for assessing potential impact [12] as well as cognitive processes and usability [13].

The test encompassed 18 simulation runs including six general practitioners (GP), six community nurses, six hospital physicians and two simulation patients. The simulation runs were bundled into six tests. In each test healthcare professionals from each of the three end-user groups were participating. 10 scenarios were composed; five about a patient with COPD and five about a patient with DM2. The scenarios covered planning of therapy and further diagnosing concerning a recently diagnosed patient at the GP, visitation at the community nurse, rehabilitation at the community nurse, treatment of a patient at an outpatient clinic due to exacerbation of the condition, and assignment of responsibility from the hospital physicians to the GP. The scenarios resembled different points of impact focusing on core functionalities and the assignments from one healthcare professional to another. Interface issues such as colors, buttons and minor functionalities were not part of the assessment. The scenarios were composed to assess nine hypotheses i.e. the first nine questions in Figure 1.

Before the simulation took place the testers were introduced to the concept and the functionalities of the PCM and they could get hands-on in order to get acquainted with the information system. During the test the same general tasks were performed. In cooperation with the "patient" and on the basis of the existing findings and plans, the healthcare professionals were asked to revise and modify the plans for the patient. The prototype had simulated integrations to other information system in order to replicate

the intended integrations to legacy information systems. A test-coordinator was sitting next to the tester during the test to assist the tester in case of problems using the system. The tester was asked to "think-aloud" [14] during the test, and the test-coordinator did obser-view [15] asking more exhaustive questions if necessary. By asking questions about the system, the "patient" was able to force the tester to describe the system and the functionalities in a close to natural setting. Health informatics experts experienced in simulation test conducted the role of the patient. In the control room a test instructor and several observers followed the test through a one-way mirror. The instructor was in radio contact with both the "patient" and the test-coordinator during the test. Hereby the instructor was able to direct the test to ensure the objectives. The observers monitored the test and their observations were used in the subsequent debriefing-interview. During each test testers from the three sectors were present, but only one was testing, while the others observed from the control room.

Data for the evaluation was acquired by questionnaire and debriefing-interviews with testers and observers. The questionnaire had nine questions concerning the hypothesis, two about quality, four about overview, two about the division of responsibilities, four about work practice and efficiency, and three questions about the simulation and the realism in the scenarios. The interview guide started with open-ended questions concerning positive and negative features of the system, followed by specific questions to clarify and elaborate on issues from the questionnaires and other issues that came to their mind. At the end of each day the data from the interviews were analyzed using Instant Data Analysis (IDA) [16]. As supplement to IDA the observations from the simulations, the notes from the interviews and the IDA notes were analyzed using Nvivo (QSR International).

2. Results

The results from the questionnaire are shown in Figure 1. The horizontal scale depicts the median of the respondents answer on a five point likert agree/disagree scale to the 24 questions on the vertical axis. The hypotheses tested in the first nine questions were verified. Among the remaining questions only one obtained a lower score than 3 i.e. the question concerning whether the PCM would release more time to be spend with the patients. From the interviews, however, the general opinion was that the PCM would reduce the time spend on the planning and coordination, but it remain unresolved, whether the time would be spend with the patients. This result was the only one with discrepancy between interview and questionnaire.

The core concept of the PCM was assessed as being very useful and creating many benefits. New ideas were brought up during the interviews – eg. the PCM could be a coaching tool for senior doctors and an instrument for communication among colleagues or between other groups of healthcare professionals. Primary care nurses were not part of the original scope, but were spotted as new potential users by a GP who saw the PCM as a very valuable tool for them. Also quality management was perceived to be enhanced, and the content of referrals and discharge letters could possibly be reduced, since information concerning the patient would be known by all parts.

Most of the healthcare professionals had difficulties understanding the concept of a PCM in the beginning. The concept was innovative and forced them to see planning and coordination in a new way. The simulation and observation of the others using the

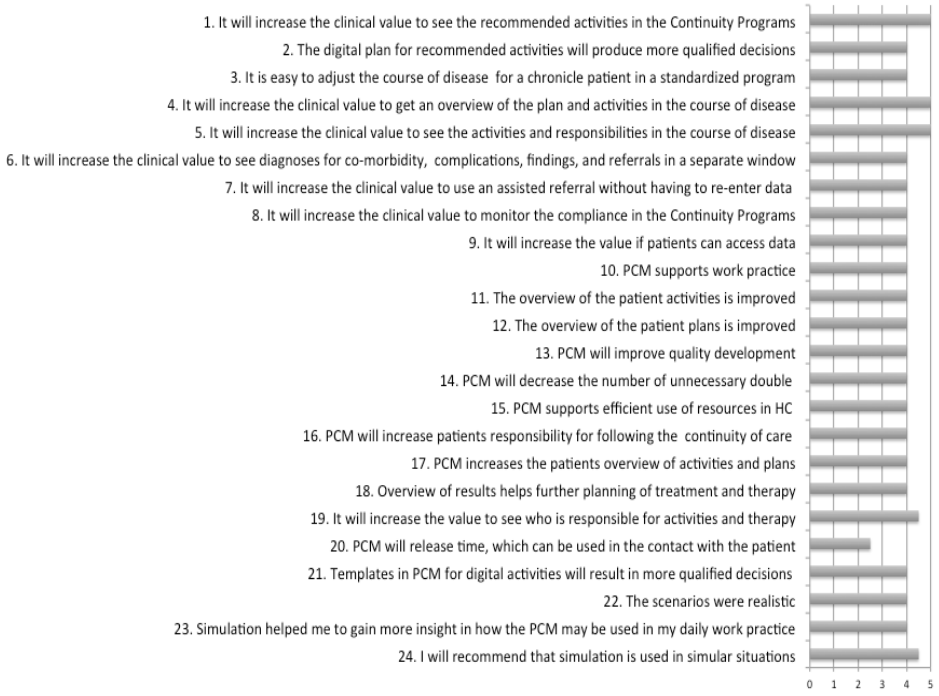

Figure 1. Potential benefits: Result from Questionnaires (n=14)

system helped them to understand the concept. Several issues of concern were also brought up. 1) The healthcare professionals found that the PCM module gave a good overview of the patients, but at the same time they wanted the possibility of looking into more details about the patient. They recommended to specify this in the requirements. 2) The test showed that the terminology used in the three sectors, differed on several central terms such as “referred to” and “deselected”. 3) Sharing of responsibility as all will have the same access to data, but should it be possible for a physician at the hospital to overrule a prescription from the PG - or vice versa? 4) Several users stressed that realization of integrations were of vital significance.

3. Discussion

The healthcare professionals found potential clinical benefits in using the PCM, which would improve quality and patient safety. Furthermore new future users were discovered and new potential ways of using the PCM were revealed. Only simulated patients were used during the test, but several potential benefits for the patients were detected. A supplementing simulation with genuine patients would therefore be recommended to test the sustainability of these observations. The healthcare professionals were quite satisfied with the realism in the simulation, and it helped them to gain insight in the possibilities of PCM.

The scenarios did not cover all possible applications of the PCM but were composed to enable assessment of the nine hypotheses. A simulation test does not fully

resemble the use of an information system in the clinic, but offers a high degree of realism, depending on the degree of fidelity. A simulation test should therefore not be a substitution for a pilot implementation, but regarded as a complementary test without risk of injuring real patients.

Several issues that were brought up e.g. terminology and responsibility had not been visible before the simulation test, but are very relevant and needed to be addressed prior to implementation. Furthermore it was discovered how the simulation was a powerful learning tool for the new users in spe.

The results from this simulation study conclude that GPs, community nurses and the hospital physicians and patients will benefit from a PCM. The benefits include improvements in communication, planning and coordination, work practice, and quality management. Several organizational issues have to be addressed including use of terminology and delegation of responsibilities before an information system as PCM can be implemented. Furthermore the results show that full-scale simulation studies are a useful method for testing the feasibility of information systems.

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Issues and Considerations for Healthcare Consumers Using Mobile Applications

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Abstract. There is a large and ever increasing number of mobile phone health, wellness, and medical applications on the market. However, there is little guidance or quality assurance available for consumers. This paper provides a health consumer focused framework for considering a range of issues associated with selecting and using mobile phone applications downloaded from the Internet.

Keywords. Mobile phone apps, M-health, data storage issues, software issues

Introduction

Internationally we have seen a significant rise in mobile phone use. According to International Telecommunications Union statistics there were over 5.3 billion mobile phone subscribers globally [1]. In 2011 491.4 million smart phones were shipped globally [2]. With the rise in mobile phone (including smart phones) usage rates, there has also been an increase in the development and sale of mobile phone applications across the globe. Many of these applications are healthcare related and consumers are identifying and using mobile phone applications to: (1) support their health decision-making and (2) assist in self-management of their disease or maintain wellness. This paper provides a discussion of some of the considerations surrounding mobile phone software and the data these applications collect to help support consumers decision-making when using mobile phones and their associated software applications. In the literature there are many discussions on the use of health applications by health care professionals or those on formal clinical trials [3], these applications are not specifically under consideration in this paper. This paper provides a consumer health focus on some of the issues for consideration when selecting and using mobile phone health and wellness applications downloaded from the Internet.

1. Background

Mobile phone applications are small software programs that provide a specific functionality and can be downloaded onto a phone via the Internet. Most frequently they are associated with smart phones, which use a proprietary operating system (OS)

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and allow the user to download specifically designed applications that run only on that OS, although cross platform mobile apps are now beginning to be developed. Many mobile phone applications can only be run using the Internet to provide real-time information and data exchange whilst others are independent from the Internet and developed as standalone applications, which do not require Internet access. Other apps can be operated in either mode, with restricted functionality in the offline mode.

It has been postulated that smart phone applications can transform mobile phones into assistive devices for people with disabilities [4]. As smart phones become more affordable and the applications remain relatively low cost there is a rapidly increasing acceptance and use of assistive applications by consumers. Consumer use of mobile applications is varied. Some consumers use mobile phones to obtain relevant health information over the World Wide Web (WWW). Other consumers have taken advantage of the growing availability of mobile applications that are specifically targeted towards assisting individuals with the promotion of their own health and wellness as well as the self-management of chronic illnesses such as chronic obstructive pulmonary disease, diabetes and cardiovascular disease. Other mobile applications are provide tools that improve communication with health care providers or facilitate the delivery of patient care, for example: animated videos to educate patients about the human body, wellness, prevention activities, disorders and diseases.

There are currently more than 13,500 medical, healthcare and fitness applications in the apple app store alone. The majority of these applications are aimed at consumers rather than healthcare professionals. Although many are potentially good applications, researchers and health professionals are increasingly advocating that consumers consider the types of applications they are downloading or purchasing with some skepticism, particularly when selecting and using health focused applications [5]. Some of these considerations form the focus of this paper.

2. Method

The authors of this paper had each independently examined and used a range of mobile applications for health and wellbeing. This examination had led to considerable concern regarding the security and quality of mobile phone applications and the data they collect. In this context we developed a "Consumer Perspective Framework" (see Table 1) within which we consider the use of mobile applications from a consumer perspective. The framework emphasizes some key aspects of mobile phones and their associated applications that need to be assessed by consumers when considering their use. Key elements of the framework will be discussed in the following section.

Table 1: Consumer Perspective Framework

Data Issues	Software Issues
Storage and Privacy	Accessibility
Ownership	Clinical Effectiveness
Corporate Use	Credibility
Location	Information Quality
Completeness	Consumer Usage

3. Discussion

Two major areas of concern relating to mobile phone software applications and data storage were identified: (1) data issues and (2) software issues.

3.1. Data Issues

There are several data issues that consumers should concern themselves with, including: (1) storage and privacy, (2) ownership, (3) corporate use and (4) location.

Storage and Privacy: One challenge is keeping personally identifiable health information secure. Essentially, mobile health requires the use of strong encryption and authentication processes to ensure the security of these data. However, as patients are increasingly recognising the potential benefits of digitally recording their health information this issue is becoming more discussed in the patient population. Researchers such as Walker et al [6] have identified that patients are less concerned about privacy than health care professionals. However, Gilbert et al [7] emphasise that ensuring privacy is not violated where sensitive information is concerned is a difficult problem to overcome. There is minimal evidence of the use of secure networks or encryption (as in eHealth applications).

Ownership: There is minimal information available about these mobile phone applications at the point of purchase regarding data storage, use (primary and secondary), durability and ownership. These issues need to be considered when entering personal data, including health data, into a mobile phone application. This information may not be available to the consumer via the app store prior to purchase. There is a requirement that all applications cover these issues in their licensing agreement, which the consumer accepts at the time of initial use. However, some users do not understand the importance of these licensing agreements (which by requirement are very long). One application's licensing agreement, containing standard information, was 26 screen pages long and difficult to read on a mobile phone due to the small screen size. Thus the important elements of the agreement may be difficult to read.

Corporate Use: Some low cost mobile phone applications are sponsored by private enterprises, which can have implications for data privacy and security. One of the key issues is the secondary use of data as application sponsors often provide support to developers in exchange for access to end user personal data. Although, through licensing agreements, this is agreed to by end users it is unlikely that the implications of such agreements have been understood by consumers. Third parties do not have to disclose their actual use of the data and application developers have little or no control over secondary data use. There is limited information about the duration of data storage, or its subsequent use. In the event that the consumer is aware of secondary data transmission, there is the element of consent to the frequency of data transmission. There is concern about the timing of data transmission and to what extent consumers expect their information to be transmitted automatically, and what information is transmitted?

Location: The applications available through the Apple iTunes store are required to meet certification requirements regarding the content and development of the application [8]. This certification does not extend to when and where personal information may be sent once the application's disclaimer has been accepted by the user. No certification process is required for apps available through the android market [8] and so there is little evidence of where the data is processed or stored. The location

of data storage or transfer can be important, particularly if users are anticipating personalised responses to data inputs. If data are only stored locally, on the mobile phone, then it is necessary that users be aware of this so they do not anticipate others will be 'monitoring' them. The reverse is also important where users may consider that they are undertaking a personal venture and then discover their information is being reviewed by others. Consumers need to understand the importance of these issues in a computerised world.

3.2. Software Issues

There are several software issues that also need to be considered: (1) accessibility, (2) clinical effectiveness, (3) credibility, (4) information quality, and (5) consumer usage.

Accessibility: One of the first issues confronting consumers of health and wellbeing applications is the issue of how to locate them. Each of the different phone operating systems (e.g. android) has its own propriatary application stores (app stores) where applications can be purchased and downloaded. The sheer number of applications currently avaliable has the potential to make the search and selection of a useful health or wellness app overwhleming. The majority of app stores have relatively unsophisticated search mechanisms and so for individuals who are uncertain of what they want may find identifying and selecting an app time consuming and cumbersome.

Clinical Effectivness: There are a large number of medical, health and wellbeing applications. Most of these applications have a limited description of the application's purpose and few reviews documenting the application's clinical quality (thereby making selection of mobile applications on the basis of clinical effectiveness more difficult for consumers). Thus, mobile applications may or may not even function as expected, let alone be of use to the individual in supporting a wellness behaviour or helping with the self-management of a consumers' disease. Where applications are calculating health or wellbeing measures from data inputs it is important to know and understand the means, or algorithms, by which these calculations are being made. Inaccurate calculations, or non-standard ones, may be in conflict with current medical trends and advice and may lead to medical error [10]. It is also possible that results may be ambiguous or misinterpreted by consumers with low health literacy.

Credibility: Anyone can create an application so it is difficult to differentiate credible, safe applications from those which are not. There is little information available in an app store to indicate credibility and if there are reviews these can also be biased or based on unhelpful metrics. As a result of this, there is a need for undestanding of the possible issues for both consumers and health care practitioners. There is potentially a role for policy development which will assist people in classifying these applications. For example inn the USA the Food and Drug Administration recently released draft guidelines for Mobile Medical Applications [9].

Information Quality: As with health related websites, there is concern about the quality and accuracy of information and advice provided through mobile phone apps. For the scope of this paper the concept of information quality is made up of several elements: (1) quality of the information in the application program incorporated by developers, (2) quality of the information entered into the application by consumers, and (3) quality of information received by the user through their interaction with the application.

Consumer Usage: The motivations behind the use of mobile apps have the potential to impact on the quality of the information recorded. Is the health consumer

after real behavioural change or are they after information to show a healthcare provider to illustrate compliance with a care program? Information quality has the potential to impact on healthcare consumers overall program of care, depending on the credibility that the application holds with the healthcare provider and the methods by which it is used by the consumer.

Having devised and described this framework the authors are intending to move to the next stage and conduct research with consumers to test the reliability of the framework. This work is intended to provide a consumer focused understanding of the most appropriate method by which the framework can be implemented for use by individual consumers to assist them in selecting the most reliable applications. This work will include a comprehensive exploration of literature relating to the framework.

4. Conclusion

There are many facets to consider when selecting a mobile app for use with health and wellbeing in mind. Consumers are encouraged to consider the security and secondary use of the data prior to engaging with these applications. App stores and developers should be encouraged to provide more reputable information about the privacy and security of the data as well as the efficacy and source of the programs. Healthcare professionals as well as consumers, providers and developers have a role to play in ensuring that only high quality efficacious apps are developed into the future. In this paper we describe a framework that can be used by consumers and health professionals when considering mobile application for healthcare use.

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The Introduction and Evaluation of Mobile Devices to Improve Access to Patient Records: A Catalyst for Innovation and Collaboration at BCCA

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Abstract. Prompt and efficient access to patient records is vital in providing optimal patient care. The Cancer Agency Information System (CAIS) is the primary patient record repository for the British Columbia Cancer Agency (BCCA) but is only accessible on traditional computer workstations. The BCCA clinics have significant space limitations resulting in multiple health care professionals sharing each workstation. Furthermore, workstations are not available in examination rooms. A novel and cost efficient solution is necessary to improve clinician access to CAIS. This prompted the BCCA and IMITS to embark on an innovative provincial collaboration to introduce and evaluate the impact of a mobile device to improve access to CAIS. The project consisted of 2 phases with over 50 participants from multiple clinical disciplines across BCCA sites. Phase I evaluated the adoptability, effectiveness and costs associated with providing access to CAIS using a generic viewer (Citrix). Phase II incorporated the feedback and findings from Phase I to make available a customized mobile device-specific application. Phase II also addressed privacy and security requirements.

Keywords. Mobile technologies, Technologies as agents of change, Electronic Health Records, Human Computer Interaction

Introduction

Searching about the clinical use of mobile devices produces impressive results about their increasingly ubiquitous use by care providers. Anecdotes about Apple iPads having improved teaching and medical practice are common. However, is this technology hyperbole or are there tangible benefits?

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1. Statement of Problem

The BC Cancer Agency (BCCA) uses an electronic health record named CAIS; however, it lacks adequate physical space for clinicians to access records via desktop computers. Also, clinicians do not have access to computers in the patient rooms, during clinical conferences or grand rounds.

2. Purpose

Determine if providing a mobile device with access to CAIS, clinical reference applications and administrative tools improved care delivery and clinicians' experience.

3. Methodology

The project followed a two-phased approach. Phase I gave users the ability to download clinical reference applications and access the Cancer Agency Information System (CAIS) using a generic viewer (Citrix). Phase II incorporated usability feedback from Phase I to deploy a highly configurable health record viewer delivered as a native iPad application.

3.1. Phase I – Methods and Procedure

3.1.1. Sampling and Recruiting

Thirty-four (34) Radiation Oncologists (RO) at Vancouver Centre BCCA were supplied with iPads. Each RO active in clinic was invited to participate in the study and evaluate the effectiveness and utility of the iPad.

3.1.2. Instrumentation

Participants were emailed with a link to complete two confidential surveys. This involved a survey before the iPads were distributed and a survey after twelve weeks of use. Participants rated items on a Likert scale.

3.1.3. Data Collection

The survey tool collated data collected from participants. As well, informal interviews were completed before Phase I and at the end of Phase II.

3.1.4. Data Analysis

The responses to the second survey assessed if and how iPads were effective in a clinical setting. Information collected was analyzed and interpreted using descriptive statistic analysis. For qualitative answers, the research team interpreted the written responses.

3.2. Phase II – Methods and Procedures

3.2.1. Sampling and Recruiting

There were 50 participants in the study. Twenty-five (25) radiation oncologists from multiple BCCA sites, some of whom participated in Phase I, were included in Phase II. Additionally, 25 medical oncologists from Systemic Therapy groups across all 5 BCCA Centers were invited to participate.

3.2.2. Instrumentation

Communication was addressed with an intranet website. Participants were emailed with a link to the intranet site and listed the four steps required to enroll in the pilot initiative. Step 1 provided information about the purpose of pilot; Step 2 incorporated privacy and security requirements by having participants sign a project privacy agreement; Step 3 provided a baseline survey that aligned with Phase I; and Step 4 provided instructions on how to launch the patient record viewer application on the iPad.

3.2.3. Mobile Patient Record Viewer Application Functionality

The mobile application presented information from CAIS in a user interface designed for an iPad. The application provided users with read-only access to all of the patient information available on CAIS (outside of imaging). Also, the application provided access to clinicians' clinic schedule and patient appointments. The application has a user-defined configuration for the visual layout of the patient record.

3.2.4. Data Collection

At the end of Phase II, participants were asked to complete a post-implementation survey to measure the effect of the iPad and patient record application. A subset of participants was observed while using the current tools such as desktop computers and paper charts. This was compared to the post-pilot observations when the iPad and patient record viewer application was available. The observations captured data about time required to access patient information, turnaround time between patients, and challenges with using the tools. Twelve semi-structured interviews were also conducted during the project period.

3.2.5. Data Analysis

A multi-method research study was used for the evaluation that involved surveys, observational studies, and interviews. The responses to the post-implementation survey and interviews determined if and how iPads and the patient record viewer application are useful and effective in a clinical setting. The baseline survey results were compared to the post-implementation survey results. Similarly, the results of the baseline observations were compared to the post-implementation observation results. The interview results were analyzed using grounded theory methodology to identify the major themes.

4. Results

4.1. Phase I - Preliminary Findings

Pre Usage

In the pre-usage survey, the user group rated themselves as very comfortable with mobile devices, with a large majority (86%) of the group using mobile devices daily and 78% already finding mobile devices useful in their professional practice. A majority (67%) of the users envisioned that having a mobile tablet would enhance their clinical workflow, with 43% of users already having an idea of what functions they could employ, and close to all users (91%) looking forward to adding a mobile tablet to their clinical practice.

Post Usage

Upon completion of the three-month pilot project, a large majority of the users (83%) reported having an overall positive experience using the mobile tablet, with only 3% of users summarizing the pilot project as a negative experience.

The mobile tablet was reported as being easy to carry around (70%), had satisfactory screen resolution (63%) and an appropriate screen size (50%). Users found using the mobile tablet an efficient way to check and write email (62%) and review electronic records (55%), with a majority (63%) of users noting a positive impact on their workflow through the use of a mobile tablet; highlighted by 76% of users explaining that CAIS through their mobile tablet was more up to date than the patient's paper chart. In addition, once users became comfortable with the mobile tablet, over 60 percent of users began searching out other medical application to incorporate into their clinical workflows.

Initially, a number of users had minor complaints regarding Internet connectivity (38%), and login issues to PHSA Network (16%). In most cases, the help of on-site support addressed these issues. Another suggestion was to increase the font size of the CAIS viewer (55%).

In summary, users found that the use of a mobile tablet was a useful tool in their clinical practice (73%), with the tablet primarily being used for email (96% of users), review of imaging and pathology (90% of users), and review of labs and appointment notes (87% of users). For 75% of users, the use of a mobile tablet met or exceeded their expectation in terms of functionality in their practice.

4.2. Phase II - Preliminary Findings

Pre Usage

In general, the results show that clinicians at BCCA are among the early adopters of mobile computing technology according Rogers' Diffusion Theory (with more than 90% of the respondents are using mobile computing technology in their clinical practice). The majority of the respondents (> 80%) are either very comfortable or comfortable with using mobile computing technology.

BCCA clinicians highly appreciate (98%) the in-time availability of information, a privilege peculiar to mobile technology that subsequently offer clinicians the ability to respond instantly to patients questions and enquiries. Other highly ranked and expected functionalities include: using the iPad for patient education, communication purposes, and for clinical decision-making. Moreover, almost all respondents (98%) expect that

the iPad and other mobile computing technology to be become larger part of the cancer care experience for both clinicians and patients.

Post Usage

The majority of the post-implementation survey respondents (92%) are either highly or moderately satisfied with the iPad and VH Chart application. BCCA clinicians rated the iPad project between 4 and 5 with 5 being extremely positive. The iPad application visual interface, multiple functionalities, and ease of use were the main drivers for clinicians' positive feedback. Figures 1, 2 and 3 illustrate early utilization.

Based on the results of the post-pilot survey results, most of the post-implementation survey respondents (92%) found that the response time, security and reliability of the iPad and the mobile application to be either moderately or highly acceptable. In terms of the information quality, most of respondents (92%) found the information within mobile application to be either highly or moderately acceptable. Similarly, most participants (90%) agree that there were sufficient technical support and training resources for the iPad Mobility project. in general, most of the respondents (95%) rated the project implementation process either moderately or high acceptable.

In terms of productivity and efficiency, clinicians reported reduction in the number of interruptions during patient visits and a reduction in the need for printing (reports, conference documents). Most of the survey respondents (> 80%) believe that the iPad improved their workflow as it facilitated the retrieval of information from CAIS. This allowed the clinicians to involve the patients in care planning, increase collaboration with other healthcare providers and enhance support in decision.

5. Conclusion

The majority of clinicians supported the use of a mobile device to improve access to patient health records, but recognized limitations of a generic viewer to simulate a desktop view of CAIS. Clinicians preferred the iPad mobile application because of its ergonomic features and ease of use. Also, clinicians provided feedback to enhance the mobile application features. Notable is that most clinicians viewed the iPad application as complementary to their desktop computer and improved their workflow.

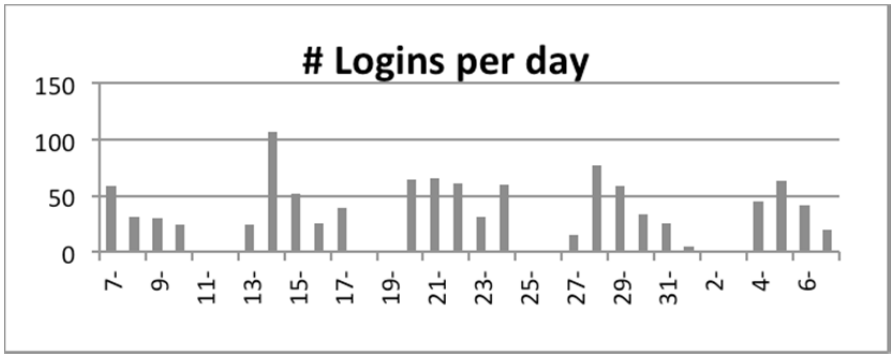

Figure 1. Phase II – Usage Statistics for First Month - # Logins per day.

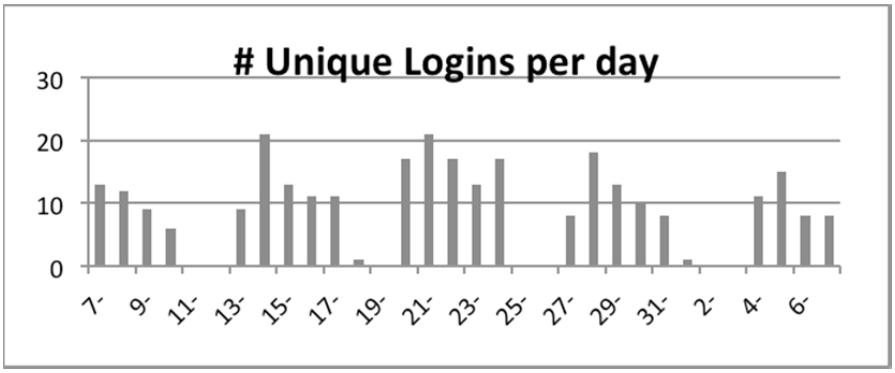

Figure 2. Phase II – Usage Statistics for First Month - # Unique Logins per day.

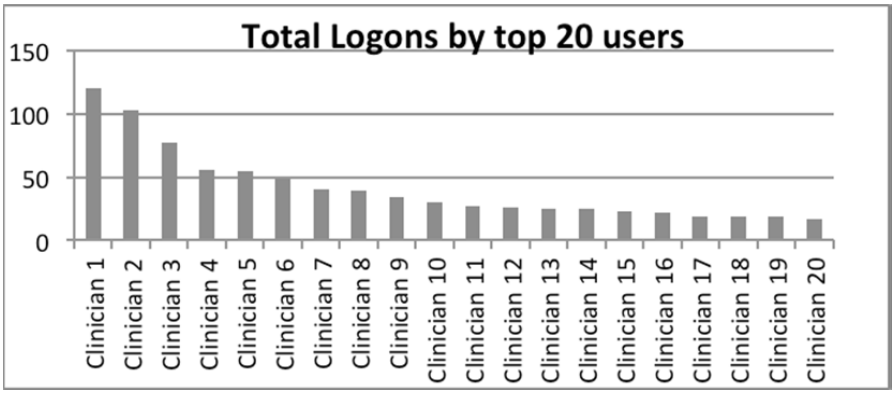

Figure 3. Phase II – Usage Statistics for First Month – Total Logons by top 20 users.

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Moving Mobile: Using an Open-Sourced Framework to Enable a Web-Based Health Application on Touch Devices

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Abstract. Computer devices using touch-enabled technology are becoming more prevalent today. The application of a touch screen high definition surgical monitor could allow not only high definition video from an endoscopic camera to be displayed, but also the display and interaction with relevant patient and health related data. However, this technology has not been quickly embraced by all health care organizations. Although traditional keyboard or mouse-based software programs may function flawlessly on a touch-based device, many are not practical due to the usage of small buttons, fonts and very complex menu systems. This paper describes an approach taken to overcome these problems. A real case study was used to demonstrate the novelty and efficiency of the proposed method.

Keywords. APEX, jQuery Mobile, tablet, touch-based, database, web-based, health, informatics, open-source, iPad

Introduction

Over the past thirty years, personal computer use has traditionally tethered users to a fixed point due to both the physical size of devices, the requirement of an electrical outlet as a power source, and the use of hardwired network cabling. Recently, personal computer technology has seen an immense change through the decrease in component size, increase in microprocessor performance, advancements in battery technology and the rise of cellular communications and mobile Internet. Since the introduction of the Apple iPad in the spring of 2010, an immediate shift in the form of touch-based tablet computer devices has been observed. Touch enabled technology is becoming more and more prevalent today and its influence can be observed in the interfaces of the latest computer operating systems such as Microsoft Windows 8's 'metro' interface and the Launchpad in Apple's Mac OS 10.8 Mountain Lion.

Computer devices have become extremely portable with fingers and voice replacing the mouse and keyboard as the primary means of control. Although the introduction of such technology has been exciting, especially to many in the health care industry, it has not been quickly embraced by all health care organizations [1].

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A major issue with touch-based technology is the fact that previous software, which was designed with a traditional mouse and keyboard interface in mind, was not intended for use with a touch-based interface. Regardless of how accurate the touch screen at recognizing the user's touch, the accuracy is restricted by the size and position of a user's finger [2, 3]. Although these software programs may function flawlessly on a touch-based device, many are not practical due to the usage of small buttons, fonts and very complex menu systems. This paper describes the approach taken to overcome this problem when encountered by a team of students at the School of Health Information, University of Victoria (UVic).

1. Background

The project began as a team assignment in a graduate level database design course offered at the School of Health Information Science, UVic. This course is one requirement of the MSc degree in Health Informatics, a unique program in Canada. The four student team members came from a variety of backgrounds and experiences, all with strong clinical backgrounds but only one with technical expertise. None of the team members had experience programming in SQL though skills were developed throughout the course with the guidance of the instructor, Dr. M.H. Alex Kuo. This course ran for just over a three-month period, from January until the beginning of April
2012.

In the class, teams were instructed to design and build an electronic medical record (EMR) application using Oracle 10g/XE and the application builder in Oracle Application Express (APEX). For this project, it was decided to design the application to be used in the Aging Brain and Memory Clinic (ABMC) at Parkwood Hospital, in London Ontario Canada. This clinic's primary function is to assess referred geriatric patients who have complaints of memory impairment.

Through a needs-assessment conducted in the ABMC, tablet computers were identified as the preferred primary clinical data-capturing device, with a desktop version also being required. Currently, the data recorded in ABMC clinical assessments is completed on paper as no electronic tool has been found which meets the needs of such a specialized geriatric clinic. The preference for staff to use a tablet device was not surprising, as mobile computing is fast becoming one of the main methods in which electronic information is utilized today. Some of the newest and most popular computer tools on the market are not provided or supported by hospitals, but yet are still being carried by the physicians, residents, fellows, and nurses [4].

The omnipresence of powerful handheld communication devices, such as smartphones and tablets, are fundamentally changing both the quantity and quality of information available to clinicians at the point of care [5]. These mobile devices are far more than storage devices; they are sophisticated tools with beautiful full-color screens, high-speed internet access, and offer users the ability to communicate, via voice or text, to anyone in the world. Tablet computers have become noticeably popular as physician adoption for professional purposes nearly doubled in the United States between 2011 and 2012, reaching 62% according to the *Taking the Pulse* survey [5]. In addition, the study stated that one-half of

tablet-owning physicians, who participated in the national survey, have used their device at the point-of-care.

Due to the increasing demand for mobile information, the team began to research options for enabling an Oracle APEX application to be used conveniently on a tablet device with a touch-based interface. Team members first came across the Internet blog of Marc Sewtz, a senior software development manager at Oracle in APEX [6]. The blog post was entitled *Getting started with mobile in apex* and familiarized team members with the jQuery Mobile open-source user interface framework. As summarized in the jQuery Mobile documentation, jQuery Mobile is "a unified user interface system that works seamlessly across all popular mobile device platforms"[7]. Through careful examination, the jQuery Mobile framework was selected as the user interface for the mobile version of the EMR application.

2. Methods

Dr. Michael Borrie, Director of the ABMC, provided the team with the paper based assessment tools and clinic forms which were used to create the dataset for the EMR system. The dataset was normalized and then each table was programmed into Oracle 10g/XE in the SQL Workshop in APEX. The latest version of APEX (version 4.1) for this project, however version 3 and above would have met the basic requirements to complete the project while allowing for the use of the jQuery Mobile framework.

The core application, entitled *mEMRy,* was created for use as a desktop version of the EMR and was able to perform the features that were required by the clinic staff. These features included a modular design, being able to capture required data fields, the ability to database the images of completed cognitive tests, and the generation of summary reports based on the data collected in clinic visits. Using the desktop version of *mEMRy* as a framework, the team began to create new APEX templates, which allowed the standard APEX user interface to be replaced by the jQuery Mobile interface.

In APEX, the way in which data is displayed on the screen is determined by the selected template. For jQuery Mobile to be enabled and used as the user interface in the application, mobile templates needed to be created for every data element chosen for display on a page. *Figure 1* shows a storyboard illustration of the initial search page and is labeled to indicate the type of APEX element along with the name of the template used to enable the element for use with the jQuery Mobile interface.

Templates were created with the awareness of the ergonomics of touch screen use and then tested using a trial and error process [2, 3, 8]. Team members tested and took observations of the mobile and desktop versions of the mEMRy application on the iPad 3, Samsung Galaxy Tab, Windows XP desktop computer (1024x768 resolution display), Windows 8 Tablet (Acer Iconia Tab W500), and an Apple Mac Mini (1920x1080 resolution display). As the development of these applications was completed for academic purposes, no formal evaluation or usability assessment was conducted on either version of the application.

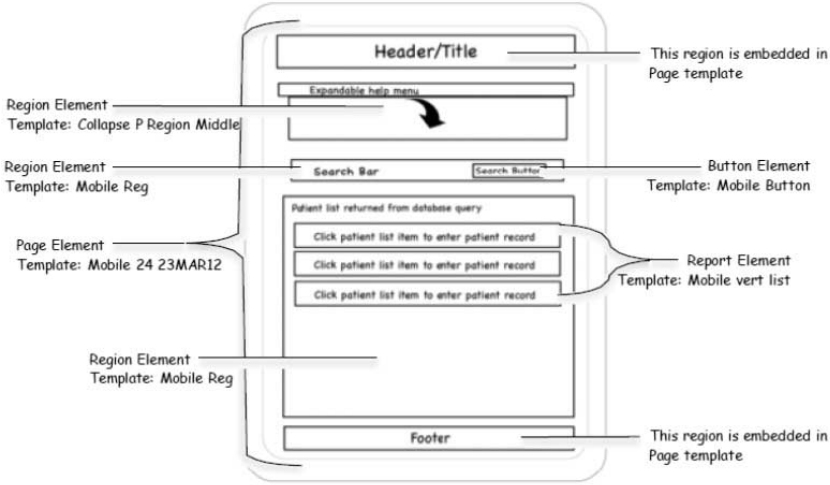

Figure 1. Creating templates to enable jQuery Mobile in Oracle APEX

3. Results

Once the final prototype version of the mEMRy mobile EMR had been completed, 41 new mobile APEX templates had been created. Of those, 22 templates were used in the application with 2 being button templates, 5 page templates, 8 region templates and 7 report templates. The desktop and mobile versions of mEMRy are featured in *figure 2* respectively. When viewing both the mobile and desktop versions of mEMRy on a tablet device, a number of interesting points were observed. In the desktop version on both the iPad 3 and Samsung Galaxy Tab, text and visual elements overlapped one another consistently. Screen orientation needed to be locked in order to prevent the page from being reoriented when the tablet was rotated. Many buttons were difficult to activate by touch and were found to be much smaller than the 20mm size recommended by ergonomists [8]. Text based links were also found to be difficult to select and activate.

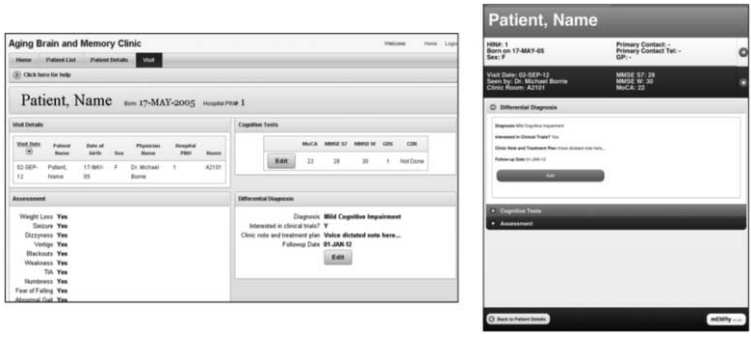

Figure 2. The desktop (right) and mobile (left) versions of the mEMRy application.

In using the mobile application, it became quickly apparent that there was a conflict between the jQuery Mobile framework and APEX. If page transitions were enabled, page links seemed to act erratically with some links functioning correctly, others becoming inactive, and others pulling information from linked pages and displaying it on top of the previous page content. Through troubleshooting and consulting the jQuery Mobile source documents, it was found that page transitions operated using Asynchronous JavaScript and XML (Ajax) could be disabled with a simple command in the header of the page template. In the upcoming release of Oracle APEX 4.2, jQuery Mobile is planned on being fully supported, with a base mobile theme included in the package, and full support for Ajax [9]. Once Ajax was disabled, the jQuerly Mobile framework was successfully incorporated into APEX as the user interface. All pages displayed properly on every device and no limitations in performance were observed.

4. Discussion

As technology advancement continues at a staggering pace, it is essential to ensure that older technology can continue to be used on new device platforms. One of the major benefits to using web-based technologies is the fact that despite of advancements and development in web-based programming languages, web browsers continue to provide legacy support for older versions of web-based languages. Another key point is the fact that web content, excluding select content such as Adobe Flash, is universally accessible across most computer platforms. Computer users can securely access web sites from a desktop computer at home or work, a kiosk, gaming console, smartphone, tablet computer or even a web enabled television. With computer hardware technology changing so quickly, it only makes sense to continue to embrace web-based computing and consider it as the future universal standard platform of computer information systems used in healthcare. For instance, one could easily imagine the application of a touch screen high definition surgical monitor that is web enabled, allowing not only high definition video from an endoscopic camera to be displayed, but also the display and interaction with relevant patient and health related data.

Another important point that has arisen through this project is the use of an open sourced framework such as jQuery Mobile to ensure that tools developed using previous technologies can function and remain supported on newer devices. The jQuery Mobile framework was incorporated into an Oracle Apex database application by a team with little experience, with no associated financial cost, and in a very short period of time. This illustrates the ease with which a user interface can be programmed in a web-based environment. By including platforms such as jQuery Mobile, accessibility is opened to virtually all commonly used devices and operating systems. It is expected that this shift, partnered with innovation, will continue as a trend for developers and leaders in both the software and healthcare industries.

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The Use of Social Media in Healthcare: Organizational, Clinical, and Patient Perspectives

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Abstract. The purpose of this review paper is to explore the impacts of social media on healthcare organizations, clinicians, and patients. This study found that healthcare organizations, clinicians and patients can benefit from the use of social media. For healthcare organizations, social media can be used primarily for community engagement activities such as fundraising, customer service and support, the provision of news and information, patient education, and advertising new services. The study also found that the most widely used social media venues for physicians were online communities where physicians can read news articles, listen to experts, research new medical developments, network, and communicate with colleagues regarding patient issues. Patients can benefit from the use of social media through education, obtaining information, networking, performing research, receiving support, goal setting, and tracking personal progress. Future research should further examine other financial, technological, informational, ethical, legal, and privacy issues surrounding the use of social media in healthcare.

Keywords. consumer informatics, Saudi Arabia, health websites, patient empowerment.

Introduction

The use of social media by healthcare institutions, clinicians, and the public has increased over the past few years. This use of social media is part of a growing trend and is due to a realization that healthcare institutions and clinicians need to be more engaged with their patients. Social media provides an online platform for interactions to occur around various health topics relating to patient education, health promotion, community outreach, public relations, and crisis communication [1]. Social media includes various approaches such as blogs, microblogging (e.g., Twitter), social networking (e.g., Facebook and Patients Like Me), video and file sharing (e.g., YouTube), e-games, and wikis. Despite the use of social media related to healthcare, the effects of social media on patient care have not been well documented, and with

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over 80% of Americans seeking health information online [1], the impacts of social media on health cannot be ignored.

With the widespread use of the internet and the relatively low cost of bandwidth, social media, especially social networking, is being adopted by healthcare professionals and patients. There has been growth in the use of social media, especially online social networking, related to healthcare. Perhaps one of the earliest studies carried out to assess the use of social media in healthcare focused the use of the Bulletin Board System for the education of nurses [2]. That study found that the major impediments to implementing such a system were cost, maintenance, and the lack of training of nurses. In a commentary published by the *Journal of the American Medical Association,* Shachak and Jadad argue that the use of social networks will eventually lead to a more patient-centered healthcare system that will improve communication and information flow between patients, providers, and administrators [3]. Other studies have shown that Facebook users seek health information [4], and social networking websites, such as Patients Like Me, are beginning to cater to the need for social networks devoted to providing health information [5, 6]. With the growing use of social media in healthcare, the purpose of this paper is to review the impacts of social media on healthcare organizations, clinicians and patients.

1. Organizational perspective

It is estimated that approximately 70% of U.S. healthcare organizations use social media as part of various community engagement activities, such as fundraising, customer service and support, the provision of news and information, patient education, and advertising new services, with Facebook and YouTube being the most widely used [1, 7]. Social media has allowed healthcare institutions to increase visibility and improve their overall image. As a result, 12.5% of surveyed American healthcare organizations have successfully attracted new patients through the use of social media [8]. In addition, there seems to be an increasing rate of social media adoption by non-profit healthcare organizations [9]. In 2010, the Mayo Clinic established the Social Media Health Network with a stated vision of being "the authentic voice for patients and healthcare professionals, building relationships through the revolutionary power of social media." There are currently over 100 members affiliated with the Mayo Clinic initiative, and some of their broad initiatives include blogs, Twitter posts, conferences, and webinars to engage various community stakeholders.

One of the main challenges for healthcare organizations is related to understanding the meaningful use of social media sites by patients. Merely visiting a Facebook page or viewing a YouTube video does not signify meaningful use. Higher levels of interaction are needed between the patient and the healthcare institution, and studies to evaluate such interactions should be conducted. Other challenges include dedicating resources to design, maintain, advertise, and update social media sites. Healthcare organizations have not made sufficient investments in this area, and some are beginning to abandon or neglect their social media sites [7]. Yet, the potential for community engagement through social media remains an opportunity for healthcare organizations to engage their communities and market their services.

2. Physician perspective

Physicians have also been users of social media for both professional and personal interests. It is estimated that 65% percent of physicians use social media for professional purposes [10]. The most widely used social media venues for physicians are online communities where physicians can read news articles, listen to experts, research new medical developments, network, and communicate with colleagues regarding patient issues [10]. Physicians rarely use social media sites to communicate with patients. In fact, the American Medical Association has advised physicians to maintain "appropriate boundaries of the patient-physician relationship" and has recommended that physicians should "consider separating personal and professional content online." A study documenting patient privacy violations on the Facebook profiles of medical students and residents found that medical students were more likely than residents to violate privacy, especially when working in medical missions in developing countries [11]. The study concluded that medical professionals have a responsibility to use social networking sites in an ethical manner that does not violate patients' privacy rights. However, physicians are beginning to develop an interest in interacting with patients online. Approximately 60% of physicians favor interactions with patients through social media, showing strong support for patient education, followed by monitoring patients' health, behavior and drug adherence and giving care advice to patient groups that would lead to "better education, increased compliance, and better outcomes" [10]. The challenge in the future will be for physicians to develop guidelines regarding how to interact with patients through social media websites in a manner that is ethical and that does not violate patients' privacy rights.

3. Patient perspective

Patient groups have benefited the most from the use of social media for health purposes. It is estimated that in the United States, 74% of all internet users utilize social media [12], and searching for health information online has become one of the most popular online activities [1]. Patients can use social media for a variety of reasons that include education, obtaining information, networking, research, support, goal setting, and tracking personal progress. Patients have the ability to express themselves, share their stories, learn from others and spread health knowledge [10]. Social media creates a forum for patient participation that extends beyond the reach of the hospital or the local clinic. These forums can help empower and uplift patients when they read the experiences of other patients [10]. Some physicians believe that social media can be beneficial for patients with chronic diseases, cancer, rare diseases, and depression and for patients with questions or goals related to maternal and infant care, wellness and prevention, and weight management [10].

The introduction of social media sites such as Facebook, Twitter, and YouTube has revolutionized the way individuals seek, share and use information, specifically health information. A recent study on the sharing of sensitive health information through Facebook found that Facebook users openly sought and shared behavioral, mental, and genetic information [6]. An interesting finding from this study was that most Facebook users included in the study publicly identified themselves by divulging their name, photo, and location when seeking sensitive health information through online postings. The author of the study suggested that the growing use of social media

and the sharing of personal information may be changing society's perceptions on privacy from the strict implementation of privacy to a policy that is more lenient.

Research is starting to show that there are positive impacts of the use of internet-based interventions, including interventions based on social media, on weight loss, tobacco cessation, and physical activity. Studies have also found that different age groups, income groups, and gender groups use social media in different and similar ways. For example, Korda et al. note that women are more likely than men to look for information relating to symptoms, treatments, diseases and conditions, and medication, whereas men are more likely to search for information about vitamins and supplements, health insurance providers, and physicians [1]. The benefits to the patient in connecting with other groups and communities are understandable, but many challenges with moving forward remain.

4. Discussion

Various challenges arise when social media is used by healthcare institutions, physicians, and patients. For healthcare institutions, reaching out to the community is an activity that requires more resources, and more research is needed to determine the impacts of the use of social media on healthcare outcomes, the quality of healthcare services, and revenue or costs. Any conclusions based on the limited and anecdotal evidence available are premature. More robust evidence is needed to justify the case for healthcare organizations making social media an integral part of their healthcare service delivery models. For physicians, there needs to be a very strict separation of their personal identities and their professional identities when dealing with patients and colleagues. Many issues arise, especially when interacting with patients, regarding compensation, privacy (both patient and physician), and the regulation of such interactions. Although physicians realize that using social media to communicate with patients has potential benefits, the evidence regarding the effects on health outcomes remains premature and is mired by ethical and professional considerations.

Regarding patients, the primary threat when seeking health information through social media is the intentional or unintentional spread of false information that could harm a patient. Another threat is the adverse impacts of sharing sensitive personal health information online, such as genetic, sexual, and psychological information, as this information can be traced back to the individual if he/she does not take the proper precautions [11].

5. Conclusions

Moving forward, healthcare organizations, policy makers, physicians, and patient advocates should collaborate and communicate regarding the development of social media platforms as part of a healthcare model that addresses the needs of all stakeholder groups. Further studies should focus on the utility of social media in healthcare. These activities are needed to improve and ensure the safe use of social media related to healthcare information [7]. In one study, most patients discussed the health information found online with their physician and believed that sharing such information improved the patient-physician relationship [2].

Future research should further investigate other financial, technological, informational, ethical, legal, and privacy issues surrounding the use of social media in healthcare. There are many privacy issues, for example, when sharing information online or using social networking data for research. There are also technological issues, such as usability and network security, when using social media. There are legal and ethical issues surrounding clinical communication with patients. There are also financial issues regarding the compensation of physicians and revenue generated from social media websites focused on health. Regarding information issues, misinformation or disinformation may harm patients who seek health information through social media sites.

More research needs to be performed, and policies and guidelines that can help patients understand the impacts of using social media to obtain health information should be developed. Additionally, healthcare organizations, as well as clinicians, should take the lead in providing healthcare information that is reliable, credible, and trustworthy.

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Evaluation

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POND4Kids: A Global Web-based Database for Pediatric Hematology and Oncology Outcome Evaluation and Collaboration

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Abstract. The Pediatric Oncology Network Database, (www.pond4kids.org, POND), is a secure, web-based, multilingual pediatric hematology/oncology database created for use in countries with limited resources to meet various clinical data management needs including cancer registration, delivery of protocol-based care, outcome evaluation, and assessment of psychosocial support programs. Established as a part of the International Outreach Program at St. Jude Children's Research Hospital in Memphis, Tennessee, POND serves as a tool for oncology units to store patient data for easy retrieval and analysis and to achieve uniform data collection to facilitate meaningful comparison of information among centers. Launched in 2003, POND now has 233 sites registered with over 1,000 users in 66 countries. However, adoption and usage of POND varies widely among sites. This paper reviews some of the challenges to developing a global collaborative clinical platform based on the experiences of developing POND. The paper also presents a case study of POND use in Guatemala, where the Guatemalan National Oncology Unit (UNOP) has developed extensive internal and external global collaborations using POND.

Keywords. cancer registry, pediatric oncology, international, collaboration, clinical improvement, clinical informatics, e-health, data management programs

Introduction

Developed by International Outreach Program at St. Jude Children's Research Hospital, the St. Jude Pediatric Oncology Networked Database (POND, www.POND4Kids.org) is a secure, online, multilingual database for pediatric hematology/oncology patients. Its purpose is to improve the care of pediatric oncology patients in countries with limited resources by the exchange of information and experience between oncologists in diverse geographic regions who practice in a similar medical environment [1-4]. The major objectives of POND are to:

1. Allow oncologists to store, share, and control access to patient data.
2. Provide uniform data collection to facilitate meaningful comparisons

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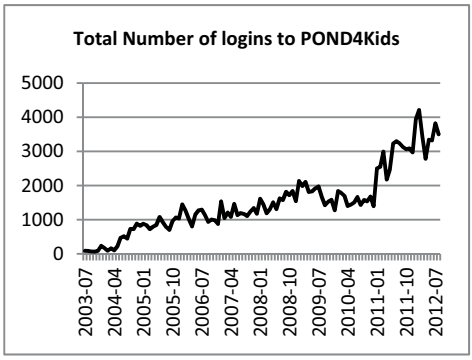

Figure 1. Total Number of Logins (all sites)

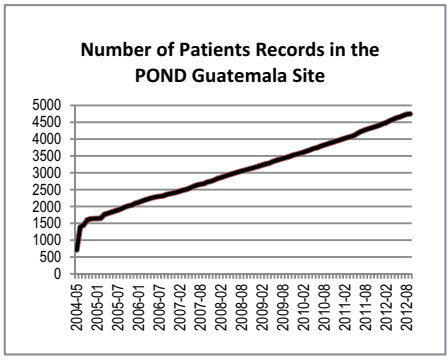

Figure 2. Records in POND Guatemala

3. Provide educational support for data collection, quality control, and analysis.
4. Provide a multi-lingual system that supports data sharing and comparison in a universal format while allowing data entry and reporting in the user's native language.

This paper presents a technical overview of the system, reviews global usage of POND, identifies some of the barriers and facilitators for adoption and usage of POND, and provides an example of successful POND use at the National Pediatric Oncology Unit of Guatemala, and highlight on-going challenges.

1. POND4Kids Systems Design

POND4Kids allows uniform data collection so that clinical data can be shared and meaningfully compared between centers. POND4Kids uses a centralized web server (Linux, MySQL, and PHP) that can host multiple virtual sites. Each site has an administrator that can add users and control the level of access of each user. Data can be shared with individuals at another POND site, and sharing can be deactivated at any time. By design, personal information such as names cannot be shared between sites, such that shared data always complies with HIPAA privacy rules in the US, which are similar to privacy rules in many other countries. The intent is to allow data about a particular disease to be shared with a disease expert to assist with analysis and development of strategies to improve outcomes. Users can create Quick Data Entry forms that can be used within a POND site or shared with other sites via a common library. Protocols templates can also be created and used locally, or shared with other sites via a common library. Using the online meeting capabilities of the Cure4Kids website (www.Cure4Kids.org), training is provided on best practices for clinical data collection and clinical quality improvement programs. Additional details of the POND system can be found in [4-6]

2. Outcomes

Since its launch in 2003, POND use has increased steadily, with use spreading only by word of mouth in the pediatric hematology/oncology community. As of September 12, 2012, POND has 1,222 users from 233 sites in 66 countries. There are over 50,000 records and 800 collaborative data shares and 4,000 logins each month (Figure 1).

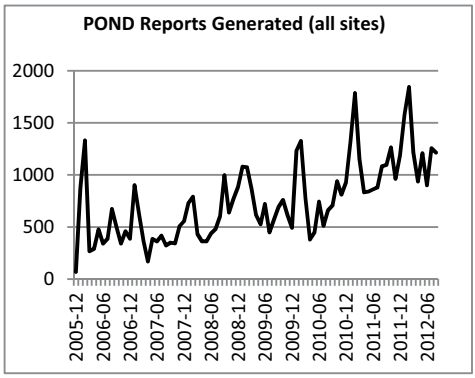

Figure 3. Total Number of POND reports.

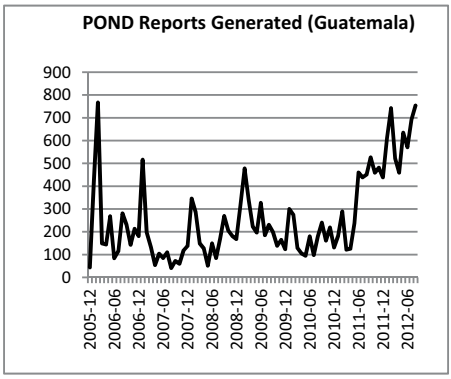

Figure 4. Number of Guatemala Reports.

In Guatemala, a pediatric oncology clinic called Unidad Nacional de Oncología Pediátrica (UNOP) was established with a focus on pediatric cancer. Given the limited government resources, a non-profit foundation called Fundación Ayúdame a Vivir was founded in May 1997 to provide the necessary resources for the proper maintenance, operation, and growth of UNOP as a center of excellence for treating pediatric cancer in Guatemala. Each year, about 400 children newly diagnosed with cancer are treated at UNOP. Survival rates for some types of cancer have increased from 28 percent in 1996 to 70 percent in 2012. Fundación Ayúdame a Vivir subsidizes the treatment for patients who cannot pay. The rate of abandonment of treatment has decreased mostly due to psychosocial intervention, and the provision of housing and transportation. The use of POND by UNOP was initiated in 2004 and has grown consistently with the support of five dedicated data managers. The UNOP clinic has entered data for both current and past patients. As of September 12, 2012 UNOP POND Site had 4748 records of patients (Figure 2). The UNOP site is currently the most active of all POND sites. UNOP accounts for almost half the logins to POND each month. Over the years the number of active data shares has increased as UNOP expands its collaborations with experts in specific diseases at other pediatric cancer centers. UNOP accounts for more than half of the 800 data shares among all POND sites, and UNOP participates in collaborative clinical protocols with many other Latin American countries. Over 1000 reports are generated each month (Figure 3) by all POND sites and UNOP accounts for over 700 of them (Figure 4). These reports are used widely by a multi-disciplinary team of doctors, nurses and allied health professionals at the clinic for patient care, administration, and outcome evaluation. The increased usage and analysis of clinical data is a contributing factor to the increase in survival rates at the UNOP clinic.

3. Discussion

POND provides clinical tools that fill an unmet need at many pediatric oncology hospitals, particularly those that have common protocols and wish to share information. There are several reasons for the success of POND at some sites, and lack of use at other sites. Challenges include training, adequate data manager staffing, and quality management. Availability of online training and support is one of the factors that has helped the deployment of POND but at times it can be difficult due to limited bandwidth and lack of Internet reliability. POND is sufficiently easy to use with minimal training for most users. Online help and training are available in English and Spanish. However, data managers need to have computer experience, and some may need additional supervision and guidance. A regional network of POND data managers was formed in Central America that allows for continued training and mutual support and encouragement. The UNOP site in Guatemala has provided regional training support for other Latin American centers both online and by hosting data managers from other Spanish-speaking sites when they are starting their data management programs.

The availability of appropriately trained data mangers and funding for salaries is a major challenge for many sites. Lack of consistent funding for data managers at some sites has led to inconsistent data entry. Since 2004 a grant from the Pediatric Oncology Group of Ontario (Canada) and financial support from St. Jude Children's Research Hospital (Memphis, TN) have funded full-time data managers in several Central America countries, and these tend to be the sites with most active use. Other sites do not have sufficient funding to hire data managers, and the clinical staff does not have the time to enter records. The UNOP site now has 5 data managers that facilitated the widespread use of POND by doctors, nurses, nutritionists, and psychosocial support staff.

High-quality data is the cornerstone on which quality improvement rests, so POND has specific quality reports that identify the most common data entry errors, including unlikely and impossible values [4]. However, these reports need to be regularly run and acted upon to improve areas of missing or incomplete data. There may also be a lack of standard operating procedures, inconsistent data collection methods, or missing paper records. More training and on-site audits could facilitate additional improvement in data quality and efficiency. Recent additions to POND include error-checking tools that show missing or possible out of range data. UNOP also has implemented a daily review all data entered in POND in the previous day that has greatly improved data quality.

Security is an important part of any medical records system. The POND software resides in a dedicated server with a security firewall. Users with administrator credentials manage access to data by users of the site and control sharing with external collaborators. Although the data are encrypted and password protected, some administrators are reluctant to store data outside their institution. The location of the POND server in the United States has provided some concern to some sites. Future development of a local POND system would facilitate use by those sites that do not wish their data to reside on foreign servers.

To obtain benefit from the data-sharing capabilities of POND, access to clinical experts is essential. Common treatment protocols used by pediatric oncology units in Central America were created in POND. Principal investigators of shared protocols have regular virtual meetings to review individual patients with complicated medical problems, protocol data, and administrative issues, and to develop strategies to improve

clinical outcomes. These clinical meetings are held online on www.Cure4Kids.org, a web-based education and conferencing platform [5]. UNOP regularly participated in multiple online meetings per week to discuss clinical cases that are in POND.

POND is upgraded regularly in response to feature-specific requests from users. Developing features that meet the priorities of each site remains a challenge not only because of the volume of requests, but also because countries have different data standards, different systems of units for common laboratory values, and other national/regional particularities that must be stored both in the original value and converted to other values when comparing data. Some sites also suffer from slow or unreliable Internet connections, and POND currently lacks offline functionality.

4. Conclusions

POND4Kids provides pediatric hematology/oncology units with platform for data collection and outcome evaluation that facilitates local evaluation and multicenter collaboration. Despite many of the challenges that developing countries [1,2,3,7] face in health care, many sites in developing countries have been able to use POND to collect data for clinical improvement. The UNOP site is one of the most active POND sites, and its staff has been able to overcome many of the challenges related to funding, training and data management. Further efforts are still needed in the areas of standard operating procedures for data collection, data entry, data quality monitoring, and data analysis. The increasing usage of data shares shows that global collaborations can occur between low income countries as well as between low and high income countries. Protocol template forms have allowed consistent data collection and enabled comparison of data across multiple countries. Future development plans include improvements in usability, more flexible reports with additional customization options, support for additional languages, enhanced statistical analysis, the ability to enter and access data while offline, and synchronization across a network of online and offline POND4Kids servers. Future challenges include the prioritization of requests for new features and the need for common data standards for comparisons among centers.

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Knowledge Translation in eHealth: Building a Virtual Community

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Abstract. Knowledge can be powerful in eliciting positive change when it is put into action. This is the belief that drives knowledge translation. The University of Victoria (UVic) eHealth Observatory is focused on deriving knowledge from health information system (HIS) evaluation, which needs to be shared with HIS practitioners. Through an application of the Knowledge-to-Action Framework and the concept of a virtual community, we have established the virtual eHealth Benefits Evaluation Knowledge Translation (KT) Community. This paper describes the foundational elements of the KT Community and our overall KT strategy.

Keywords. knowledge translation, virtual community, health information system

Introduction

A common saying is that 'knowledge is power'. However, knowledge without application can be powerless to invoke change. The gap between knowledge and practice needs to be closed to turn knowledge into action [1, 2] to make it powerful. Use of information technology in healthcare is on the rise. In 2007, the National Physician Survey found that 12.3% of Canadian family practitioners and general practitioners used electronic medical records (EMR) exclusively and 19.4% used a combination of EMRs and paper-based charts [3]. These figures rose to 21.5% and 27.5% respectively in 2010 [4]. For eHealth adoption in Canadian hospitals, the Ontario Hospital Association found the percentages of hospitals at Stages 1 through 6 of the Healthcare Information Management Systems Society's (HIMSS) Electronic Medical Record Adoption Model (EMRAM)^{SM} rose from 2010 to 2012 [5]. The potential benefits of such systems are driving adoption. However, adoption does not ensure benefits are realized [6]. Thus, there is a need to ensure benefits are being achieved and that demonstrated achievements are shared and applied broadly. This is the idea behind eHealth benefits evaluation. Organizations need to measure and demonstrate the impacts systems are having which requires knowledge of the methodologies and tools available for evaluation. However, this knowledge is often held in large organizations or academic settings and is not readily available to those who need it. To address this gap we initiated a knowledge translation (KT) activity to

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increase capacity in conducting eHealth benefits evaluation. This paper describes the theory behind KT and describes how it has been applied in the context of eHealth to create a KT strategy.

1. Knowledge Translation Background

1.1. Defining Knowledge Translation

KT is "a dynamic and interactive process that includes synthesis, dissemination, exchange and ethically sound application of knowledge to improve the health of Canadians, provide more effective health services and products and strengthen the health care system" [7]. Knowledge needs to be put into practice to be useful. Additional terms have been used in the literature such as "knowledge transfer" and "knowledge exchange". In Canada, all three are used [2], however "knowledge translation" is gaining prominence [8]. The Canadian Institutes of Health Research (CIHR) definition encompasses knowledge transfer and exchange as well. According to Reardon et al. [9], knowledge exchange is one model of knowledge transfer in which relationships are built between knowledge producers and users to exchange information, ideas and experience. This describes the intent of our KT activity.

1.2. Theoretical Basis: Knowledge-to-Action

In terms of KT theories CIHR has adopted the Knowledge-to-Action Framework developed by Graham and colleagues [2]. This framework divides KT into two concepts: knowledge creation and action [8]. Knowledge creation is shown as a cycle containing a knowledge funnel whereby knowledge becomes refined through the phases of knowledge inquiry, synthesis, and tool creation. Although it is primarily research based, knowledge also includes experiential knowledge. The action cycle represents activities for knowledge application which are to: identify problem; adapt knowledge to local context; assess barriers to knowledge use; select, tailor, implement interventions; monitor knowledge use; evaluate outcomes; and sustain knowledge use. Collaboration between knowledge producers and users is inherent in this framework. Our role as researchers is typically focused on the knowledge creation cycle but as the framework shows, the boundaries between the two cycles are fluid. Information and Communications Technology (ICT) can be applied throughout this framework and is referred to as Technology-Enabled Knowledge Translation (TEKT) [1].

1.3 Knowledge Translation Components

To effectively translate knowledge in any context, a planned approach is required. Numerous guides exist for preparing a KT plan. Barwick et al. [10] developed a comprehensive KT planning template which guides planners through a series of steps from identifying research partners to describing how the KT strategy will be implemented. In a KT training workshop they identified five key pieces as goals, audience, main message, strategies, and assessing impact. CIHR's KT casebook for end-of-grant KT [11] outlines the key components for a KT plan as: goals, audience,

strategies, expertise, and resources. Based on these guides, we describe our KT activity below in terms of:

- Goal: the purpose of sharing knowledge and its expected action
- Message: the knowledge being shared
- Audience: individuals and/or groups that should receive the knowledge
- Strategy: approaches used to translate the knowledge
- Expected Impact: effect of the KT activity

2. The KT Plan

2.1. Goal

In discussing healthcare innovation, Berwick stated "in healthcare, invention is hard, but dissemination is even harder" (2003, p. 1970) [12]. He went on to say that the most powerful driver of adopting innovation is the perceived benefit of change. A parallel can be drawn for health information system (HIS) adoption. Systems have been developed but adoption relies on potential users believing they will receive benefit. Heathfield and Pitty [13] examined the roles of evaluation for creating accountability, strengthening development, and creating knowledge. This is why benefits evaluation is important. There is a need to demonstrate benefits and impacts to drive adoption and to do this, one needs to know how to conduct an evaluation and assess the evidence to apply it. Unlike previous work around knowledge translation in healthcare which has been about translating research evidence on medical interventions and innovations, our KT activity is not about translating evidence on the benefits of eHealth, but rather translating the knowledge on *how* to determine the benefits of eHealth. As explained in the introduction, the push behind this KT activity stems from a need to empower individuals in conducting eHealth benefits evaluation. To do this we need to put the knowledge and tools into the hands of evaluators who can apply them.

2.2. Message

In terms of knowledge creation, the UVic eHealth Observatory was created in 2009 to monitor the effects of HIS deployment in Canada [14]. Researchers at the eHealth Observatory have been collaborating with Canada Health Infoway to explore and synthesize evidence around HIS evaluation. Five types of knowledge products have been created: (1) conceptual eHealth evaluation models; (2) a rapid evaluation toolkit; (3) systematic literature reviews; (4) educational materials, and (5) the results of eHealth evaluation studies. For example, the Benefits Evaluation Framework specifies a set of dimensions and categories for factors which influence HIS adoption [15]. A knowledge product stemming from the Benefits Evaluation Framework is the updated Infoway Benefits Evaluation Indicators Technical Report [16]. We are also aware of other sources of knowledge that would be valuable to those working in this area. For instance, the Agency for Healthcare Research and Quality in the United States has developed the Health IT Evaluation Tookit [17]. This particular KT activity focuses on the HIS domains of EMRs in physician offices, prescribing, and consumer health systems such patient health portals, with data quality as an overarching area. Emphasis is placed on the exchange portion of KT as we are stressing the need for individuals to

contribute their own knowledge and experiences as well. In this way, knowledge creation and sharing is the message at the core of this KT activity.

2.3. Audience

Since this KT activity is to foster learning to increase capacity in and application of benefits evaluation, the audience for our message is quite broad. Four target groups will benefit most from this knowledge. The first includes individuals from healthcare organizations who are directly involved with benefits evaluation or wish to learn about them. This can include managers and staff from ministries of health, health authorities, and so on. The second group includes HIS researchers who work to create evidence-based knowledge in this area. They bring expertise in knowledge creation. The third group consists of clinicians such as physician, nurses, and pharmacists who are the adopters of HIS. They work on the front lines and directly experience the impacts. The last group includes individuals from the private sector who wish to learn how their products are evaluated in practice.

2.4. Strategy

In terms of methods to facilitate KT, there is a plethora of approaches available and they do not need to be used in isolation. Barwick et al. [10] reviewed evidence for KT strategies and found that combined interventions are mostly effective. In designing our KT strategy we considered the goal, message and audience and determined the best approach is the creation of a virtual eHealth benefits evaluation KT community to facilitate the use of several KT strategies. Our concept of a web-based virtual community borrows elements that have been described for virtual communities of practice and virtual learning communities. They enable people to share their experience and knowledge to improve their abilities and skills and foster learning [18].

McCartney et al. [19] performed a review of virtual communities of practice in healthcare, identifying some characteristics for success. These include: being problem driven; having organic involvement; diverse champions, facilitators or leaders; having administrative support; and regular incentives to participate. While there is no specific "problem" our virtual community is working towards solving, there is a clear goal of sharing knowledge about benefits evaluation. We outline the goals and expectations for participants in the terms of reference. People are not obligated to join yet do so because of a shared interest in learning. From this group, we have identified mentors (including our own team members) to act as leaders within the community. Since this is a web-based virtual community, a technical infrastructure and support is needed. Specific roles have been established within the eHealth Observatory team for administration. The incentives to participate consist of the activities within the community.

Our KT Community offers five KT features. The first is a series of live online sessions on benefits evaluation topics which are presented by mentors. The sessions are scheduled and conducted using web conferencing software so that participants can join in regardless of where they are. Didactic lectures have had mixed results in terms of effectiveness for KT but interactive education sessions with participation have been generally effective [9, 10]. Therefore each session also includes three key discussion questions to be discussed in the session or afterwards. This links to the next feature of the KT community which is an online discussion forum. Here, participants are able to communicate with each other asynchronously. Currently there is limited evidence on

effectiveness of electronic communication for KT [9,10] so this project presents an opportunity to contribute findings in this regard. Since many of our knowledge products are in the form of reports and tools, we have made them available through a repository on the KT Community website. Since the sole distribution of educational materials has had mixed results for effectiveness in KT [10] the materials provided will also be referenced in the sessions where possible so that context of use is provided. Participants are also encouraged to contribute their own materials. The links page is another feature that points to knowledge in other places. Finally, a section of the KT Community is dedicated to case studies. This represents another collaborative KT strategy where participants contribute their experiences in benefits evaluation methods as examples for others to learn. It is also a goal of the KT Community to produce case studies that can be compiled into a new knowledge product.

2.5. Expected Impact

KT activities should expect to elicit change or have a positive impact. For example, the impact can be a direct change in practice or indirect such as informed decision making [9]. According to McCartney et al. [19] there is no consensus on measures of success for electronic communities but some potential areas are effectiveness in meeting objectives and health of the community in terms of member satisfaction and level of activity. Barwick et al. [10] list examples of reach, quality, and use indicators and potential output and process measures. For this KT Community, our impact measures include statistics on participation in live sessions and discussion forums, contributions to the repository and case studies. The majority of our impact evidence will be collected through user feedback surveys completed upon joining the community, after each live session, and at the conclusion of the project. The KT Community currently has attracted over 70 health care professionals, researchers and developers, demonstrating a great interest and need. Although we may not be able to measure it directly, the larger impact will be in terms of the frequency and quality of benefits evaluations conducted in the field using the knowledge shared through the KT Community as well as the new knowledge and ideas generated from interactions between community members. Evaluation is often not included within the scope of HIS projects, and is sometimes considered the exclusive domain of HIS researchers. By bringing together a diverse audience, the community hopes to challenge perceptions around roles of evaluators and to encourage broader participation in evaluation.

3. Conclusion

Knowledge translation is an important mechanism to ensure that the best available evidence and research is put into practice. In the context of eHealth benefits evaluation, individuals involved with HIS adoption need to be aware of the methodologies and tools already available to ensure that systems are achieving the desired benefits. Through the creation of the KT Community we have established a combined intervention of KT strategies that will enable knowledge translation for this context.

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Complex Interventions in Healthcare and Health Informatics: A Scoping Review

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Abstract. Complex interventions are pervasive in healthcare. There is a need to make sense of complex interventions to support their better development, implementation and evaluation. This paper summarizes the results of a scoping review undertaken to identify attributes of, and logistical considerations for complex interventions in healthcare. Results suggest five distinct attributes that can assist researchers to identify, conduct, and appraise complex interventions studies. Considerations for applying results to evaluate complex health informatics interventions are discussed.

Keywords. Complex interventions, health informatics, health services research

Introduction

Complex interventions are increasingly becoming a focus in health services research. They are common in many areas of healthcare such as complementary and alternative therapies, health promotion and rehabilitation [1]. In fact, many health services activities may be considered complex [2]. The most commonly cited definition of complex interventions indicates that they are comprised of several interacting components [3]. The main objective of this scoping review is to identify key attributes of complex interventions, and in so doing provides additional definitional elements to the term. Recognizing complexity in the development, implementation and evaluation of healthcare interventions is important to ensure that they are addressed with due diligence and consideration. For instance, the lack of impact found by a study may not mean the complex interventions are ineffective. It may reflect implementation failure, which may arise from a lack of fully accounting for complexity [3].

The overall aim of this scoping review was to understand the current state of knowledge on complex healthcare interventions, including complex health informatics interventions. These complex interventions attributes identified can be used planning, conducting, reporting and critiquing complex interventions studies. A second objective was to identify logistical considerations for operationalizing complex interventions. The results from this scoping review should help researchers and practitioners identify, conduct, and appraise complex interventions studies.

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1. Methodology

A scoping review addresses broader topics than a systematic review and determines what literature exists on a topic to summarize what is known and to identify gaps. It does not synthesize the evidence the same way that a systematic review does. It is a literature review that examines the extent, range and nature of activities in a domain, then summarizes and disseminates the findings [4].

1.1. Search Strategy and Sources

The search strategy involved the identification of literature through MEDLINE. This was supplemented with select articles found in a previous search on complex health informatics interventions, and a prior collection. Search parameters used were 'complex interventions' in the title, English language publications, and publication between the year 2000 and June 2012.

1.2. Selection

As is common with scoping reviews, some exclusion criteria were devised post hoc based on increasing familiarity with the literature [4]. Articles were excluded if they were not available online. Interventions on dental care, alternative or Chinese medicine, or sports medicine, interventions for research and physical interventions such as stents were excluded to limit the review to health service interventions in traditional healthcare settings. Literature was selected for final inclusion on the basis of a full text review.

1.3. Charting the Data, Collating, Summarizing and Reporting the Results

Charting the data is equivalent to data extraction as carried out in systematic reviews. It is "a technique for synthesizing and interpreting qualitative data by sifting, charting and sorting material according to key issues and themes" [4, p. 15]. For this scoping review, a key theme was the attributes of complex interventions, which emerged from data charting iteratively in a ground-up approach. Data about complex interventions logistics was also charted and analyzed. The scoping review involves no assessment of the quality of literature.

2. Results

2.1. Selected Articles and Characteristics

The MEDLINE search yielded 154 articles; 99 were selected for the review. An additional 19 were added from the previous search and prior collection. This led to 118 articles included in the study. Of these, forty-six articles were identified for the synthesis. They included frameworks, commentary on a broad range of complex interventions topics, editorials and reporting criteria.

The remaining 72 articles included 16 systematic reviews and meta-analyses, 27 primary studies, seven pilot studies, eight study protocols, and 14 intervention development studies. These are to be examined in a subsequent review.

2.2. Common Attributes

Synthesis from the review led to the identification of five common attributes that would identify interventions as complex interventions and the extent of their complexity. These attributes support a multi-dimensional definition of the term 'complex interventions', and a view that complexity should be seen as existing along a continuum. These attributes are described below.

Complex interventions are comprised of *multiple components* [3]. The lack of specificity of those components is problematic in conducting and reporting studies as some view complex interventions as an overall 'black box'. This hinders the ability to examine effects of each 'unpacked' component of complex interventions and determine effectiveness [5]. Specific types of intervention components have been proposed for health service interventions [6] and health informatics interventions [7]. One or more components may be 'active ingredients' within the intervention, and it is important to understand how they exert their effects [3]. It is possible that it can only be speculated which components are (most) active [8].

Interactions, whether among components, the behaviors of those delivering the intervention or the behaviors of those receiving the intervention [3] are another attribute of complex interventions. Where people and organizational levels are involved, the intervention can be viewed through multiple levels of abstractions and sociotechnical lenses [9].

The more complex an intervention, the more it is necessary to have a *theoretical foundation* [10]. The theory underlying the intervention should provide an understanding of how the intervention causes change so that weak links in the causal chain can then be identified and strengthened [3]. It should also ideally articulate distinct groups affected by the intervention and how they differ in this regard, as well as the mechanisms by which this occurs [11]. A number of theories, frameworks, and models were found in the complex interventions literature [3][12].

Complexity can also lie in *context* [8], which includes the environment in which complex interventions exist. Context may be the most significant aspect of complexity [13]. The investigation of how intervention effects are influenced or modified by context is a recently emerging focus for community intervention trial research [14]. The components of a health informatics intervention can contain many elements of context. They are: technical components, organizational factors, logistical factors, behavioral factors and informational components. Some of these may facilitate delivery of the intervention and others may be barriers to implementation. These components and factors should be pre-identified and accounted for when conducting studies of complex health informatics evaluations [7].

Measurement is the final attribute of complex interventions. Complex interventions themselves must be measureable in order to be studied, and there are multiple ways in which each component can be measured such as frequency and intensity. The effects of complex interventions must be measured, whether on people, groups and organizations [3]. One way to distinguish between simple and complex interventions is to consider the simplicity or complexity of causal chains and processes [15]. It may be that the use and interpretation of 'outcomes' as they are traditionally

viewed in medical research such as clinical trials of pharmaceutical products, is not appropriate for evaluations of complex interventions [1].

2.3. Logistical Considerations

In the *development* of complex interventions it is important to identify the evidence base, which can be accomplished through a literature review, an existing systematic review or having to conduct one [3]. Although a valid framework for methodologically developing complex interventions may not yet exist to increase understanding of how and why complex interventions work [16] there are some existing frameworks that can be used to develop and test complex interventions [3]. A lack of standardization in classifying complex interventions is a central reason for the poor reporting of complex interventions evaluations [3]. Authors for one study developed their own classification system, or taxonomy, to describe interventions used to prevent falls among the elderly [17].

The importance of *implementation*, or putting complex interventions into practice, is simple: interventions that are not implemented will not improve health or healthcare. The ease with which this may occur can be evaluated prior to the commencement of a study as an explicit consideration, but this is rarely found in practice [12]. In some cases, adherence to a strict protocol to ensure standardization of intervention implementation is appropriate. In other cases, standardizing interventions across study sites may 'over-control' the intervention [10] and standardization can undermine evaluations of complex interventions so that they may not lead to intended effects [18]. With some interventions, it may be more effective if adaptation to the local setting is allowed [3].

Evaluation of complex interventions seeks to understand the underlying nature of a clinical problem and also test theories underlying the intervention [19]. Three aspects of evaluations of complex interventions are: assessing effectiveness, understanding change processes, and assessing cost-effectiveness [3]. Pilot and feasibility studies are recommended as a precursor or initial stage [3], and process evaluations can be conducted alongside, or embedded within, the main study. Challenges in evaluating complex interventions include: systematically using relevant research evidence to develop intervention components, improving the definition and measurement of complex interventions outcomes, and using appropriate research designs [20].

3. Discussion

In this review we have identified five common attributes that can be used to define and operationalize complex interventions. Some of these attributes, such as behaviors of those receiving the intervention and of those delivering the intervention, are mentioned in the literature without definition or suggestion of how they would be implemented in practice. Even for those attributes that have been discussed in the literature, such as intervention components and theoretical foundations, there are different ways to interpret and define complexity, based on the discretion of the researcher. Examples include the importance of the context and environment and whether to base the theoretical foundation at the individual or broader level.

Few specific references to, or distinctions made for, complex health informatics interventions were found. It could be that they are not different than complex

healthcare interventions. Alternatively additional consideration for, and study of, complex health informatics interventions is required. This may reveal additional or different attributes of complex health informatics interventions and nuances for consideration when developing, implementing and evaluating them.

The common attributes identified can be further refined to assist in designing and evaluating complex health informatics interventions. Intervention components may include hardware and infrastructure as well as applications of information systems. Theoretical foundations could include, as examples, the Delone and McLean information systems success model [21], or the diffusion of innovations theory [22]. The context and environment could include technology governance, policies, and other systems.

There is no single all-encompassing guide or framework for complex interventions. Additional research and analysis is required to make sense of complex interventions to guide and support researchers in development, implementation and evaluation.

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Consumer Informatics

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Forumclínic: the shaping of virtual communities to assist patients with chronic diseases

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Abstract. Information and communication technologies (ICTs) provide new opportunities to complement traditional care while enhancing patient autonomy. With the objective to supplement patient care, a group of health professionals at the Hospital Clínic de Barcelona created Forumclínic, an online networking website in Spanish and Catalan. In 2008, seven web- and DVD-based chronic disease portals (Diabetes, Schizophrenia, Cardiac Ischemia, COPD, Depression, Breast Cancer and cardiovascular risk) were created with the following resources: multimedia patient education material; physician-specialist transcribed research (articles) news; an open question forum (for clinician-user and user-to-user interaction); and patient and specialist interview videos on the progress of disease, common diagnosis and treatment procedures; and information on the best or worst prognoses. Using data from Google Analytics, server logs were used to observe online behaviour patterns and user postings. This data combined with a mixed methods approach were used to evaluate the development of a virtual community (VC). A virtual community was developed when the number of forum visits was greater than those in the disease portal (definition). While nearly half of the visitors were from the Americas, the Schizophrenia, Breast Cancer, Depression and COPD forums met the criteria for and developed a virtual community. However, the Diabetes and Cardiac Ischemia forums did not reach VC status. It is also interesting to note that users in their late thirties and early forties were primarily women. The development of four virtual communities in Forumclínic seems to support the self-care needs of virtual patients. Users also reported appreciating the increased interaction with experts online and commonly collaborated with the forum moderator to guide and support other users with similar conditions in managing their health. Thence, we believe that Forumclínic is a good model to complement traditional patient care. A formal evaluation of this adjuvant form of care, from both the users' and moderators' perspective, is currently in its final stages.

Keywords. e-health, Virtual Communities, Patient Communication, patient education

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Introduction

Information and communication technologies offer a promising opportunity for complementing the information provided by health care professionals in a clinical interaction and enhance patient autonomy [1]. It has been suggested that people with a high level of autonomy make a more intensive use of the Internet; with this use, patient autonomy increases [2]. For this reason, the Internet is a powerful tool for complementing the health care process in patients with chronic diseases. At present, there is paucity in the literature about how this approach may be of benefit (or risk) to health [3].

Facebook, YouTube and Wikipedia are all examples of what Tim O'Reilly originally described as Web 2.0, virtual environments that promote collaboration with a rapid exchange of information among users [4]. This same approach, applied by health information users, allows some groups to become working virtual communities or "networks of interpersonal links that provide sociability, support, information, a sense of belonging, and social identity", as described by Barry Welman [5].

A group of health care professionals at Hospital Clínic de Barcelona launched Forumclínic, a Web 2.0-based health programme for patients with chronic conditions in the Spanish and Catalan languages. Our aim was to test a model that would support the clinical management of chronic disease, by providing patient education materials (e.g., videos and lay-transcriptions of emerging medical research), and peer support-moderated forums. Professionals from: 1) Hospital Clinic de Barcelona, a university hospital and leading research institution; and 2) associated health centres moderate each of the forums, according to their specialty. The Banco Bilboa Vizcaya Argentaria (BBVA) Foundation has recently renewed the funding for this programme. Fundación BBVA is the philanthropic non-profit arm of the BBVA bank.

1. Objectives

This report evaluates the absence or presence of a virtual community in the Forumclínic patient portal through a mixed methods approach.

2. Methods

The following data were used to analyze the presence or absence of a virtual community:

- Google Analytics' downloadable data.
- Sociodemographic indicators reported during user registration. (This allowed crossreferencing to server logs, in order to evaluate general behaviour; such
- as the number of times a user logged into the system, posted, etc.)
- Forum postings.

A virtual community was defined to exist when the number of user visits to a chronic disease forum was greater than those for the portal's main page. Each portal has information classified according to the following categories: 1) general summary of

the disease; 2) weekly news, where recent research articles are transcribed into lay language by our board-certified health professionals; 3) specialist-moderated forums; and 4) patient, health provider, and 3D biological animation videos which explain in simple terms the pathophysiology, treatment, and rehabilitation of disease. This structure facilitates a dynamic relationship between patients and health professionals, and aims to foster autonomy. The proceeding results correspond to data from the 2008 calendar year. More recent data was not used due to a server upgrade problem. The necessary ethics approval was acquired and data was de-identified in accordance with [6].

3. Results

Table 1 displays overall web site activity. As can be seen, the data indicate that nearly half of visitors accessed information from the Americas (primarily South America). Schizophrenia and Breast Cancer were the most-accessed portals. It is also intriguing to note that cardiovascular risk was not as popular as the other forums, despite its prevalence in Hispanic communities.

Table 2 displays the activity of forum users in the five portals that were evaluated for the status of virtual community along with their corresponding user profiles. In total, a third of Forumclínic's visitors accessed the forums. Proportionately, this was as high as 62% for the Breast Cancer portal. The overall percentage of forum visits when compared portal visits was 23.25%. Chronic Obstructive Pulmonary Disease (COPD), with a percentage of 20.75%, is considered a VC but does not reach this average.

It can be seen that users are in their late thirties or early forties and, are primarily female, except for cardiovascular disease. Family members, rather than patients suffering the condition, are increasingly present in the Schizophrenia and COPD communities (self-reported in the forum). *Italics* and the colour red were used in the table to show forums which did not meet the definition for a virtual community.

4. Discussion

The data support the Forumclínic portal model as an effective and social approach for chronic disease information consumer engagement.

Table 1. Activity at the Forumclínic web in 2008

Total	Users	Visits	Pages /visit	Americas (% Visits)	Pages	Seen forum
Schizophrenia	44,488	63,622	5.11	40.4	122,106	37.6
Diabetes	51,345	59,490	4.21	42.1	21,192	8.5
COPD	40,039	49,299	4.32	41.0	44,172	20.8
Cardiac Ischemia	47,005	54,773	3.62	48.2	20,554	10.4
Breast Cancer	41,874	59,715	4.86	36.1	180,028	62.0
Depression	35,195	45,717	3.95	37.7	58,329	32.3
Cardiovascular risk factors	14,291	18,910	2.41	46.7	4,208	9.2
Home page	99,229	103,563	5.00	56.0	11,479	
Forumclínic	373,466	455,089	4.37	44.6	462,068	23.3

Table 2. Activity at the Forumclínic moderated forums in 2008

	Users	% visit to forum from all visits	Registered users				Topics	Post per topic	% posts from the moderator
			Registered users	% men	average age (year)	% patient			
Schizophrenia	44,488	37.6	214	45.4	35.8	39.2	188	8.0	17.6
Breast Cancer	41,874	62.0	274	7.3	38.2	77	240	5.0	31.9
Cardiac Ischemia	*47,005*	*10.3*	*39*	*73.3*	*41.3*	*64.1*	*30*	*2.0*	*60.5*
Depression	35,195	32.4	121	33.1	37.1	68.8	77	13.5	26.6
Diabetes	*51,345*	*8.5*	*45*	*33.3*	*37*	*71.1*	*24*	*6.3*	*37.5*

The large number of visits in the cancer and schizophrenia portals, despite the lack of a virtual community also advocated the need for high quality information in the area. Of interest is the demographic distribution of forum users, which is not congruent in web-traffic with the prevalence of disease. Cardiac ischemia patients, for example, tend to be older and uncomfortable using the Internet. However, forum postings reveal that the digital divide is not a major obstacle for elderly people (women, for the most part) who are using younger family members as a proxy for information access. The impact and determinants on access by these users however requires further investigation as in Latin societies, women (mothers and daughters) generally act as the health agents for the family. They take care of the ill, manage the relationship with the health system, and seek information (on the Web) for older family members.

When compared across other forums and its own portal, the diabetes forum had an amount minimal views (<10%). We speculate that this may be due to: a) the large number of diabetes resources available in the Spanish language; (a simple Google search limited to Spanish reveals over 2.5 million sites; b) the potentially younger age of participants (preliminary analyses of the user registration database reveal that this characteristic); and c) the increasing use of social media for patient support (supported by the former and likely plausible given that younger diabetics, Type I diabetics, tend to be more involved in social media tools).

Through unsolicited emails and forum postings, Forumclínic's users have expressed the importance of moderator engagement for their interest and participation. The moderator filters malicious content, cleans the discussion board of unwanted publicity or inappropriate material and also redirects new users to previously answered questions. This service, along with the portal's structure, as been successful at engaging consumers and appears to be responsible for the high level user satisfaction.

There are a number of limitations in this study. First, the sociodemographic data used in the characterization of users is self-reported. Second, the Internet Protocol tracking database used does not allow cross referencing with usernames, which means that one person could have posted in the forums with multiple computers or web aliases, without the corresponding adjustment. Lastly, the qualitative method used for observing forum participants is subjective, depending on the viewpoint from which it is evaluated.

Future research will be required to determine the quantitative impact (e.g., Quality Adjusted Life-Years gained) and other contextual incentives for participation in the Forumclínic portal. Using a similar dataset and a new server log, we are currently implementing a multivariate analysis model that will contribute to our understanding of moderator-user interaction dynamics. We also aim to study other factors that lead to the

development of a virtual community.

The results of this report are homogenous with other studies of virtual communities in the health domain [7]. In particular, a recent study by Frost and Massagli reported that sharing health data with a community fosters patient engagement and self-management of disease. At the time this report was written, we believe that this element is also an important factor for success. To evaluate this more objectively, we are currently in the final stages of two phenomenological evaluations that characterize the emotional aspects of portal participation (one for clinicians and the other for target users).

5. Conclusions

The development of four virtual communities confirms that patients need participative role health-related web sites. Patients appreciate an increased degree of interaction with experts and fellow patients which allows for more collaborative self-management.

The portals that were successfully characterized as virtual communities in this study continue to grow and be populated by a high proportion of female users. The Depression and Schizophrenia portals were particularly useful in providing access for communities that are commonly stigmatized.

Forumclínic is a living project that is growing both in activity (e.g. visits) and participation (e.g. number of registered users engaging in forums). We have been successful in creating functional virtual communities by providing health information access through a model of patient education resources and user interaction. Future research will increase our understanding on the contextual determinants of success for user engagement in the Spanish and Catalan-speaking chronic disease community.

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The PLU Problem: Are We Designing Personal ehealth for People Like Us ?

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Abstract: The near-pervasive introduction of ehealth systems, and the more recent implementation of systems intended for patient use offer patients the opportunity to participate in their own care. Unfortunately the design of these systems means that they may work better for "People Like Us' rather than for those on the wrong side of the 'digital divide'. This paper looks at the professional, practical and ethical implications of this conundrum.

Keywords: electronic health records, disadvantage, information systems

Introduction

This paper argues that the current approach to the design of personal ehealth systems may serve to accentuate the gap between privileged and disadvantaged end users and healthcare recipients, rather than improve equity of access to health care services.

The problems facing healthcare services in the developed world are well documented and understood. They include financial challenges from increasing treatment costs [1], resource scarcity with an aging workforce, and an increasing burden of chronic disease [2]. Where healthcare is publicly funded, Governments also face the politically sensitive challenge of determining appropriate healthcare service levels in an environment of increasing citizen demands and expectations for care.

Health reform remains a critical area for policy debate and has led to a range of solutions to address the problems faced. In Australia, ehealth systems are seen as one set of solutions to these problems. Unfortunately many of these ehealth systems have delivered mixed results or have not generated the predicted savings as a result of designs that under-estimate the complexity of healthcare practice.

One response to these design challenges has been to focus on personal ehealth systems tailored and customised to the needs of individual health users. One example is Australia's personally controlled electronic health record (PCEHR) which was launched in July 2012. However, differences in individual knowledge, skills and inclination to use such systems may be resulting in system designs primarily suitable for a privileged group of literate and motivated end users, rather than for those most urgently in need of improved health service delivery.

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1. Methods

To explore the argument that the design of contemporary personal ehealth systems maybe problematic, a literature review was conducted to better understand research on the relationship between literacy and personal ehealth. Using a combination of search terms ehealth/personal ehealth and literacy/health literacy 100 papers available through PUBMED were identified and reviewed. 17 of these papers were also identified as providing insights on the characteristics of healthcare recipients.

2. Analysis

From an analysis of the literature, a conventional approach to segmentation of the population of healthcare recipients is to use socioeconomic status (SES) along a linear scale. However, there was also evidence of other factors and as a result this population was viewed as a collection of groups or clusters that could not easily be plotted along the SES scale. Two clusters providing simplistic archetypes of healthcare recipients were identified to focus the analysis of ehealth design issues in the literature. These two clusters were differentiated according to their willingness and ability to use a personal ehealth record. One cluster includes people who understand healthcare and health issues, take care of their own health, are literate, well to do, tech-savvy, and hold a tertiary qualification. These are the People Like Us (PLUs). The other cluster includes people disinclined to take exercise for its own (or their own) sake, or to eat sensibly. They are not textually, technically or health literate. They struggle financially, and may not have finished secondary education. We characterized them as disempowered, disengaged and disconnected (DDDs).

The literature review highlighted a general enthusiasm for personal ehealth systems and their capacity to improve the 'quality' of healthcare by reducing cost, improving safety, facilitating access to health services, and ensuring timely care. Australia's National E-Health Transition Authority (NEHTA), for example, suggests that a Personally Controlled Electronic Health Record will improve: "…the self-management of stable chronic diseases…communication between clinicians and individuals…[and] decision making by…individuals..." [3]. Pagliari and colleagues, writing in the *British Medical Journal*, suggest that personal electronic health records "…have the potential to empower patients through greater access to personal data, health information, and communications tools" [4]. Broadly, the justification for the development and implementation of personal ehealth solutions relies on the notion that they will enhance one or more measures of the 'quality' of healthcare services.

Significantly however Clarke and Leigh [6] highlight how differences in life expectancy between demographic groups in Australia provide stark evidence of continuing health inequality. They identified significantly increased mortality associated with income (odds ratio 1.88), education (1.25) and a low socioeconomic index (1.32). According to the Australian Institute of Health and Welfare [7] those living in the least advantaged areas of Australia are more likely to smoke, be physically inactive or obese, have diabetes, behavioural problems, asthma, heart disease or arthritis, and have higher mortality across most chronic conditions. Adult literacy also presents a problem for many in Australia. The Australian Bureau of Statistics reported in 2006 that 16.7% of adults were at prose literacy Level 1 (trouble completing a basic form; may find some information on a medicine label), and 29.7% at Level 2 (may not

be able to summarise text) [8]. Health literacy is also a problem. The US Agency for Healthcare Research and Quality found that poor health literacy was "...associated with increased hospitalizations, greater emergency care use…and, among seniors, poorer overall health status and higher mortality." [9] The disadvantaged are less likely to have home internet access, and there is evidence that living in a rural area and having a medical condition will make home internet use even less likely. [10] The inter-relationship between all of these factors is complex, and it can be difficult to separate cause from effect. However, it is apparent that there is an association between low income, poor literacy (textual, technical and health), chronic disease, and poor health outcomes.

For better or worse, healthcare systems are developed predominantly by white, educated middle class professionals (PLUs) who design systems and processes which they see as being appropriate and user-friendly. This tendency to design for ourselves (the PLU problem) results in patient instructions using complex language; patients receiving complex verbal descriptions of health issues using clinical terminology; and the explicit assumption that online tools are an important and appropriate option for healthcare service delivery.

Catwell and Sheikh [11] considered the evaluation of ehealth systems, and argued that the evaluation should be continuous and systemic. They cautioned that "[l]arge investments in eHealth may, by diverting resources result in a shortfall in funding for basic infrastructure, equipment, and staffing elsewhere in the system. …investing in developments such as telemedicine, which are only likely to be accessible to a minority, would exacerbate the digital divide and existing health inequities." [11]

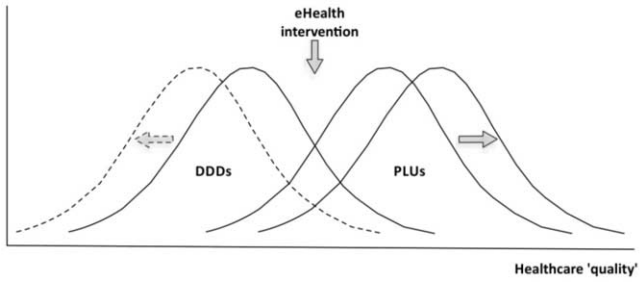

Figure 1: Risk of unintended consequences – the disadvantaged may end up worse off

Any diversion of health budgets towards generic personal ehealth systems is likely to deliver benefits to PLUs, while leaving the 'quality' of healthcare for DDDs unchanged. In fact, there is a risk that diversion of health budgets to ehealth will be used to justify and facilitate a reduction in funding from other, more conventional healthcare services. The potential for these unintended adverse consequences from ehealth investment for DDDs is illustrated in Figure 1.

3. Results

Many of the processes, systems and technologies intended to provide supportive care and self-care are tailored for a potential user who is very like the designer. Patient focused ehealth initiatives may well be suited to a demographic cohort that is well off,

tech savvy and street smart, but may be less helpful in areas of healthcare where the individual's needs are great, and the cost of meeting those needs is high.

PLU systems will place additional resources at the disposal of those who are adaptable and capable — those who probably do well with existing systems and services. Making reasonably healthy people a little bit healthier is not necessarily the most effective use of scarce health resources. Better cost benefits in terms of health outcomes are likely to be achieved by focusing on the DDDs whose health is worst, rather than designing and implementing for the PLUs.

A report from the European Union [12] comments on the introduction of Ambient Intelligence (AmI) in healthcare. The report notes:

"AmI claims to be particularly people-oriented, implying that it will also be inclusive - providing, of course, it lives up to its promises of being user-friendly, unobtrusive and controllable. But…the fundamental question remains…[will] AmI … include the majority of people or…benefit mostly young, urban and mobile techno-freaks. In the latter case, AmI could become an additional source of exclusion in society." The report cautions that "[t]he relation between social exclusion and health status is well known. Digital divides…can negatively affect health." [12]

The greatest challenge (arguably) is providing healthcare services to those who lack the motivation and capacity to make positive changes in their lives. They show little interest in adopting a healthy diet; regular exercise doesn't interest them; if they smoke, they'll probably continue to do so. Their poor literacy will make it hard for them to adapt to a routine of regular medication, and they will struggle to monitor their symptoms effectively. They may benefit from some form of mentoring, possibly with a technology component, but it will need to be carefully targeted at their capability, skills and worldview. The solution to the challenge of poor uptake (by DDDs) is often framed as requiring better solutions, including eHealth, Internet access, or training. But many of the processes and systems designed for supportive care and self-care are tailored for the designers and PLUs. This paper argues that there is a greater need in the design of personal ehealth systems to recognize the constraints imposed by a class of potential users who face very high barriers to technology adoption and effective use.

4. Discussion

Solutions to healthcare problems should be targeted at those with the greatest need. However, a PLU-designed health service, or a PLU designed ehealth system is unlikely to deliver equitable benefit to all groups of patients and has the potential to further disadvantage some groups. The needs of the DDDs should be considered as a special case, and explored in some detail. Once those needs are clearly understood, they should either be incorporated into the overall design, or provided for through a focused alternative, that may not initially require citizen/patient use of an eHealth system.

It may be more appropriate to design and implement solutions tailored for the capabilities of DDDs, and to then extend implementation progressively to other groups until marginal benefits become too small to fund. Designers should focus on user centred design, as many do, but in doing so should take care to identify and specify the class of user to which the initiative is targeted. The sense of disempowerment among DDDs will make them reluctant to participate in design activities. They may struggle to express themselves, or to see their opinions as having merit. Because of the many categories of limited capability which interfere with the use of technology by DDDs,

this approach is likely to be more difficult to implement. These solutions may also be less interesting for designers, developers and academic researchers due to the lack of feature and functional complexity. Indeed the design activities may produce systems that their creators and implementers might not want to use. It is argued however, that in terms of overall cost benefit, approaches like these could be potentially very rewarding as illustrated in Figure 2.

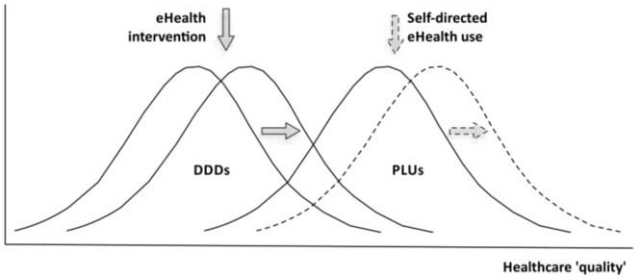

Figure 2: Preferable to adopt a specialised focus on those with greatest need

A modified design process could include: a positive effort to engage with "lowest common denominator" users; using observation as a way to understand how DDDs interact with systems and with healthcare; matching prompts and documentation to the reading level of users; and using pictograms ('IKEA instructions') to enhance understanding. Implementers should also be clear about whether there is a workable "non-e-" alternative to the personal ehealth option for those who cannot or will not use the technological solution. Can it be provided at the same or lower cost? And what is the overall cost to the health system to provide that service to those who need it most?

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Islamic E-Health: Definitions, Applications, and Challenges

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Abstract. The purpose of this exploratory study is to introduce the concept of Islamic E-health. The study defines Islamic E-health and discusses various applications of this concept. Data collection methods used for the study included interviews, Facebook, Google, and iTunes searches using a variety of Islamic E-health-related terms. The results show that some Islamic E-health applications focus primarily on spiritual health, followed by Hajj systems for surveillance and monitoring and the use of electronic medical records to monitor the blood glucose levels of Muslim patients who fast during the month of Ramadan. Future research and research limitations are also discussed.

Keywords. Islam, e-health, spirituality, healing, Ramadan, Hajj

Introduction

Information and communication technologies play a pervasive role in our lives. They impact how we communicate and interact with our families, loved ones, colleagues, friends, government, healthcare, and private institutions. In the healthcare domain, the use of information and communication technologies (ICTs) to improve clinical care and administrative decision-making has been referred to as e-health [1]. The primary goal of e-health is the use of the Internet and related applications to improve access to, efficiency of, and quality of care within healthcare with the goal of improving the health status of patients [2]. The discipline of e-health has existed for many years and includes an increasing number of multifaceted interventions that are aimed at improving health status through the use of information technology. One relatively unknown area of research within this domain is referred to as spiritual e-health. Spiritual e-health is the use of the internet and related technologies to improve the spiritual well-being of a patient [3]. Several studies have focused on the concept of spiritual e-health, but none have researched the role of e-health applications within the context of the Islamic spiritual belief system [3].

Spirituality plays a large part in Muslim daily life. Muslims are required to pray five times a day, fast during the holy month Ramadan, give to charity, and make a pilgrimage to the holy city of Mecca. Each of these religious obligations is a

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manifestation of the spiritual Muslim belief system. As part of the healing process, Muslims believe that prayer, supplication, recitation from the holy book, the Quran, and other religious rituals can help in improving health. Muslims are also taught through prophetic teachings that fasting during Ramadan can help to improve health. There are many public health issues during the month of Hajj, when millions of Muslims from around the world gather in Mecca to fulfill their religious obligations.

The country of Saudi Arabia, the birth place of the Islamic faith, has significant concerns about Muslim daily life. For example, all public hospitals in Saudi Arabia have Islamic religious affairs departments that help to provide religious guidance, education, and spiritual healing to patients. In addition to establishing various places of worship, these religious departments use technologies such as web pages, SMS messaging and web-based information to assist in the patient care process. Furthermore, users on social networking sites such as Facebook have developed spiritual healing groups for Muslims.

The holy month of Ramadan and the Hajj pilgrimage are two important annual Islamic events that affect the spiritual and physical health of Muslims. During the holy month of Ramadan, it is obligatory for Muslims to fast. Patients who decide to fast are likely to be monitored by their primary care physicians using technologies such as electronic medical records to monitor blood sugar levels. During the Hajj season, when more than two million worshipers converge on Mecca from more than 180 countries, public health issues related to communicable diseases have become a significant concern, and various public health information systems are employed to monitor disease outbreaks.

Given the uses of information and communication technology to support Islamic spiritual practices, the purpose of this exploratory paper is to define Islamic e-health and to describe its applications and future development.

1. Definition of Islamic E-Health

This paper proposes the following working definition of Islamic e-health:

> *"The application and use of information and communication technologies to monitor and support Islamic spiritual health practices with the goal of improving Muslims' spiritual, mental, and physical health status."*

The above definition takes into consideration the use of information and communication technologies, such as the internet, electronic medical record systems, public health information systems, and mobile health technologies that can be used to help monitor and support the spiritual, mental and physical health status of practicing Muslims.

2. Methodology

Data collection, including interviews and internet searches, began in November 2011 and ended in January 2012. The interviews included one interview with hospital religious affairs personnel in Saudi Arabia that lasted 120 minutes, a brief 10-minute interview with one family care physician, and two separate 10-minute interviews with one public health expert and one health informatics expert in Saudi Arabia.

Internet and social media sites, such as Facebook and the Apple iTunes Store, were searched using terms such as Islamic healing, ruqya (spiritual healing), fatwa (Islamic Law), Hajj, Ramadan, informatics, electronic medical record, public and health informatics. Various results were returned through Facebook groups, through the Google Search engine and through the Apple iTunes store.

3. Results: The Application of Islamic E-health

3.1. Spiritual Healing

Most of the Islamic e-health interventions that were identified were related to education and information on spiritual healing. In Islam, spiritual healing is referred to as Ruqya and is a form of supplication that is supposed to protect and heal. A Muslim can perform Ruqya on himself or on others [4]. Ruqya was used by the Muslim Prophet Muhammad, Peace Be Upon Him (This is a supplication that a Muslim performs when mentioning the name of the Muslim Prophet), and Ibn Alqayyim, a 13th-century Muslim scholar, said, "Ruqyah is one of the greatest remedies that the believer should use regularly." [4] A prophetic tradition collected by Muslim, a famous collector of authentic Muslim prophetic sayings, narrates the following story [4]:

> *Uthman complained to the Messenger of Allaah (Peace be Upon Him) about pain that he had felt in his body from the time he had become Muslim. The Messenger of Allaah said to him: "Put your hand on the part of your body where you feel pain and say 'Bismillaah (in the name of Allaah) three times, then say seven times, 'I seek refuge in the glory and power of Allaah from the evil of what I feel and worry about'."*

Google web searches identified various sources of information in English on how to perform Ruqya, such as Islam Q&A, which provides detailed descriptions of how to correctly perform Ruqya, its benefits, and some common misconceptions. Several Facebook groups on Islamic spiritual healing were found, such as the Islamic Spiritual Healing group. Various iPad applications, such as Ayat Ruqya, list religious supplications and how to perform them. Furthermore, within Saudi Arabia, religious affairs departments perform Ruqya on patients who request these services. However, patients are informed that the service is complementary to the medical treatment they receive.

3.2. Hajj

Hajj is a religious obligation for Muslims that was prescribed by God at the time of the Prophet. Muslims believe that its roots date to the time of the Prophet Abraham. Every Muslim who is financially and physically able to perform Hajj is required to do so once in his or her lifetime. Every year, approximately 3 million Muslims converge in Mecca, Saudi Arabia, to fulfill this important religious obligation. In the Quran, God says, "And Hajj (pilgrimage to Makkah) to the House (Ka'bah) is a duty that mankind owes to Allaah, those who can afford the expenses (for one's conveyance, provision and residence) [5]."

Much of the information related to Hajj was found through Google and through interviews conducted with various public health and informatics experts within the

field. The results show that health information systems are used intensively during the Hajj period to control the flow of pilgrims, to track movement, and for health surveillance. Yamin discusses a framework for the use of information systems to improve Hajj management [6]. The author suggests the use of information technology for 1) collecting information on pilgrims and providing them with RFID tags; 2) processing pilgrims and collecting additional matching information; 3) installing wireless remote sensors; and 4) processors and display screens. The author argues that these methods will help to reduce wait times at airports, track the movements of individuals, contain the spread of disease, improve future planning and assist in tracking illegal immigrants.

3.3. Ramadan

Ramadan is a holy Muslim month in which it is obligatory for every healthy Muslim to avoid eating from sunrise to sunset. God revealed the following in the Quran [7]:

> *"The month of Ramadan [is that] in which was revealed the Qur'an, a guidance for the people and clear proofs of guidance and criterion. So whoever sights [the new moon of] the month, let him fast it; and whoever is ill or on a journey - then an equal number of other days. Allah intends for you ease and does not intend for you hardship and [wants] for you to complete the period and to glorify Allah for that [to] which He has guided you; and perhaps you will be grateful."*

Participants in this study noted that Muslims living with diabetes are significantly affected by fasting during the month of Ramadan. The participants noted that diabetic Muslim patients are encouraged to fast and follow a prescribed regimen in which the patient takes a full dose of medication prior to breaking the fast and one half of a dose prior to beginning the fast before sunrise. During this month, diabetic patients are monitored, and their blood test results are transferred to an electronic medical record that helps their family physicians track fasting patients' blood glucose levels. The interviewed participants did not mention any other benefits to patients from the use of information technology during Ramadan.

4. Discussion

This exploratory study defined the concept of Islamic e-health and surveyed some of the existing applications that support this concept. This study revealed that the primary focus of Islamic e-health has been spiritual health, followed by Hajj systems and Ramadan. Information technology may provide significant benefits for Muslims' connections for spiritual guidance, improvements to Hajj systems and the use of technologies such as the EMR to monitor Muslim patients who fast during Ramadan. This research is exploratory and examines some of the relevant issues related to Islamic e-health.

5. Limitations and Future Research

The study has several limitations worth mentioning. The numbers of interviewees were small and could have been expanded to include other stakeholders, such as patients and

clinicians. Furthermore, the searches on Google and Facebook were performed in English. Arabic searches would reveal more information on this topic.

Future research should focus on developing and studying the impacts of Islamic e-health applications on health-related outcomes. Other research could focus on the development of Islamic health privacy and confidentiality guidelines, the impacts of virtual Ruqya on spiritual and mental health, the use of Hajj and Umra information systems, and the use of telehealth for Hajj and Ramadan. Furthermore, to improve future Islamic e-health services, religious authorities should monitor and develop guidelines for the development of Islamic e-health applications. This process will provide credibility to the field and will assist in advancing this research discipline.

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A User-centred Methodology for Designing an Online Social Network to Motivate Health Behaviour Change

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Abstract. Positive health behaviour is critical to preventing illness and managing chronic conditions. A user-centred methodology was employed to design an online social network to motivate health behaviour change. The methodology was augmented by utilizing the Appeal, Belonging, Commitment (ABC) Framework, which is based on theoretical models for health behaviour change and use of online social networks. The user-centred methodology included four phases: 1) initial user inquiry on health behaviour and use of online social networks; 2) interview feedback on paper prototypes; 2) laboratory study on medium fidelity prototype; and 4) a field study on the high fidelity prototype. The points of inquiry through these phases were based on the ABC Framework. This yielded an online social network system that linked to external third party databases to deploy to users via an interactive website.

Keywords. health behaviour change, online social network, user-centred design, ABC framework, prevention

Introduction

Leading a healthy lifestyle and making positive health behaviour changes have been found to be key to preventing illness and managing chronic diseases. In fact, self-management of ones health has been shown to be of key significance in achieving positive health outcomes for all people, healthy and sick [1, 2, 3]. Furthermore, we intuitively understand that our life choices are heavily influenced by family, friends, colleagues and other connections we have. A significant factor in health behaviour is one's close and distant social networks, which have been found to be a contributing factor to health outcomes, where ones social networks can be used to improve health behaviour through facilitating social integration and social support [4].

There is recent interest in the field of Human-Computer Interaction (HCI) to explore online social networks and health behaviour change [5, 6]. Further, HCI researchers have looked at designing technologies to promote a more active lifestyle [7, 8] and a more nutritious diet [9].

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Existing research has not looked specifically at designing online social network and online social games to motivate health behaviour change. For this reason, we explore the design space for an online social network system for positive health behaviour change through a user-centred design process. User-centred design is a methodology used in Human-Computer Interaction (HCI) as a process of interaction design [10]. We base the user-centred design process on existing theoretical models on health behaviour change and participation in online social network. These theoretical models provide specific behavioural determinants that yield the *Appeal Belonging Commitment (ABC) Framework*. The determinants from the *ABC Framework* provide the points of inquiry throughout the user-centred design methodology. We use this methodology by first completing an initial user inquiry and developing prototypes with increasing fidelity for an online social network system that we call **VivoSpace**. The prototypes that were developed included a low-fidelity paper prototype, an interactive medium-fidelity prototype and fully functional high-fidelity prototype.

1. User Centred Design Methodology

The user-centred design methodology that we used to develop **VivoSpace** is shown in Figure 1. The methodology starts with a literature review of existing theoretical models for motivating health behaviour change and participating in online social networks to yield the ABC Framework. The determinants of behaviour then provide the points of inquiry throughout the methodology. The user-centred design method begins with initial user inquiry that is evaluated through questionnaires and interviews to better understand motivations of health behaviour change and participation in online social networks. Based on the results of the initial user inquiry, paper-prototypes are developed that are evaluated through interviews. The design is iterated and a medium fidelity interactive prototype is developed and evaluated through a lab study. Finally, the design is iterated again into a working high-fidelity prototype that is evaluated through a field study.

1.1. Appeal Belonging Commitment (ABC) Framework

The **ABC Framework** was developed through the distillation of 13 theoretical models. The theoretical models for health behaviour change included in the **ABC Framework** are *Health Belief Model*, *Social Cognitive Theory*, *Theory of Reasoned Action*, *Theory of Planned Behaviour*, *Common Sense Model*, and *The Transtheoretical Model*. The theoretical models for participation on online social networks included in the **ABC Framework** are *Uses and Gratification Theory*, *Common Identity Theory*, *Common Bond Theory*, *Social Identity Theory*, *Organizational Commitment Theory*, *Behaviour Chain for Online Participation* and *social network threshold*. These theories yield a framework that provides: individually-based determinants (**appeal**) that include self-efficacy, knowledge, social enhancement and expectations about outcomes; socially-based determinants (**belonging**) that include sense-of-belonging, subjective norms and social categorization; and temporal stages (**commitment**) [11, 12].

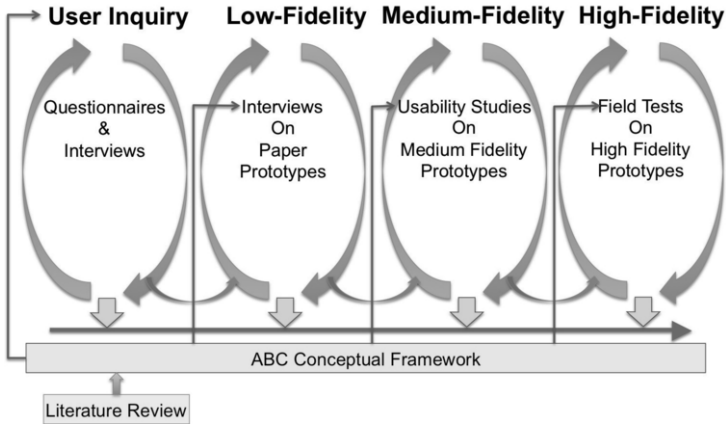

Figure 1. User-centred design method by using the ABC Conceptual Framework to form the inquiry through the iterative evaluation techniques.

1.2. User-Inquiry

The initial user inquiry for this methodology used online and paper questionnaires. The questionnaires inquired about demographic information such a gender, age and ethnic identity. The inquiry then used a 5-point Likert Scale to inquire each respondent's agreement to the determinants from the **ABC Framework**. The results yielded good agreement to the **ABC Framework**. Generally respondents felt that they were living a healthy lifestyle, understanding how to live healthy, eating healthy food and exercising regularly. However, interestingly, the majority of respondents felt that they are capable of living a healthier lifestyle. Most respondents also recognized the social influences on their health. Furthermore, older respondents (over 65 years old) felt that they ate healthier food more than young adults. Furthermore, Chinese and South Asians used online social networks for *social enhancement* (a determinant from the **ABC Framework**) more than Canadians. Generally, respondents felt stronger about connecting with similar individuals than belonging to a group or community, but both showed strong motivation [13, 11].

1.3. Paper Prototypes

Based on the determinants from that **ABC Framework**, an initial design for **VivoSpace** was developed. The paper prototypes were developed using Adobe Illustrator. There were 14 pages in total. The paper prototype was evaluated through individual in-person interviews with 11 participants. They were shown each page of the prototype and described the key functionality of the design. Participants felt that they did not want to have their health data in the same place as other personal digital assets. However, they liked the idea of social interaction with their health information and the dashboard. They also wanted to see a greater focus on goal setting and gamification [13].

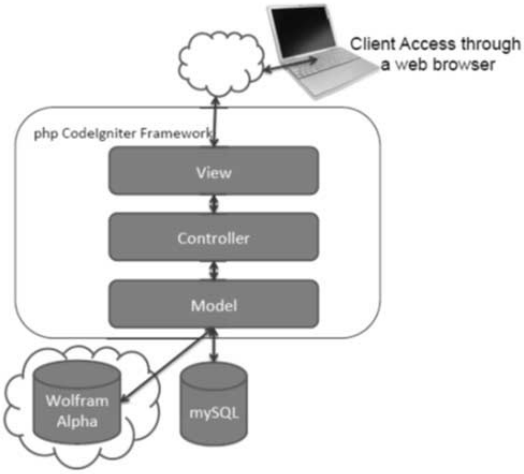

Figure 2. VivoSpace application's system architecture.

1.4. Medium Fidelity Prototypes

From the results of the interviews conducted on the paper prototype, an interactive medium fidelity prototype was developed for **VivoSpace**. The medium fidelity prototype was developed using HTML, CSS, Javascript and jQuery with the vision to develop a realistic interactive representation of our system. In total there were 32 HTML pages, 1 CSS file, and 2 javascript files. The medium fidelity prototype was evaluated in a laboratory with 36 participants. There were 6 groups of tasks that participants were asked to complete; after each task group, they were asked to complete a questionnaire that was based on the **ABC Framework**. *Belonging* was evaluated using indirect inquiry through the adaption of the *Helping Game Experiment* from behavioural economics. Similarly, *Commitment* was evaluated through the *In-Group Experiment* from social psychology. The results showed good agreement with the **ABC Framework**; however, the design should provide greater motivation for users to provide information [14].

1.5. High Fidelity Prototype

Based on the previous designs and evaluation, a fully functional high fidelity prototype has been developed for **VivoSpace**. The system architecture for the high-fidelity prototype is shown in Figure 2. The online social network system was developed in PHP using the CodeIgniter [15] web application framework. The CodeIgniter web application framework enforces a Model-View-Controller (MVC) development pattern, which separates the application logic from the presentation: the *model* represents the data structures; the *view* contains the code for presenting the information to the user; and the *controller contains* the bulk of the application logic and processes. The database used was MySQL, and nutritional information for food was obtained from an external database, Wolfram Alpha [16], through an Application Programming Interface (API). The high fidelity prototype is then used to allow people to use **VivoSpace** in

their day-to-day lives.

2. Conclusions

The user-centred methodology augmented by the **ABC Framework** provided a means to engage users in the design through a methodology that has theoretical underpinnings. This methodology can be used for similar systems that have an end objective beyond usability, as it allows the inquiry to be based on a conceptual framework that is validated in the context of the system being designed.

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Social Media and Patient Self-Management: Not all Sites are Created Equal

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Abstract. This paper compares two social media sites that aim to support patients to enhance self-management. The first site, PatientsLikeMe is a well established global site designed to allow peer-to-peer communication between people with similar conditions. The second, HealthShare, is a recently developed site for Australians described as "Australia's Social Health Network". The comparison conducted examines the purpose, ownership, and design of both sites as well as how the data they collect is used. Analysis highlights that PatientsLikeMe actively facilitates patient self-management, while HealthShare is revealed to be a professionally moderated health information portal presented as a social networking site. While the impetus for the development of PatientsLikeMe is clear, the motives underpinning HealthShare are less obvious. With increasing patient interest in connecting with, and sharing information with one another, awareness of the nature and motivations underpinning sites that provide these services is of increasing relevance.

Keywords. social media, self-management, PatientsLikeMe, HealthShare

Introduction

Rising costs of health care and an aging population are placing strains on most health care systems. Alternative mechanisms are being sought to provide support for patients, especially those with chronic disease.

Self-management has been described as "…a dynamic process incorporating an individual's capability and confidence to engage in activities which enable them to deal with the impact of living with a chronic condition on all aspects of their life" [1].

Opportunities for self-management have recently increased with the development of Web 2.0 [2]. Social Media provide opportunities for patients to support each other outside the formal medically controlled environment by sharing personal health information and experiences. In some instances, these opportunities are changing the traditional 'Patient-Physician' relationship to one where patients interact with one another to acquire mutual support, learning and self-management [3]. Technology now provides a mechanism to create person-to-person support groups online, providing patients with peer support from others with similar diseases, along with 'expert' advice from the patient perspective [4].

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In order to better understand how these identified trends are working in practice, two social media sites offering support for patient self-management were identified for comparison. The two sites were: PatientsLikeMe [http://www.patientslikeme.com/] and HealthShare [http://www.healthshare.com.au/].

1. Method

In comparing the self-management support offered by both sites a simple content analysis was conducted that examined each site's stated purpose, ownership, design and the information provided on how any data collected is used. While the comparison could have adopted the HON Code criteria [5] the aim was to primarily focus on how these sites described and subsequently supported patient-to-patient interactions to support self-management, rather than to assess the quality of any information they provided per se.

2. PatientsLikeMe

PatientsLikeMe was co-founded in 2004 by three MIT engineers, Ben Heywood, Jamie Heywood and Jeff Cole, as a means of providing support for Stephen Heywood, the brother of Ben and Jamie, who had been diagnosed with amyotrophic lateral sclerosis [ALS]. Their aim was to use Web 2.0 technology to provide a mechanism for people like Stephen to connect and share information with other ALS patients [6].

The aim of the site is for patients to use it in conjunction with other patients who have the same disease. Patients report their own health information which is then presented graphically in their profile and shared with other patients, providing opportunities for active dialogue amongst patients [3]. The goal of the PatientsLikeMe website is to help patients answer the question: "Given my status, what is the best outcome I can hope to achieve, and how do I get there?" [7].

Used responsibly PatientsLikeMe can also be an important tool for medical research [6]. Through member participation information is gathered to better understand disease trajectories, medical treatments and medications. Data provided by patients is used to discover trends and evaluate new possible treatments [8]. PatientsLikeMe conducts research by investigating the patient data. Researchers administer surveys to groups on the site to gather additional patient self reported data. This has resulted in numerous publications that have contributed useful information to the broader medical community [7, 9, 10].

The PatientsLikeMe site provides clear information about the founders, and how and why the site was originally developed, including a declaration that the company is 'for-profit' but not one with a 'just for profit' mission. It states "We follow four core values: putting patients first, promoting transparency ["no surprises"], fostering openness and creating 'wow" [11].

While the site offers privacy settings and indicates that patients can volunteer their "personally identifiable information," PatientsLikeMe retains the right to share the de-identified data with their partners and with other patients [12].

3. HealthShare

HealthShare, was established in 2009 by Darryl Jackson and Gavin Solsky, it is owned by Adin Holdings Pty Ltd. Jackson has expressed the view that "…technology [can] change and improve the 'old world' way of sharing healthcare experiences and recommendations" [13]. The site was founded to help Australians with life saving medical advice. The death of a 25 year old fitness instructor by overdosing with paracetamol was given as an example of the reason for establishing the site by helping people by providing information to them [14]. HealthShare's vision is to become the leading online presence in Australia for health consumers, professionals, community organisations and service providers to collaborate. The co-founder Darryl Jackson previously worked for the Australian Self-management Industry [ASMI], the peak body representing companies involved in the manufacture and distribution of consumer healthcare products in Australia. The site claims that "HealthShare's program delivers enhanced public perception of your brand" and "trust and an emotional connection with health consumers and practitioners" [15].

The site is designed as a set of moderated communities, each dealing with a single disease. The site includes a range of health communities covering over 350 health topics. HealthShare has the support of health organisations such as the Heart Foundation, Diabetes Australia and Alzheimers Australia. HealthShare identifies itself as "Australia's Social Health Network" where people can find other people with similar health experiences. The structure of HealthShare is similar to Wikipedia, but with credible moderated information, a type of 'Facebook' for health. The site was designed to provide information for a range of communities commencing with the major health issues affecting many Australians and then subsequently growing to added those issues affecting smaller numbers of Australians. Overall the site displays a strong focus on chronic diseases and topics related to healthy living.

Although the site is privately funded, the founders have a sponsorship program that involves content partners working with HealthShare to have the opportunity to sponsor particular health communities through the site [16]. HealthShare also provides the opportunity for patients to recommend healthcare professionals. This is not a rating system, and there is a need to explain why you would recommend that particular healthcare professional. The CEO states that the average Australian needs more information when choosing a health practitioner. HealthShare has a statement identifying that the owners take privacy seriously by providing complete privacy protection and unparalleled security. Personal information will not be released to any other party.

4. Results

Web 2.0 has provided opportunities to support communication and information sharing in a way that has not been available before. PatientsLikeMe has taken advantage of these new opportunities by providing a social networking site focused on the patient and her individual health. From initial registration onwards the focus is the patient as an individual (your health, your current status, and the medication you are taking and how this is affecting you). The site then offers individuals the opportunity to see other people with similar health issues, taking similar medication or having similar reactions. PatientsLikeMe also allows a patient to identify multiple concurrent conditions for

example registering for breast cancer and menopause together. The site is moderated and professional healthcare information is available. Forums are grouped into higher level categories such as *Women's Health* and *Pregnancy* thereby facilitating broader discussion of cross-related issues.

In contrast, although HealthShare has expressed its aim as being "Australia's Social Health Network" the site's functions and features mean it is actually a conventional web-portal that is tightly moderated to primarily provide health information from healthcare professionals. When registering for HealthShare the focus is on the particular medical condition, not the patient. Users are unable to link medical conditions together into one community and instead, individual conditions are presented in medically defined condition specific silos. For example, a patient with breast cancer and menopause would be required to access different parts of the site to acquire information on these conditions and would not be able to easily integrate the separate streams of information and advice provided, even though both conditions affect the same individual patient. HealthShare primarily operates with an 'information push' model such that information is sent out to the user. Most of the content on the site appears to be provided by numerous healthcare provider moderators. Where a question is posted on the site it is usually answered by the healthcare moderator, rarely by another patient user.

5. Discussion

The US based, PatientsLikeMe is a global site for all to use and share. HealthShare is a site expressly designed for Australians. The HealthShare perspective is that a localised service is necessary to avoid a situation of information not being relevant to Australians (such as the unavailability in Australia of a particular drug being prescribed for a particular disease). This perspective highlights the different underlying assumptions in the two sites about the role of social media in supporting patient self-management and how the advice, experiences and support available from patients for patients is valued.

Significantly, while both sites are owned and operated by private companies and both purport to be about supporting patients to enhance self-management, there appears to be a strong contrast in the nature, motivations and interests these sites and their owners display in relation to patients.

PatientsLikeMe transparently declares that the business is a profit making enterprise. The site uses the data collected from the site to support research and clinical trials. PatientsLikeMe have their own research team and a brief scan of the current literature soon reveals that these industry researchers also work in conjunction with academics to investigate the data. While some recent discussions have begun to question the use of this data [17] to date, PatientsLikeMe have continued to be 'transparent' in declaring how data is used and by whom.

In contrast HealthShare provides no clear information about whether or how any de-identified data is used. There is no clear information relating to the profit status of the company, or its business models and prospective business plans. Is HealthShare an altruistic initiative motivated by a concern for Australian patients, or is it an example of Astroturfing – a commercially driven activity leveraging patient interest in social networking to generate profit from health profiling and data usage of its user base? From the information available through the site it is difficult to tell definitively!

The rapid emergence of health focused social media has leveraged the strong interest and appetite amongst many 'internet empowered' patients to connect with one another and to openly and interactively share knowledge, experiences and attitudes about their health and well-being. Simultaneously, on-going debates on data protection and the security of electronic patient records as well as risks associated with personal health profiling and business ethics related to harvesting patient data for profit have emerged.

As the comparison of the two sites above illustrates, different health focused social media sites support and value patients in very different ways. These differences however are most evident, not in the health information provided by each site per se, but rather in how patients are able to interact about their conditions with other patients. Understanding and identifying the nature and motivations underpinning health related social media sites is another dimension for patients to consider when seeking internet support to self-manage.

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Empowering Saudi Patients: How do Saudi Health Websites Compare to International Health Websites?

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Abstract. Little information is known about how Saudi health websites compare internationally. The purpose of this paper is to compare two leading Saudi health websites with leading international health websites. The study was conducted as a convenience sample at a graduate health college in Saudi Arabia. A total of 42 students participated in the study. The study found that, in general, English websites have higher levels of performance with regard to quality of information, authority and objectivity, coverage and currency, and design. However, the respondents considered Saudi health websites to be superior with regard to maintaining privacy and security. The results indicate that much more work is needed in designing Saudi Health to make them more trustworthy and credible. The limitations of this work and future research directions are also discussed.

Keywords. consumer informatics, Saudi Arabia, health websites, and patient empowerment

Introduction

For years, the development of websites with trustworthy health information within the Arab world has been neglected. Much of the available Arabic health information has focused on a particular healthcare organization's goals, services, and policies [1]. A study conducted by Al-Tuwaijri determined that, of the 122 Arab health websites evaluated in terms of providing high quality health information, only five provided trustworthy health information to the Arab consumer [1]. As a result of this research, various healthcare organizations within the Arab world began to develop health information websites that are trustworthy and credible to improve health literacy and empower patients. A recent study on how Saudis use online health information found that 58% of those surveyed used the internet to search for health information [2]. In the study, most patients discussed the health information found online with their physician and believed that sharing such information improved patient-physician relationships [2].

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With the growing need for trustworthy and credible health information in Saudi Arabia, various healthcare organizations have developed health information websites for the Saudi public. This paper evaluates two leading healthcare information websites sponsored by public healthcare organizations within the country. It compares two leading Saudi health websites to leading English websites in Canada, England, and Australia. The study evaluates various dimensions related to providing trustworthy health information online. The King Abdullah Bin Abdulaziz Arabic Health Encyclopedia (KAAHE), one of the largest initiatives for providing credible online health information within the Arab world, was not included in this study because it was not available online when the study was conducted.

1. Methodology

A convenient sample survey was conducted using male and female students at the College of Public Health and Health Informatics at King Saud Bin Abdul Aziz University for Health Sciences, Riyadh, Kingdom of Saudi Arabia from November 2011 to January 2012. The College of Public Health and Health Informatics is the first college in Saudi Arabia to offer a graduate program in Public Health and Health Informatics within the country of Saudi Arabia. The program accepts applications from the various regions within the country as well as the Gulf region. The sample represents some of the most highly educated groups within the country of Saudi Arabia.

1.1. Data Collection

The survey used by Ali et al. to evaluate Egyptian health websites was used in the present study to evaluate two leading Saudi health websites [3]. The tool consists of one technical category and one ethical category. The technical category evaluates six items related to authority, objectivity, coverage, currency, design, privacy and security. The ethical category evaluates the quality of information, informed consent, and professionalism.

The administered questionnaire included 49 questions and took approximately 3 hours to complete. The questionnaire was e-mailed to each participant with a Microsoft Excel attachment. The Microsoft Excel attachment included survey questions and clear instructions on how to input data and return the survey. The participants were provided one week to complete the survey. Participation in the study was voluntary, although completing the survey constituted 20% of the student's final grade.

The participants were asked to evaluate two Saudi websites using the survey. Through random selection, two students were asked to evaluate a leading English-language health website. A total of 21 English websites were included in the evaluation: 9 from the U.S.A, 5 from the United Kingdom, 3 from Australia, and 3 from Canada. In addition, after they completed the survey, the participants were asked to rank all 21 English health websites from 1 to 10, with 1 being the least trustworthy and usable and 10 being the most trustworthy and usable. The researchers then added the scores and divided them by 21 to give a total score between 1 and 10. Any number between 1 and 4 was classified as having low trustworthiness and usability; health websites that scored 5-7 were classified as having medium trustworthiness and usability; and websites with scores of 8-10 were classified as having high

trustworthiness and usability. In this study, the Saudi health sites were compared to the four highly rated and trustable English websites (as ranked by the respondents).

1.2. Analysis

Data was analyzed by descriptive data analysis and graphs using Microsoft Excel.

2. Results

All 42 students returned their survey within one week of receiving it. The participants in the convenience sample included 31 females and 10 males. Their ages ranged between 24 and 55 years. Most of the students were in health sciences programs encompassing various professions such as health informatics, medicine, nursing, pharmacy, medical sciences (laboratory technologists, x-ray techs, etc.), and dentistry.

2.1. Quality of information

Every respondent noted that all highly rated English sites provided a higher quality of information than Arabic websites and mid-to-low quality English websites. Each respondent also noted that medical professionals provided the health information available on top rated English websites, while nearly half the respondents noted that Saudi health websites contained information that was written by medical professionals (52% and 55% for the two Saudi websites considered). Furthermore, every respondent noted that the information provided by highly rated English websites included scientific studies, while this was the case for only 43% and 36% of the two Saudi websites. All respondents indicated that the language was clear for the top rated English websites; in this regard, high ratings were also given to the Saudi websites (98% and 95%.) Only 63% of respondents found that the highest ranked English websites provided a publication date, while a much lower percentage respondents found that the Saudi websites did so (33% and 26%).

With regard to the use of references, 88% of respondents noted that the highly ranked English websites provided information on their sources, while much lower rates for Saudi websites were reported (24% and 7%). With respect to HONCODE certification, which certifies credible and trustworthy websites, 75% of respondents reported that highly rated English websites have HONCODE certification, while none of the Saudi websites were found to have HONCODE certification.

2.2. Authority and Objectivity

This study also considered the authority and objectivity of each website. When considering the highly ranked English websites, 88% of respondents reported that authors were identified. Much lower rates of author identification were reported for the Saudi websites (31% and 26%). Three-quarters (75%) of respondents found that the highly ranked English websites clearly stated institutional affiliations on their website; on the other hand, most respondents noted a lack of clarity in this regard on the Saudi health websites considered (67% and 57%). Respondents also found that most of the highly rated English health websites contained the authors' contact information (75%),

while much lower rates were indicated for the Saudi health websites considered (33% and 24%).

Regarding the websites' purpose(s) and objectives, all highly ranked English websites were found to clearly state their objectives. Most respondents reported that the purposes of the Saudi health websites were clearly stated (71% for both sites). Respondents also noted that, for all highly rated English websites, the material presented was in line with the objectives. Most respondents also noted that the material presented on Saudi health websites corresponded with the objectives (75% and 62%).

2.3. Coverage and Currency

All respondents noted that the top English websites satisfied their information needs. Similarly, almost all respondents (95%) noted that one Saudi health website satisfied their information needs, but the other Saudi website had a much lower rate (63%) for satisfying the informational needs of the respondents.

The majority (88%) of respondents found the highly ranked English websites to be current and up to date. This measure was lower for Saudi websites, 79% and 33%. All respondents noted that all highly rated English websites were up to date, while only 86% considered one Saudi website to be up to date and only 48% considered the other to be current.

2.4. Design

All respondents noted that the highly rated English websites could be accessed and navigated easily. The respondents also indicated that both Saudi websites were easily accessed and navigated (86% and 83%). Almost all respondents (88%) noted that the highly ranked English websites used visuals to convey information. Students reported that one Saudi website was better than the English websites in using visuals to convey information (95%). For the other Saudi website, only 74% of respondents reported the use of visuals to convey health information.

All respondents reported that high quality graphics were used in the highly ranked English websites, while the respondents indicated lower satisfaction with Saudi websites (81% and 62%). The respondents also found that all highly ranked English websites were useful, while a much lower number of respondents (76% and 52%) found the Saudi health websites to be useful. Most of the respondents (88%) noted that the highly ranked English websites had interactive features that were easy to use, while the respondents reported lower satisfaction with the Saudi health websites in this regard (74% and 64%).

Regarding software updates, all respondents reported that the highly ranked English websites could be accessed without additional viewers or plug-ins. Only 86% and 81% of the respondents noted that the Saudi websites could be accessed without software plug-ins. With regard to informing or providing support for downloading the software required, both Saudi health websites ranked higher (52% and 29%) than the high-ranking English language websites; only 25% of the respondents noted that the highly ranked English websites provided information regarding where to download the plug-ins required.

2.5. Privacy

Regarding privacy, almost all of the respondents (95% and 79%) considered the Saudi websites to be more secure than the highly rated English websites (which had a support rating of 75%). Regarding unauthorized data access, most of the respondents (79% and 75%) considered both Saudi websites to be better than the highly rated English websites (which had a support rating of 75%).

3. Discussion

This study assessed and compared two highly ranked Saudi websites with highly ranked English websites. Overall, the study found that English websites performed better with regard to quality of information, authority and objectivity, coverage and currency, and design. However, the respondents also indicated that the Saudi health websites were better in maintaining privacy and security. The results indicate that much work is needed in designing Saudi Health websites to be more trustworthy and credible compared to English sites.

A current initiative is attempting to address these shortcomings. The King Abdullah Bin Abdulaziz Arabic Health Encyclopedia (KAAHE) was launched on the Internet in Saudi Arabia in April 2012. This initiative, led by the Saudi National Guard Health Affairs organization, aims to provide credible and reliable health information to the Arab world [4]. It is, therefore, different from the websites evaluated in this study, because the websites in this study are more local and focus on specific populations or disease groups. By providing a credible and trusted source of health information, KAAHE is expected to improve health literacy and to indirectly improve patient safety in Saudi Arabia and throughout the Arab world.

4. Limitations and Future Research

The present study compared two highly ranked Saudi websites with highly ranked international English websites. This research was limited by its use of a convenience sample, which may limit the results' generalizability and validity. The sample used in this study was composed of students who were highly educated and familiar with the use of technology and health websites. Future research should be conducted in hospitals using a wider and more diverse population and should assess the performance of the KAAHE project within Saudi Arabia and the Arab world. Another limitation of this study is the use of descriptive statistics; future plans include providing more detailed statistical analyses.

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Taming Mental–Health-Focused Popular Literature: A Crazy Idea?

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Abstract. Providing tailored and easily accessible health information for mental health clinicians and patients can be enabled through Information Technology and Communications (ITC). The literature is mixed regarding the quality, utility and accessibility of health information in the popular press for this purpose. However, there is consensus that mental health information in the popular press is readily available, easily comprehended by patients, and is continually updated. We report the process by which mental–health-focused articles in the popular press are identified, screened, and disseminated to a large network of doctoral level psychologists (the PsyUSA network). We analyze 4-year article distribution and access data, and conclude that the distribution of mental–health-related popular press articles prompted article access. We leverage this experience to formulate a model for direct access to clinician-vetted mental–health-related popular press through a curated web based archive.

Keywords. consumer health, information sharing, information retrieval, patient education, knowledge representation/organization, consumer informatics

Introduction

As early as 2003, 80% of American consumers searched for health information on the web, with 21% searching mental health-related topics [1]. A vast array of health information is readily available online via newspapers, magazines, television news outlets, and press releases; i.e., "the popular press." Health information may be provided via such outlets through reported research results, review articles, news articles, exposés, expert interviews, book reviews, tips and advice. This information educates and entertains, increasing awareness of mental health-related issues.

A major advantage of popular press psychological resources is that they are written in laymen's terms and can be understood by most. Further, articles in the popular press are often available for free or nominal charge. However, health information delivered by popular media can be compromised by quality, accessibility, and utility issues [2-7]. Relevant information needed to evaluate article quality often is missing [3, 8], and articles can "disappear" or be sequestered behind pay walls.

The increasing focus upon patient-centered care warrants increasing the availability of applicable, reliable, and valid information related to patient needs.

The PsyUSA network, a network currently consisting of 428 doctoral-level clinical and counseling psychologists, offers insight into clinician access of popular-press psychological information. One of the PsyUSA network's main functions is to increase psychologist awareness of new articles of psychological import. Network clinicians have noted using these articles in patient education, as well as for increasing their breadth of knowledge and keeping abreast of new developments in the field.

1. Background

The PsyUSA network initiated operations on October 28, 1995, with a goal of providing a forum for doctoral-level psychologists to exchange information, interact, broaden exposure to psychological topics and stay current. Toward the lattermost goals, mental–health-related articles are disseminated by listserv (push technology) via email "posts," wherein brief portions of the article (as well as relevant links connecting to the article in its entirety) are sent to psychologists by email each day. From May 1, 2006 through September 1, 2012, a total of 10,603 article snippets and links have been distributed though the PsyUSA listserv—an average of 4.64 articles posted per day.

Volunteer doctoral-level clinical psychologists, referred to as "Newshounds," identify and disseminate posts to the network; i.e., upstream versus downstream filtering [9]. Today, three Newshounds (first three authors) work for the network in this capacity on a rotating weekly basis and spend an estimated 1.5 to 2 hours to prepare weekly article postings. This time is spent in identifying, reading, and discerning which popular psychology articles should be distributed, in formatting the information sent to comply with copyright and listserv requirements, and in obtaining shortened universal resource locators (URLs) to access the full article.

Identifying articles focused on popular psychology for dissemination to the PsyUSA network is done manually, using different article identification strategies. They include utilizing website aggregators of psychology-focused articles, Rich Site Summary (RSS) or general website aggregators to track websites with frequent fresh mental health related content; and setting up alerts to notify Newshounds of new articles.

Screening articles for PsyUSA network distribution is based on Newshound experience, educational background, and personal interest. Articles are screened in a two-part process. Initially, titles and brief portions of articles are scanned. Based on perceived interest to PsyUSA network members, Newshound interest, and perceived quality of the article source; articles are selected for further review. The second phase of the screening process begins as articles judged potentially worthy of dissemination are read in full. Criteria considered include presentation of novel information or ideas likely to stimulate discussion and thought, completeness of topic coverage, transparency of information sources and assumptions (or full disclosure of primary data or evidence), methodological rigor and relationship of the article's discussion of relevant research. Language use, general clarity, and organization are also considered when judging article quality.

Selected articles are then prepared for dissemination. Fair Use provisions of U.S. copyright law dictate that only the title, attribution, and short snippet from copyrighted articles be distributed in a post. A web link to the original article is always provided.

2. Methods

This observational study reports analysis of data pertaining to one PsyUSA network Newshound (the first author). All articles posted by this Newshound Since July 12, 2009 were assigned links using the Bit.ly URL-shortening service (www.bitly.com) for all non-press release articles; full press releases are intended for public dissemination and thus were distributed directly in the post. Because Bit.ly has been reported as the most popular URL-shortening service since May of 2009 [10, 11], it offers the best indirect means of estimating article popularity for the general public.

The Bit.ly service provides one Bit.ly link for each article. Standard Bit.ly metrics break down the total number of clicks by referrer (in this case, the Newshound), as well as the total number of clicks on Bit.ly to the article from any referrer. The Bit.ly metrics were analyzed to explore full article access by PsyUSA network members. These analyses were conducted on aggregate web statistics, from which individual behavior cannot be determined. Additionally, the first author kept records of article screening, e.g., articles that he read through fully but did not disseminate because of quality concerns (using a service called Instapaper <http://www.instapaper.com/>).

This research was submitted as Pro00041763 to the Duke University Institutional Review Board and was granted exemption.

3. Results

From July 12, 2009 to August 21, 2012, the first author sent 1,170 posts to PsyUSA members (approximately 324 per year). Bit.ly observational data during this period shows that each post to the PsyUSA network generated on average 7 clicks (median of 3) to the full article. During the same period, PsyUSA members logged an average of 215 clicks per month on these posted articles. In the general population of non-PsyUSA members, each of the Bit.ly links generated an average 320 clicks per article (median of 18) and 9,843 clicks on average per month.

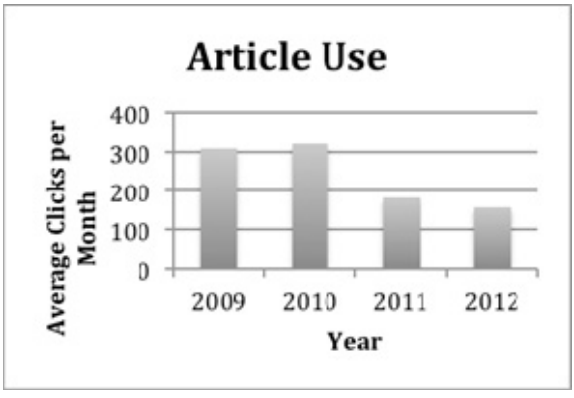

Figure 1. Access by Year for PsyUSA Network Members

Figure 1 shows the average number of clicks per month on posted articles disseminated by the first author, by year. The drop in Bit.ly referenced articles from 2010 to 2011 corresponds to an increase in press release distribution starting in 2011.

In 2009 and 2010 an average of 6.5 and 4.9 press releases were distributed each month respectively; whereas in 2011 and 2012, the Newshound distributed 25 and 29 press releases each month respectively. Recall that the full press releases text is distributed; obviating the need to use Bit.ly and therefore lowering the average Bit.ly clicks per month. A drop in PsyUSA network membership from 2007 to 2012 of about 75 members may have also contributed to the decline in Bit.ly accessed articles.

4. Discussion

Full access to psychologically focused articles as indicated by Bit.ly metrics was robust, especially considering that articles were popular press, and "pushed" to psychologists without regard to individual need or interest. We interpret clicks on Bit.ly links disseminated by Newshounds as an indication that the recipient found the article of sufficient interest to follow the link to the full article. We leave the reader to form opinion as to whether or not exposure to psychological information of interest to a practicing psychologist is of use to them in their practice. Network clinicians have noted using these articles in patient education, as well as for increasing their psychological breadth of knowledge and staying current in the field. There has been no formal assessment of the uses and perceived helpfulness of distributed articles to network members. Future survey research with PsyUSA network members could provide such insight.

Given the article access with the "push" model of information dissemination in the PsyUSA network, we posit that a "pull" model could be even more useful- e.g., a searchable archive of vetted mental health focused articles accessible by patients with a clinician-gated recommendation, or even the general population on demand. A recent report that consumers receive a majority of their health information from "traditional media and interpersonal sources" [12] underscores this need.

For such a "pull" model to work, a comprehensive, organized, easily searched web archive of high quality popular press information must be created and maintained. Finding relevant articles for inclusion in the database can be accomplished by augmenting current methods with intelligent-search web crawlers to automate article identification, application of heuristic algorithms to identify articles most likely to be topically pertinent; and application of existing heuristics for health information quality on the internet. While Newshounds currently operate informally to assess article quality (described above), heuristics exist for assessing the quality of health information on the web [13] that can also be applied and semi-automated. Further other indications of article quality such as user feedback and rating may be employed.

Article tagging to facilitate information retrieval could be accomplished by leveraging the Library of Medicine's Medical Subject Headings (MeSH) database. It uses common language, has natural language definitions, and provides a hierarchical structure that could aid organization and search. Additional research is needed to clarify patient and caregivers search and navigation strategies, and to ascertain the usefulness of including a brief abstracted article summary along with the basic information now provided of article an article snippet, title, attribution, and link to full article.

Copyright considerations figure prominently in constructing such a database. Because of the non-profit, educational nature of this work; inclusion of the article title,

as well as one or two article paragraphs should be allowed under Fair Use provisions of U.S. copyright law, and Fair Dealing Doctrine of the Commonwealth Nations.

Maintenance of such a web-based archive would be needed. Such maintenance would include ensuring that articles continue to be available at their cited web location, and that they still are available freely (or at nominal fee).

As with all web based health information, users of this data base should be clear that although psychology-focused popular media articles may offer advice and tips (often by experts in the field), the information they provide should not be construed as professional advice suited to an individual's psychological health issues and needs.

Further research should include content analysis of high-use popular press to discern which mental health articles generate the most consumer interest- and why. Additional research may also inform how popular media psychology focused articles can best be used for education purposes.

5. Conclusion

Mental–health-related popular press articles are accessed at a high rate by PsyUSA network members. Our experience has highlighted necessary considerations for increasing the scope of such information dissemination from doctoral level clinicians only, to a patient resource open to the general public; and for changing the model from a push of articles without regard to individual interest, to am on-demand resource.

6. Limitations

Due to the observational nature of this work, we cannot attribute cause. And we cannot directly link clinician access to usefulness. Further, generalizability of our conclusions is limited because PsyUSA network membership have self-selected based on perceived value of receipt of popular-press articles. These findings are further limited by the retrospective nature of data collection that relied on aggregate counts from Bit.ly as an indicator of article use and popularity.

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Considerations for Personal Health Record Procurement

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Abstract. Patients with chronic illnesses require tools and resources to facilitate self-management. Personal Health Records (PHRs) are a promising option for delivering these tools and resources to patients with chronic illnesses. As such, many organizations are becoming interested in PHR procurement. However, traditional procurement methods may not ensure the system success and adoption. In this study a group of subject matter experts discussed the possibility of converting a paper-based PHR into an electronic tool. These discussions resulted in generation of several important criteria for assessing commercially available PHR solutions and other considerations related to PHR procurement. These considerations should be contemplated and discussed with stakeholders prior to PHR procurement. In order to realize the benefits PHRs, it is imperative that the appropriate selection is made. Prior to purchase commitment, a trial period can prove extremely useful for performing usability analyses and ensuring interoperability. Supplementing traditional procurement methods with these preliminary user evaluations will increase the likelihood that the selected system best matches the needs of users and purchasers. Moreover, the risk of system failure and the risk of limited adoption of the PHR by the public will be reduced as a result of adopting these methods.

Keywords. Personal Health Record (PHR), procurement, usability, chronic illness

Introduction

Chronic illnesses (e.g., arthritis, cancer, chronic obstructive pulmonary disease, diabetes, heart disease, high blood pressure) cannot be cured and often occur in conjunction with other chronic illnesses. Many of those suffering from chronic illness do not receive sufficient care from their primary care providers. [1]. Chronic illnesses place a heavy burden on the resources of the health care system and the demands on healthcare are going to be exacerbated by the aging population [1].

Patients are the most important figures in chronic disease management because they must deal with their illnesses on a daily basis [2]. Further, patient self-management is an integral component to treatment to help mitigate both the physical and psychological effects of chronic illness and improve the effectiveness and efficiency of care [3].

An individual with chronic illness requires a *set* of tools tailored his or her condition(s). Solomon [2] asserted that "by providing people with chronic disease the

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tools and support to self-manage their conditions, individuals become more knowledgeable about their health situation and are more apt to adhere to self-care practices that lead to better outcomes" (p. 400). One application that shows promise for providing customized toolkits to patients with chronic illnesses is the Personal Health Record (PHR).

The Medical Library Association (MLA) / National Library of Medicine (NLM) Joint Electronic Personal Health Record Task Force [4] defines a PHR as:

> A private, secure application through which an individual may access, manage, and share his or her health information. The PHR can include information that is entered by the consumer and/or data from other sources such as pharmacies, labs, and health care providers. The PHR may or may not include information from the electronic health record (EHR) that is maintained by the health care provider and is not synonymous with the EHR (p. 244).

The adoption of PHRs reflects a paradigm shift from the patient as a passive recipient of health care to one who is actively engaged in the health care process by collaborating with providers and making decisions [5] as part of a patient-centric care model. Moreover, although chronic illness may be the catalyst for launching PHRs, healthy populations benefit can from their use as well.

Despite the praise for their potential to transform healthcare, patients have proven to be reluctant to adopt PHRs on their own accord. In Canada (n = 2 304), merely 6% of consumers already maintain a PHR; however, 61% would be receptive to their physicians, hospitals and/or the government to providing them with a PHR [6]. The majority of the usefulness of a PHR hinges upon its interoperability with EHRs [7] and thus, Canadians may be waiting to be offered a PHR that is integrated with the systems their providers use. Deloitte's [6] survey also revealed that majority of Canadians would like to access a family member's PHR and would appreciate online tools to help them assess, monitor and manage their health (e.g., risk assessment questionnaires, health diaries). In summary, despite low adoption rates, Canadians support the functional capabilities of PHRs and would be receptive to a PHR selected for them by their health provider or organization.

Given their potential to benefit patients with chronic illnesses, many organizations are considering PHR procurement. The selection of a PHR to be used by citizens in a large region within Canada is an important and critical task in attempting to achieve the potential advantages that might result from widespread use of such systems. In this paper we describe how conventional procurement methods can be combined with plans for conducting usability analyses of candidate PHR systems in order to increase the chance of successful deployment. It is argued that a combination of methods will be needed to reduce the risk of system failure and the risk of limited adoption of the PHR by the public once the selected system is deployed.

1. Methods

A chronic disease interest group was developing a paper-based PHR and was interested in also offering their PHR to patients in an electronic format. The purpose of study was to generate a set of criteria to assess commercial-off-the-shelf (COTS) PHR products as potential options for converting the existing paper-based PHR into an electronic tool.

1.1. Team Members

The principal investigator coordinated and chaired the meetings. Two subject matter experts from different arthritis groups provided insight on the paper-based PHR, clinical and patient requirements. During the development of the paper-based PHR patients were questioned and consulted about their needs and preferences for an electronic PHR; however, given that this study was only preliminary, patients were not included on the team. Two other representatives were subject matter experts in information technology and provided insight on functional and technical requirements.

1.2. Procedure

The group met on multiple occasions to discuss and come to consensus on a set of criteria to compare commercial-off-the-shelf (COTS) PHRs with the paper-based PHR. Additionally, criteria were developed to assess issues unique to electronic tools (e.g., privacy and security). Criteria ranged from user focused aspects of PHRs (e.g., functionality, usability) to criteria important from the perspective of the dispensing agency (e.g., vendor stability, pricing).

In conjunction with the identification of criteria, questions were generated to assess these criteria. Some questions were adopted from PHR evaluation questions developed by the former California Regional Health Information Organization (CalRHIO). However, many of these questions were not well suited to the Canadian context so they were supplemented with questions created by the project team.

To improve the likelihood that an appropriate PHR selection was made, limitations of conventional procurement processes were considered through discussion to arrive at extensions and new approaches.

2. Results

In addition to the criteria that were developed (summarized in Table 1), other important considerations for PHR procurement discussed by the group are outlined here.

2.1. Potential for Integrating Complementary Apps and Resources

Integration of specialized mobile apps is especially appealing because of their desirability among younger demographics and their potential to facilitate monitoring. For chronic illnesses where consistent monitoring plays an important role in management mobile apps are ideal because they:

- Are designed simplistically which facilitates quick and easy data entry.
- Are built for devices that users frequently carry with them.
- Are capable of setting timed reminders to prompt users to enter data.

Existing health resources could be integrated into the PHR that have been designed with health literacy considerations specifically for health promotion and education. For example, for British Columbians, HealthLinkBC (www.healthlinkbc.ca) would be an excellent resource to integrate with a PHR. HealthLinkBC provides trusted health information on over 5,000 health topics, symptoms, medications, medical tests and tips for maintaining a healthy lifestyle. The site can be also used to find local health

services. Nurses are available 24 hours a day by phone and dieticians and pharmacists are available during specific times. By integrating existing resources such as HealthLinkBC with a PHR, users could be presented with credible, personalized information according to a multitude of variables (e.g., gender, weight, illnesses, location). Not surprisingly, personalized educational information has been shown to be popular with patients [8].

Table 1. Summary of Criteria for PHR Procurement

Criteria	Description
Functionality	The range of personal health information stored and the health management and health promotion tools offered.
Usability	The effectiveness, efficiency and satisfaction with which the PHR can be used to achieve specified goals in a particular context.
Communication Tools	The ability to securely exchange messages and information using the PHR.
Shared Access / Permissions	The capacity for patients to share aspects of their records with health care providers and family members.
Health Literacy	The ability for users to understand the content, apply the information and use health resources.
Language Flexibility	The availability of multiple languages and the capacity of the PHR to translate between languages.
Accessibility & Portability	The ability to protect users against loss of access to the service and their records.
Mobile Accessibility	The capacity for the PHR to be accessed on computers, tablets and mobile phones and apps developed specifically for mobile devices.
Interoperability & Standards	The ability of the PHR to communicate with other clinical information systems (e.g., EMRs, lab systems, pharmacy data etc.).
Compatibility with Medical Devices	The ability to connect with and upload data from other devices (e.g., glucometers, pedometers, scales).
Privacy & Security	The ability to protect users from unauthorized access or use of records.
Support	The ability for users and the dispensing agency to get help with how to use the PHR and problems they encounter.
Development Feasibility	The ability to create and/or augment tools.
Vendor Stability / Sustainability of Data	The ability to archive data and keep a long-term detailed record assured that vendor remain in operation.
Data Accessibility	The ability to access data and know where it is located.
Scalability	The ability to handle growing amounts of work and the ability for the infrastructure to be expanded to accommodate that growth.
Ability to Customize	The ability to tailor the PHR based on specific user & provider wants and needs.
Pricing	Expenses for deployment, maintenance and user subscriptions.
Usage Auditing	The ability to log use pattern data.

2.2. PHR Flexibility

It was imperative that any COTS PHR considered was generic enough to support the self-management of any chronic illness, but could be tailored according to the specific condition(s) of individual patients. This strategy would be most effective for integrating the entirety of a patient's health information as well as streamlining the data entry process for users. That is, users would likely be deterred from using different PHRs for their different conditions. Thus, a common foundation of tools for all patients (healthy and ill) with complementary modules for specific illnesses would be the ideal solution. This would bolster the appeal for a variety of chronic illness special interest groups. Additionally, the core components could be used by all health consumers not only those affected by chronic illness.

2.3. Procurement Commitment

Before committing to purchase a PHR, the dispensing agency was encouraged and advised to negotiate a trial period (e.g., 6 months). This trial period allows for the PHR to be evaluated with usability methods and tested for interoperability with other health information systems (e.g., e-prescriptions, test results, electronic health records). This would involve testing with a wide range of participants from the public. Given that usability is a key factor in system adoption and interoperability plays a fundamental role in the usefulness of the PHR, it is imperative that the selected PHR demonstrate its capabilities in these areas before a purchase commitment has been made. This is following a framework described by Kushniruk and colleagues for reducing risk of system failure and adoption by carrying out usability testing of candidate systems prior to final purchase of regional health IT systems [5].This trial period also provides an opportunity for users to provide feedback on their likelihood of system adoption and the advantages and disadvantages of the product itself.

3. Discussion

There are a variety of criteria to consider before purchasing a PHR solution. Furthermore, these criteria may be prioritized differently depending from the perspective taken (i.e., user vs. dispensing agency). It is also important to weigh the advantages and disadvantages of selecting a COTS PHR versus a custom development solution. Moreover, it is imperative that as many groups as possible collaborate to deploy a common PHR foundation to improve the likelihood of adoption.

One limitation of this study is that no users were included team as it was still the preliminary phase of the project. However, it is encouraged that patients are involved in the evaluation of a shortlist of candidates. Furthermore, their opinions are perhaps among the most important of all stakeholders, given that patients will ultimately decide whether to adopt or reject the selected system.

Learning from the challenges associated with EHR adoption, ideally, the government should dispense a single, standardized PHR. Although a national initiative would benefit the maximum number of Canadians, a provincial strategy is more realistic, given the healthcare infrastructure. This approach would likely result in a variety of implementation, financial and user benefits. For example, the challenges associated with interoperability would be mitigated because all supporting systems

would be required to interface with a single system. Given that the core functionality was developed, the costs of creating specialized modules would be minimized. Additionally, this strategy would ensure the dispensing agency had the most bargaining power regardless of whether a COTS or custom developed PHR solution was selected. A provincial PHR is also likely to gain favour from Canadians who are waiting for a PHR endorsed and dispensed by the government. Earlier this year, the Province of Alberta adopted this provincial PHR strategy and it will be interesting to watch the progress and outcomes of this approach [10]. Until all of the provinces have adopted a PHR solution approach, individual chronic disease groups are likely to continue pursuing PHRs procurement on their own.

Although the demands of chronic illness care are likely to motivate the deployment and adoption of PHRs, people without chronic illnesses could also benefit from their use. Furthermore, PHRs becoming more common and users demanding digitized information may be the driving force behind ubiquitous EHR adoption. However, in order to achieve these benefits, it is imperative that new and improved procurement methods are adopted to ensure the selected systems best match the needs of their users and purchasers.

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An Initial, Qualitative Investigation of Patient-Centered Education in Dentistry

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Abstract. Patient education plays an important role in the delivery of dental care. Current evidence suggests that the emergence of the Internet and other electronic resources are significantly influencing how patients learn about their healthcare. We conducted a qualitative inquiry using a combination of interviews with patients and clinicians, and direct observation of patient education episodes, to begin identifying requirements for customized, patient-centered approaches to education at the point of care. Most patients in our study felt comfortable with the amount and method of education during the dental visit, but 38% sought additional information on the Internet. Dentists and their team members provided patient education mostly verbally, supported by media such as radiographs, images and models. Electronic means, especially the Internet, were little used. Patient education occupied a significant portion of the time of initial comprehensive examination (29%) and routine (7%) dental visits. A deeper understanding of patient knowledge deficits and information needs will be needed to design effective educational interventions. Patient education should be meaningfully integrated into the workflow shared by dentists, their team members and patients, in order to maximize its outcomes.

Keywords. general practice, dental; patient education; Internet; dental informatics

Introduction

Patient education plays a significant role in dentistry, primarily with respect to oral hygiene, but also diagnostic and therapeutic aspects of care. Research in medicine has found that many patients desire considerable information about their condition [1], and that those who have a deep understanding of their diagnosis, treatment and recovery are better equipped to cope with their illness than those who do not [2]. Explanation and clarification of problems and their treatment have been found to contribute importantly to patient perceptions of quality in primary care [3] and outcomes [4]. Some argue that the same is true for dental patients and their oral health [5, 6].

According to Shouten [1], patients desire detailed information on dental topics, but are not always satisfied with the amount of information they receive from their dentist.

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Historically, dental team members, primarily dental hygienists, have educated patients about their care during the dental visit [7-10]. However, patients now have access to a huge body of information on general and oral health through the Internet [11].

Information on how dental patients use the Internet as a tool to inform themselves about oral health is limited [5]. In a study in the UK [5], 54.6% of the 269 patients surveyed in two student dental hygiene clinics had accessed the Internet for health information. Forty percent of them had retrieved information on general health, while only 5.4% had done so for dental health. In a study of 500 dental patients in Ireland [11], 177 (34.5%) had either researched their presenting dental/oral condition or had had a family or friend do so on their behalf. A study conducted in two Chinese University Hospitals in 2009 found that 45% of the 128 patients surveyed had searched for information online before receiving dental care [12]. While patient access to dental information is not uncontroversial among dentists [13], it is likely that patient access to and interest in healthcare information on the Internet will only grow [13,14].

The literature on how dental team members educate patients is also scant. A study of 222 dental hygienists found that participants educated patients individually much more frequently than in groups (99% v. 16%) [7]. Techniques such as talking (99%), demonstrating (98%) and advising (97%) were more commonly used than computers (17%) and videos (4%). Patient education was usually provided at the same time as treatment (93%), usually in time increments of up to 10 min (58%). Among dental schools in the US,, the majority (57%) present treatment plans to the patient using visual aids to illustrate or demonstrate procedures and techniques [15]. Supporting information and visual aids presented to the patients most often included a written plan (43%), a discussion of the treatment options (38%) and a written narrative (30%). Videos, photographs and graphs were used in between 17% and 28% of the schools [15].

To better understand patient education workflows, we conducted a qualitative inquiry using a combination of interviews with patients and clinicians, and direct observation of patient education episodes. Insights gained from this study will shed light on the requirements for developing customized, patient-centered approaches to education at the point of care.

1. Methods

We asked dentists and dental hygienists nine questions on patient education and two questions about their dental education (when and where they were trained). Patient education questions focused on locus of responsibility, teaching materials used, and whether respondents encouraged patients to research information themselves. Patient interviews consisted of 16 questions, of which 11 focused on patient care and education, and five on demographics.

In the second study, we observed comprehensive oral examinations. Trained observers captured actors (i.e. dentist, hygienist or assistant), education activities, and timestamps. Observations were coded by closed-choice options in a custom database application programmed in MS Access (Microsoft Inc., Redmond, WA). Raters performed pilot observations to ensure the validity and consistency of observations.

We interviewed participants onsite in a convenience sample of private practices in Pittsburgh and at the University of Pittsburgh School of Dental Medicine (Table 1).

Interviews with private practices included dentists, hygienists/assistants, and patients, with patient interviews conducted either in the waiting room or during downtime in patients' treatment. Dental clinic interviews involved only dentists and patients.

For the observational study, we observed dentists, hygienists and assistants in eight private practices during comprehensive oral examination and routine dental visits. We chose our samples with the intent to maximize the variety of observations related to patient education. We summarized key quantitative data using descriptive statistics and described qualitative data in a narrative review. The protocols for the two studies were classified as exempt (interview, protocol #PRO10060494) and expedited (observational study, protocol #PRO07090332) by the University of Pittsburgh Institutional Review Board.

Table 1. Description of interview and observational study populations.

Study	Setting	Population	Number	Comments
Semi-structured interview	Private practice	Dentists	3	Three solo general dental
		Dental hygienists/assistants	5	All staff available the practices
		Patients	5	Five patients from one practice
	Dental school	Dentists	3	Team leaders for general
		Patients	19	Patients in the pre-doctoral general dental
Observational study	Private practice	Dentists, hygienists, assistants	8 practices (8 dentists, 2 hygienists, 8 assistants)	37 comprehensive oral examination visits

2. Results

Of the 24 patients interviewed, 11 were in active dental treatment. Twenty-three had experienced dental care beyond routine cleaning and 13 had fillings, extractions, crowns, bridges and/or root canals. Table 2 provides an overview of patients' Internet use to retrieve dental information. Most respondents (83%) used the Internet; 38% used it to retrieve dental information. Lower levels of education appeared to be associated with lower use of Internet information. Six patients mentioned specific Websites for health information (WebMD, Wikipedia, doctors' sites, medical blogs and Google).

Twenty-one patients indicated that their dentist/dental team member educated them through verbal explanation about their conditions and/or treatment. Two patients had not received any explanations and one made decisions on his own. Education approaches included the exclusive use of radiographs (n=8), visuals (n=3) and combinations of multiple approaches (n=4). Twenty patients indicated that they understood the explanations, three asked questions if they did not, and one sometimes did not understand. In deciding on dental treatment, important factors included oral health (n=13), cost (n=4), the doctor's recommendation (n=2) and other reasons (n=5). Practitioner interviews revealed a strong preference for a team approach to patient education. Traditional patient education materials included pamphlets, brochures and paper handouts, TV and videos, and study models. Patient specific computer-based methods comprised digital radiographs, computed tomography scans, intraoral images and patient portals. General computer-based means included patient education software

and practice Websites. Most dental team members encouraged patients to do their own research. One dentist was not opposed to recommending online research, but did not routinely do it, and another one did not do so due to inaccurate information on the Internet. When asked about the factors that they thought patients used to decide on treatment, respondents answered (multiple responses possible): cost (n=5), oral health (n=2), dentist's recommendation (n=1) and other factors (n=2).

All observed patient appointments incorporated patient education, which was more extensive during initial visits (29 % of the appointment, avg. segment length 13 minutes) than routine visits (7% of the appointment, avg. segment length 3 minutes). Most offices educated as a team, with dentists providing 64% of total patient education time and auxiliary personnel the remaining 36%.

Table 2. Patient Internet use to retrieve healthcare information (Internet use categories are mutually exclusive. (Errors due to rounding)

			Internet use to retrieve healthcare information					
					Internet use			
	Total		**No computer**		**Non-dental information**		**Dental information**	
Gender	**#**	**%**	**#**	**%**	**#**	**%**	**#**	**%**
Male	**10**	**42**	0	0	5	50	5	50
Female	**14**	**58**	4	29	6	43	4	29
Education								
Up to high school	**8**	**33**	2	25	4	50	2	25
Some college and above	**15**	**63**	2	13	6	40	7	47

3. Discussion

We used a multi-method approach to gather initial qualitative and quantitative data about patient education in general dentistry at the point of care. From our observations, it was clear that patient education methods about dental conditions vary. Education using traditional methods and media, such as verbal explanations using radiographs, coexists with contemporary digital approaches, such as patient education software, patient portals and patient access to information on the Internet.

Patient participants appeared to feel sufficiently informed as a result of patient education interventions. Only four of 24 respondents appeared to have had questions occasionally. However, the relatively widespread use of the Internet for looking up dental information (38%) seems to indicate that occasional information needs existed, corresponding with findings about patients' use of the Internet to retrieve dental information [11,12] and their interest in the Internet as a source of oral health education material [5]. Most dental team members encouraged patients to do their own research on the Internet, which contrasts with Chestnutt's 2006 study, in which three quarters of respondents stated that they never referred patients to such sources [13].

The mix of different media and methods, such as verbal explanations, images, models and diagrams that dental professionals used for education appears to mesh well with respondents' preferred learning modes. However, an open question is whether dental professionals assess how patients prefer to learn and tailor educational interventions accordingly. In addition, few studies [16,17] seem to have been

conducted about learning outcomes of patient education interventions in dentistry.

Our study has two main limitations. First, it was conducted with convenience samples of patients, dentist and dental team members in the Pittsburgh area. Results therefore might not generalize. Second, we did not use validated instruments. However, the face validity of our observational study approach was likely good since it was built on a number of similar studies.

Our study raises an important question regarding whether and how patient education in dentistry should change and/or evolve in light of the new possibilities of information access and presentation that the digital era offers. A deeper understanding of patient knowledge deficits and information needs will be needed to design effective educational interventions. In addition, patient education should be meaningfully integrated into the workflow shared by dentists, their team members and patients, in order to maximize its outcomes.

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Tailored Care Management with Patient-Centered Web-Based Portal in Primary Health Care: Sustaining a Relational Context

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Abstract. While many innovative information and communication technologies have been offered as solutions to primary care management challenges, few have been shown to be effective and or sustainable over time. Information technology approaches have been narrow in focus, relying on designs that enhance usability, interoperability and adaptability by delimiting the traits, attributes, and characteristics of individual communication processes. It is increasingly understood in primary health care settings that relational communication continuity between the patient and the health care team is essential for optimizing co-determined treatments, interventions, and self-management strategies. Successful utilization of a patient-centered web-based portal must account for essential proximity of the relational aspect of care between the patient and the immediate health care team.

Keywords. informatics in primary care, relational care, tailored health communications, patient-centered web-based portal

Introduction

Health information is often conceptualized as some form of generic communication to the patient (such as brochures or public service announcements) that is expected to elicit a desired behavior change. This idea draws on advertisement practices, with the assumption that the more exposure to the health message, the more likely the desired outcomes will be elicited. Unfortunately, this model of patient education, while indicative of most current primary health care practices, falls short of the state of the science of communication and behavioral theory and research. Based on current literature one can theorize that there are prerequisites to effective health communication and optimal behavioral change: 1) establishing and maintaining a relational context between the patient and the primary health care team; 2) tailoring health communication and achievable care management strategies; and 3) enacting and coordinating information and communication technologies as facilitative tools. The purpose of this paper is to discuss relational contexts as an antecedent to effective tailored health communications, and optimal patient-centered web-based portal

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sustainability. The premise of a relational context is central to optimizing an integrated schema for effective health communications and enhanced health outcomes.

1. Relational Context

Relational engagement embraces an ethic of shared power through cooperative interchanges by patients and members of the primary health care team that result in creation of proactive strategies for the purpose of optimizing health well being [1-4]. From the stand point of the literature in the last decade, the objectified patient who obediently follows the prescriptive directions of the physician within the biopsychosocial context has all but disappeared. Unfortunately, most primary health care practices have not made this transition, nor have the professional medical societies that represent physicians. In contrast, relational practice represents the underlying metapardigm of the discipline of nursing since Nightingale [1-2, 5-9]. Recently, multiple disciplines have discovered the benefit of relational practice and are engaged in collaborative, interdisciplinary research, policy, and clinical guideline development that highlight this awareness [4, 10-11].

The World Health Organization reaffirmed a commitment to relational approaches to care in their recent documents outlining future world health needs [12-14] by focusing on the increasing burden of chronic illness and the need for partnerships in care spanning self-management to the community. From the stand point of quality, a recent publication by the Institute of Medicine (IOM) in the United States reaffirms and recommits to the central focus of relational approaches to patients [10]. Central tenants to the IOMs recommendation regarding relational care include the following: an approach to patient-centered care that is respectful of and responsive to individual patient preferences, needs, and values, and ensures that patient values guide all clinical decisions; care based on continuous healing relationships; care customized according to patient needs and values; the patient is the source of control; knowledge that is shared and with pertinent information flowing freely; decision making informed by evidence; patient needs that are anticipated; and transparency of the care process [10]. In Canada, Haggerty et al., [11] reaffirmed the definition of primary health care with a team of primary care experts as a central premise of "relational continuity, coordination-continuity, family centeredness, advocacy, cultural sensitivity, clinical information management, quality improvement process, interpersonal communication, community orientation, comprehensiveness, multidisciplinary team, responsiveness, and integration" [11[p. 336]]. These operational definitions are grounded in a relational context with patients. Likewise, health literacy based on a relational context assumes a dialogue for the purpose of integrating knowledge into mutually derived approaches for potential treatments, interventions, or self-management [4, 9].

2. Tailored Health Communications

Tailored health communications are defined as "any combination of strategies and information intended to reach one specific person, based on characteristics that are unique to that person, related to the outcome of interest, and derived from individual assessment" [15[p. 113]]. Computerized web-based static or non-relational approaches to tailored health communications have had little positive impact when applied in primary

health care settings [16]. Additionally, static tailored health messaging had negative outcomes when initiated in a worksite setting [17]. Tailored health communication derived through interpersonal communications has the potential for high effectiveness when coupled with relational approaches. In a recent meta-analysis, Wanyonyi, Themessl-Huber, Humphris and Freeman reported that "a significant and positive effective of face-to-face tailored health messaging upon participants behaviors" [18]. For primary health care practice, relational tailored health communications are understood to be most appropriate when accounting for communication reception and acceptance coupled with motivational behavioral change pathways [19-20].

3. Patient–Centered Web-Based Portal

Clinical information systems are those dynamic repositories of information that are created, stored, collated, and protected for the purpose of creating historical records of patient encounters. In the 21st Century these clinical information systems are evolving from static paper-based structures to electronic databases where records can be securely produced, archived, shared, evaluated, and coordinated via complex electronic input, throughput and output technologies. These health informatics technologies have created an opportunity for expanding capabilities for the delivery of primary health care.

There are four primary interconnected platforms that frame clinical information systems at the primary health care level. Presented here by reducing level of magnitude, they are Electronic Health Record (EHR), Electronic Medical Record (EMR), Personal Health Record (PHR), and Web-Based Portals (WBP). The EHR is a computer-based collection of health information that has been gathered by and is managed by an enterprise, typically a physician or hospital. EMR is a computerized platform for managing medical information collected by a hospital or physician practice and is typically understood as less in scope and functionality than an EHR. EMRs are transitioning into EHRs as sophistication requirements increase over time. PHRs are person-centered systems designed to track and support health activities across one's entire life experience, not limited to a single organization or provider. WBPs are static or dynamic web portals that house secure point-in-time health information for the purpose of education, communication, assessment, or management related to health or illness conditions. These WBPs are interconnected to EHRs, and PHRs simultaneously or separately. Following is a description of WBP implementation for primary health care practice.

Within a context of patient centered design, primary health care practices establish scalable EHR and a secure clinic practice WBP for creating expedient communication between health care providers and patients regarding tailored health/illness management strategies. WBPs adjacent to EHRs are desirable because of their flexibility in communication, scalability for PHRs, as well as fire-wall security and integrity protection of EHR content by designing customized specific interfaces.

Not only can patients access the practice web-based portal and log-on to secure modules for access to standardized screening tools, they may also free-text symptoms or concerns such as medication issues or sub-optimal treatment experiences directly to the health care team for immediate action. These WBP communications are routed to the practice EHR and imported to cue for action in the form of a pop-up notice for the case manager and or the provider of record. An assessment and action is required by a member of the health care team in response to the patient inquiry. Immediacy and

safety is enhanced by designing the pop-up to remain on the EHR screen until action is taken. A tailored action plan response by a member of the health care team is forwarded back to the patient at the web-based portal address. A text/email is automatically forwarded to the patient for notification of a pending action plan. Additionally, the action plan is routed to the patient's EHR permanent record. A notice is forwarded to the initiator of the action plan as soon as it is opened by the patient in the web-based portal. If the action plan includes clinical follow-up it is coordinated through the web-based portal with the office practice via electronic routing. This design allows for a range of complexity to be managed appropriately, enhancing clinical outcome and quality. Accommodating disadvantaged patients by developing alternative communication pathways is mandatory. For example, use of telephone, proxy care respondents, such as parents, children, siblings, and designated care givers are acceptable alternatives.

Health information technology has increasingly become more accessible to the health care team and now is one of the most important interfaces for communicating health information. Second only to interpersonal networks, the internet is the primary source for health information for the health conscious consumer with print media, television, and radio becoming more passive sources [21].

Targeted designs for web-based portals is extensive with deployment in areas of provider-patient relationship [22], health coaching for primary care patients with chronic conditions [23], as an adjunct to personal health records [24], screening for chronic conditions [25], promoting patient-centered preventive care [26], patient satisfaction and the quality of office visits [27], and disseminating of health reminders [28].

In a systematic review of web-based portals to improve diabetes outcomes, [29] it was reported that usability studies have found that many patients are open to the use of technology in their disease management, regardless of age. However, greater attempts to assist disadvantaged, older, or less computer-literate populations must be designed into any web-based portal initiative. While disadvantaged populations have shown less inclination to enroll in patient portals programs, once enrolled, participation was no different than all other participants [30]. Ancker, Barrón, Rockoff, Hauser, Pichardo, Szerencsy & Calman [31] reported that during the first two years of a patient web-based portal deployment, adoption rates for low-income populations with chronic disease experience only low rates of disparity-related participation. It is essential to recognize that web-based portal technologies focused on wellness/illness cannot be dismissed because of disparate or disadvantaged circumstances for any population. A usability strategy that focuses on an emphasis on deploying solution to include all segments of the population must be attained that reinforces and sustains the relational context.

Currently, the majority of designs for patient web-based portals can be classified as static, offering information, education, questionnaires, or providing contact conduits to the health care team. A more dynamic method is describable and would include an approach that is more dialogical, relationship-focused for the patient with the health care team. Such a system may improve both acute and chronic care outcomes.

Report of a recent random control trial of a dynamic WBP for chronic asthma control is an example of the use of a nurse case manager for patient interaction and management [32]. However, on careful examination this model design contains too much content with excessive demands on the patient to complete daily 'check in' for metric reporting, education, status assessment, hence usability will diminish long term

sustainability. This model positions the nurse case manager adjacent to the point of care instead of being integrated within the primary health care team. Langstrup [33] reported on an asthma monitoring web-based portal implementation that failed integration and long term sustainability wherein technology did not become a durable portion of the primary health care practice. What was cogent in the Langstrup [33] experience was that the primary care providers were distant to the project (delegated responsibility) instead of engaged as partners in care with their patients.

4. Conclusion

Based on review of what is known from existing models, the author proposes that by critically analyzing and incorporating experiences from the literature regarding relational contexts, tailored health communications coupled with patient-centered web-based portals present an integrated schema that will enhance effective health communications and optimized health outcomes in primary health care practices in the 21st century.

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The Social Act of Electronic Medication Prescribing

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Abstract. Prescribing medication is embedded in social norms and cultures. In modern Western health care professionals and policy makers have attempted to rationalize medicine by addressing cost-effectiveness of diagnostic and therapeutic treatments and the development of guidelines and protocols based on the outcomes of clinical studies. These notions of cost-effectiveness and evidence-based medicine have also been embedded in technology such as electronic prescribing systems. Such constraining systems may clash with the reality of clinical practice, where formal boundaries of responsibility and authorization are often blurred. Such systems may therefore even impede patient care. Medication is seen as the essence of medical practice. Prescribing is a social act. In a hospital medications may be aimed at treating a patient for a specific condition, in primary care the professional often meets the patient with her or his social and cultural notions of a health problem. The author argues that the design and implementation of electronic prescribing systems should address the social and cultural context of prescribing. Especially in primary care, where health problems are often ill defined and evidence-based medicine guidelines do not always work as intended, studies need to take into account the sociotechnical character of electronic prescribing systems..

Keywords. Electronic prescribing; Medication; Medicine

1. Prescribing Medicines

Prescribing medicine is a social act [1]. Through prescriptions physicians show their patients that they recognize their complaints and are trying to help them. Where medication is seen as the essence of medical practice, prescribing is the main thing expected from a physician. A non-prescribing physician is seen as a contradiction. Prescribing medications represents two sides of the same coin. On the one hand it shows the authority of the physician by being able to solve a problem of the patient, on the other hand the patient demands an instantaneous solution of his complaint. Prescribing a medicine comes to the rescue of offering an immediate therapy, even its efficacy is doubtful. A prescription functions as a legitimation of the patient's sickness. In some cultures a patient never goes home without a prescription, in other both physicians and patients feel restraints [2]. It may explain why medication consumption varies wildly in different Western countries. However, the overall consumption of medications has grown exponentially and has become an important cost factor of health care [3]. Health authorities and administrators have sought to contain the cost growth

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and one attempt was to make physicians aware of the notion of rational prescribing. Not only would doctors prescribe drugs that really would work for a disease, but also they would be encouraged to look at what costs the effect was achieved and whether prescriptions could be filled with cheaper medicines. A similar role was attributed to pharmacists and they were given the right to alter prescriptions to substitute with cheaper ones. Often it would mean that generic drugs would replace brand drugs. Rational prescribing was seen as one of the outcomes of evidence based medicine. Based on the results of clinical trials and meta-studies guidelines and protocols would be established to guide physicians in making diagnoses, selecting the proper course of action and assess treatment outcomes. It would be hoped that doctors would adopt these insights and put them to use in practice. In hospitals the costs of physician prescribing would be borne by the organization. The cost increase prompted one hospital in the early 70s to design and implement an electronic prescribing system for physicians and this new class of information systems became also known as computerized physician order entry (CPOE) systems [4]. Much later focus shifted to patient safety. In his seminal paper in 1994 Lucian Leape wrote that the error rate in the practice of medicine was high and that more than half of them could be attributed to medication errors [5]. Already in the late 90s studies reported a positive effect of CPOE on the decrease of medication errors [6, 7]. The landmark Institute of Medicine studies on human errors in medicine and quality of care advocated the use of electronic prescribing systems in health care [8, 9]. The adoption however has shown to be a very slow process. Aarts and Koppel reported nine years later that in seven Western countries they studied the adoption rate was nowhere higher than 20% of the hospitals[10]. Another study reported that ten years after the publication of the IOM reports efforts to reduce errors in medicine had limited success [11]. There is clearly a gap between the expectations of professional and organizations adopting scientific evidence and technology to improve practice and reality.

2. Electronic Prescribing

Electronic prescribing is a social act. Though electronic information systems are often seen as “neutral” tools to help a job done, they represent in fact social norms embedded in technology. The original Eclipsys system allowed physicians only to pick medicines from an approved hospital formulary. The hospital administrators expected that physicians would only select from this formulary and thus help save medication costs. The hospital did indeed report savings and improved efficiency of nursing documentation [12]. But embedded norms do form a clash with reality. Another norm is the authority to prescribe, which rests with physicians. Only physicians are authorized to enter medication orders. In many hospitals it was (and perhaps still is) practice that nurses in night and weekend shifts could order pain medications to relieve their patients, because of limited availability of physicians. For that purpose nursing stations would have a pile of pre-signed prescription notes that nurses could fill out. Physicians trusted this work practice because they knew that the nurses were knowledgeable and experienced. The advent of CPOE made this way working impossible and put the burden of entering orders completely on physicians. In one instance it caused physicians to protest the increased workload [13]. In other instances, users created workarounds to make their work doable. In a study of the implementation of CPOE in a Dutch hospital Goorman and Berg found how the problem of only

physicians being responsible for medication orders was circumvented in case of emergencies by an 'agent for' device. A nurse could on behalf of a physician enter medication orders, which would be signed off later by the physician [14]. Embedded in CPOE are also guidelines and protocols in the form of decision support. Guidelines and protocols represent proper practice of medicine. A medication order may prompt the physician to look for specific patient data, and not allow completion of an order unless he had acknowledged at least of having seen them. In a number of specialties it might be seen as an annoyance, delaying precious time in patient care, because using specific pieces of patient information might be routine. This is also the case in situations where physicians may receive reminders about drug interactions, when they intend to prescribe additional drugs. Reminders can prevent medication errors, but if appropriate reminders are drowning in a sea of less useful reminders, then the positive effect can be mitigated. The number of ignored reminders runs up to over 90% [15]. Similarly it has been proven very difficult to reduce the number of inappropriate reminders. In the first place doctors among themselves do not agree on which can be turned off [16]. They report that they themselves might know what to do, but that doctors from other specialties or residents would surely need them. In the second place, the technology is still far from perfect. Using medication cases as gold standard, van der Sijs and her colleagues found that CPOE systems would respond differently requiring additional pharmacy review [17]. Implementing CPOE can have unintended consequences as well. During rounding, medication orders are verbally communicated by physicians and sometimes corrected by nurses, who would know about the exact health status of a patient. It was an effective way for nurses to know when administering drugs should be started and a perfect safety net to prevent errors. A CPOE system forces a doctor to look for a computer, often sitting in a separate office, and the doctor would lack interaction with colleagues when entering the order. Koppel and his colleagues identified a number of situations that CPOE would potentially induce new errors [18]. It is clear that electronic prescribing systems are being designed and implemented with embedded intent and purpose. Often, they rather shift workarounds instead of removing them completely. Lacking the interaction with colleagues when entering an order, new workarounds may arise to compensate it, like writing down the order on a piece of paper during rounding and delay entering orders until after rounding. Because of this intertwinement with organizational context and culture, they are in essence sociotechnical systems [19].

3. The Future

In September 2010 the director-general of the Dutch health inspectorate announced that electronic prescribing would become mandatory on January 1, 2012. Most likely, it will be less of a problem in hospitals. Most hospitals in the Netherlands are currently implementing electronic prescribing technologies. The shortage of physicians have led to the introduction of nurse practitioners and physician assistants, who have received prescribing authority, supervised by physicians. In a way the problem of the informal work practice of nurses filling out orders has been removed by reconsidering prescribing authority [20]. Clinical wards are in a way a kind of a micro-cosmos, where professionals influence each other's behaviors. The wide-scale implementation of electronic prescribing will be much more difficult in primary care. More often, patients visit a primary care doctor with vague complaints. In such situations emphasis on

evidence-based medicine in the form of guidelines and protocols is problematic and physicians prescribe medications as a magic wand to address the needs of their patients. A point in case is antibiotics, one of the most successful drugs in medicine. Indiscriminate use to combat infections has caused the emergence of resistant organisms compromising their efficacy. Prescribing antibiotics is nowadays based on practice guidelines and carefully monitored because of increased insensitivity to infectious microorganisms. Yet, even in hospitals non-medical reasons still influence antibiotics prescribing [21]. One need not to be farsighted to see that the problem is much larger in primary care practice, where a physician sees such a diverse patient population of different social and cultural backgrounds. A study of prescribing antibiotics for sore throats in primary care reported that physicians were well aware of the marginal effects but yet often prescribed for good relationships with patients [22]. Most studies of electronic prescribing have been done in a hospital context. Primary care is still largely uncharted territory. Future studies are needed to understand the sociotechnical and cultural character of primary care prescribing using electronic prescribing systems. In a recent paper I described a number of conditions that need to be addressed [23]. They include interoperability allowing electronic prescribing systems to interact with other systems so that patient medication information is more readily available, improving decision support technology, and focus on the continuity of care, in which professionals, organizations and systems are better aligned. But foremost future research needs to focus on the question how the practice and social nature of health care, evidence-based medicine and technology could be better integrated. Bosk et al report in a commentary that giving a 'simple checklist' to professionals as a solution to improve patient safety is based on the mistaken assumption that a technical solution can solve a sociocultural problem [24]. Obliging exchange of patient medication information between primary, secondary and tertiary care is makes sense, but I am not in favor of mandating electronic prescribing so soon. There are a lot of issues in the practice of health care that need to be resolved before it can become meaningful.

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Improving Decision Quality in Healthcare with an Error Prevention Model (EPM)

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Abstract. Human factors involved in decision quality are critical issues in healthcare. In this paper, issues related to the impact of human factors on decision quality in healthcare are considered. Specifically, the focus is on the issue of reducing human error as well as improving decision quality. An Error Prevention Model (EPM) is presented for considering tools and techniques that can be used to analyze complex errors that may be considered latent.

Keywords: Technology-induced Error, Decision Quality, STDC, EPM Model

Introduction

According to an IOM report, somewhere between 44,000 and 98,000 people die in different American hospitals every year because of "errors committed by medical professional" [3]. The errors caused by technology-induced errors (i.e. errors that result from use of health information technology) are related to human factors can come in many forms, such as slips and lapses [2]. Although some active medical errors may be detected, current approaches may not contribute to the problem of dealing with latent errors. Even though work has been done in preventing technology-induced error in healthcare, latent errors are still difficult to prevent due to the complexity of healthcare processes and work activities. Some errors may arise from conscious, preconscious, and unconscious human factors. For the purpose of analysis, errors are conceptualized as an iceberg consisting of both active and latent errors. Active errors are associated with conscious factors, while the latent errors include preconscious and unconscious factors (see Figure 1).

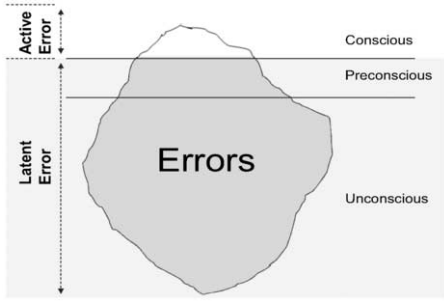

Figure 1. A conceptual diagram of decision errors as an iceberg

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Decision processes can be conceptualized as selection of a right choice from a number of available choices through the iterative STDC (See-Think-Do-Check) decision activities of seeing, thinking, doing, and checking. Each choice represents a decision alternative. In reality, what people see is far more than what people understand; what lies beyond is far more than what people see. In other words, there are a number of barriers in achieving the goal of decision quality in the process of decision making (See figure 2).

Barrier 1: how to identify what we see (i.e., from seeing to thinking)

Barrier 2: how to transform what we think (i.e., from thinking to doing)

Barrier 3: how to evaluate what we do (i.e., from doing to checking)

Barrier 4: how to measure what we check (i.e., from checking to seeing)

Despite the advantages of Clinical Decision Support System (CDSS) in healthcare, there are a number of clinical challenges for CDSS. One of the most critical issues is lack of effective and efficient ways to analyze and predict latent errors caused from human factors. In our work, the roles of CDSS are considered in reducing medical errors involved in decision-making processes. Furthermore, we propose an Error Prevention Model (EPM) to provide potential solutions to avoid preventable adverse events. In next section, some papers to related human errors and decision making are reviewed for their potential to lead to evidence-base evaluation and outcome improvement.

1. Related Work

Provision of safe patient care is a major challenge confronting today's health care system [1]. Well-designed patient safety initiatives based on systematic interventions may produce the best results in enhancing the quality of health care processes [5]. In addition, Berner and Lande [1] summarize current data on the use and impact of clinical decision support systems.

In order to bridge the gap between process and decision modeling, a formalized linkage model has been proposed to facilitate the integration of strategic, decision and process objectives within a single framework [7]. Furthermore, a number of frameworks and models for considering technology-induced error have been compared to show how they are practically employed in the prediction and prevention of such error [2] (see Table 1).

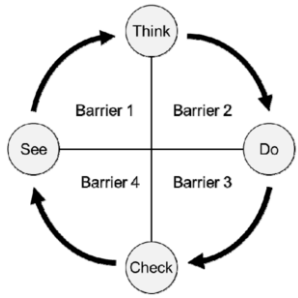

Figure 2. STDC (See-Think-Do-Check) decision process

Table 1. Category and type of error in healthcare (Extracted from [2])

Error inducing category	Error source type
Government Organization	policy, legislation
Model Healthcare Organization	model policies and procedures, model workflows, model terminologies
Vendor Organization	requirements gathering, design, programming, software testing
Local Healthcare Organization	devices, workflow, interface design, local terminologies, policies and procedures, local testing
Individual	training, support

Some evaluation models used in checking human errors are considered. A modeling process that helps decision makers in overcoming these perceptual and cognitive challenges was proposed to improve the decision effectiveness [6]. Elwyn et al. [4] measure outcomes with aggregate ratings for each criterion calculated using medians weighted to compensate for different numbers in stakeholder groups. Criteria were given the highest ratings where evidence existed. In contrast, Scott, Bellala, and Willett measure the rates of convergence of generalization error that can be measured with an upper bound theory quantifying the generalization error of various large margin classifiers [8].

Upon review of the above literatures on human errors in healthcare decision quality, the limitations of human beings are seen as a major factor contributing to this type of error in medical decision processes. Even though much work has been done in preventing decision error in healthcare, latent errors are still difficult to prevent due to the complexity of healthcare processes.

2. Error Prevention Model (EPM)

In this section, an Error Prevention Model (EPM) is proposed to provide potential solutions to avoid preventable adverse events to reduce human errors in the processes of decision making.

There is a need to extend error evaluation frameworks by using V-model to ensure their effectiveness, efficiency and safety, then the standardized methods or guidelines could be developed based on best practices from a health information industry perspective [2]. By extending the framework for diagnosing technology-induced errors in healthcare from Borycki et al [2], a process is proposed to reduce errors and to improve decision quality as well in the current work (see Figure 3).

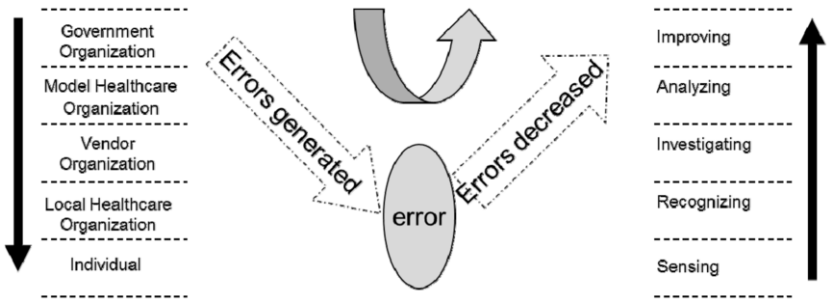

Figure 3. An extension framework to improve the decision quality by reducing the errors

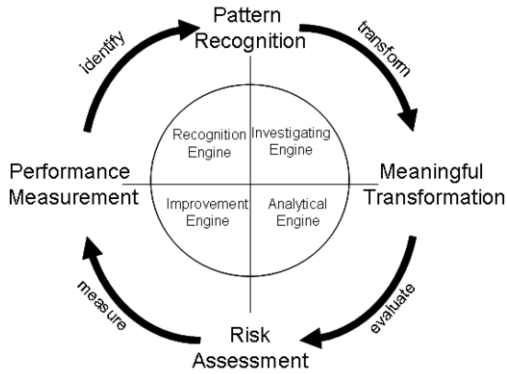

Figure 4. Error Prevention Model (EPM)

As stated in the section of introduction, decision processes can be conceptualized as selecting a right choice from a number of available choices through the iterative STDC (See-Think-Do-Check) decision activities. In the above framework, the four barriers in the STDC process can be conceptualized and translated into the EPM by combining them with four error preventive engines, i.e., recognition, investigating, analytical, and improvement engines to which we can incorporate a number of efficient and effective mathematical analytical tools (see Figure 4).

1. Recognition Engine to overcome the barrier 1 in STDC
2. Investigating Engine to overcome the barrier 2 in STDC
3. Analytical Engine to overcome the barrier 3 in STDC
4. Improvement Engine to overcome the barrier4 in STDC

3. EPM Applications: Improving Decision Quality in Healthcare

In complex systems, when one component of a system which serves multiple functions fails, all of the dependent functions may fail as well. As the dependency on technology in complex systems increases and systems become more tightly coupled in time and sequence, so does the likelihood of accidents [3]. By using this EPM model, error prevention can be integrated in one systematic approach to deal with the human errors when technology changes human tasks, shifts workloads, and tends to reduce or eliminate human decision making.

This model provides guidelines for the development of cognitive and systematic interventions to decrease medical errors to not only identify errors, but also transform problems into a warning system. In table 2, some available methods, tools and techniques (T&T) can be embedded within this model for some applications.

Discussion

In this paper, frameworks for considering error prevention were considered. Some papers related to human errors and decision making were reviewed for their relevance to error prevention and decision outcome improvement. Upon review of literature on human errors in healthcare decision quality, the limitations of human beings are seen as

a major factor contributing to this type of error in medical decision processes. Even though considerable work has been done in preventing decision error in healthcare, latent errors are still difficult to prevent due to the complexity of healthcare systems.

An Error Prevention Model (EPM) was proposed to provide potential solutions to avoid preventable adverse events for CDSS to reduce human errors in the process of decision making. Error lifecycle modeling could assist a healthcare authority to achieve strategic objectives by providing methodologies and tools to develop integrated healthcare process models, however further work is needed on how to identify the methods and analytic tools to fit the specific error pattern.

Such a model has potential application to have a hybrid decision support framework and EPM model built on best practice in healthcare. Validating this model empirically will be next step, and this will involve performing systematic experimental studies. Further study is needed to develop and test error mechanisms and the error prevention engines proposed in this paper.

Table 2. EPM (Error Prevention Model) and its interpretation

Phase	Name	Purpose	Method	Tools and Techniques (T&T)
I	Recognition Engine	Pattern Recognition	Identifying Method	Delphi Techniques, Linear Programming, Goal Programming, Network Models, Decision Analysis, Graph Theory, Statistics Tools
II	Investigating Engine	Meaningful Transformation	Transforming Method	AHP (Analytic Hierarchy Process) Technique, Forecasting and Prediction, Time Series, Moving Average, Monte Carlo Simulation
III	Analytical Engine	Risk Assessment	Evaluating Method	Fuzzy theory, Sensitivity Analysis, Network Models, Decision Analysis, Queuing Analysis, Markov Analysis, Statistical Analysis
IV	Improvement Engine	Performance Measurement	Measuring Method	Systems Dynamics and Simulation, Decision Tree, Bayesian Decision, Multi-Criteria Decision Making

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Software as a Medical Device: Regulatory Critical Issues

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Abstract. The revised Medical Device Directive has been adopted by the EU in 2010. A major change is that software for certain purposes is now considered a medical device. This entails that a new view needs to be developed on the design, development, evaluation and post-market surveillance of medical software that meets the definition of a medical device. This paper identifies some issues at stake and discusses them.

Keywords. medical device, patient safety, risk management, software, human engineering

Introduction

In 2010 the EU adopted a revised Medical Device Directive (MDD) [1]. A rather small change in the text – the insertion of the word "software" in the definition of a medical device – may have significant consequences for the health IT community. Now some standalone software are considered Medical Device (MD): a MD is "*any instrument, apparatus, appliance, software, material or other article, whether used alone or in combination, including software intended by its manufacturer to be used specifically for diagnostic and/or therapeutic purposes and necessary for its proper application*". Such software are subject to the same regulation as MDs: to introduce them on the market, it is necessary to demonstrate their safety and efficacy. The manufacturer must carry out a conformity assessment, set up a technical file and sign a European declaration of conformity. The MDD explicitly mentions the role of evaluation (technical, clinical and usability evaluations) for proving that the device is safe and meets the stated objectives.

Since its adoption, the new definition raised many questions and has been discussed in various contexts. The aim of this paper is to explore some consequences of the revised MDD on design, development, evaluation and post-deployment of medical software and to discuss the challenges for the health IT community. A brief case study

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will be presented to illustrate the purpose.

1. Difficulty to Qualify Standalone Software as MD

Most of the discussions about the MDD focused on which software meets the definition for a MD and which software does not. According to IEC 62304 [2], MD software is "*a software system that has been developed for the purpose of being incorporated into the medical device being developed or that is intended for use as a medical device in its own right*". Parallel to this definition, the manufacturer is anyway the one determining if his software is or not a MD depending on the specification of its intended use.

But, the further specification that "*software for general purposes when used in a healthcare setting is not a medical device*" has introduced a certain level of ambiguity on the interpretation of software to be classified as MD, especially when standalone and/or software modules are used for the transmission and storage of patient data for medical purposes [3]. For illustration, Electronic Health Records (EHR) are considered an electronic view of the paper file that stores data and documents on a certain patient. Given that some modules of EHR systems are the main sources for clinicians to make diagnosis and establish patient treatment, they could be considered as MD software. They should also follow the rules applied to MDs and have to be evaluated considering the risk posed to patients and users. However, the European (and Canadian) Directive tends to exclude EHR from the definition of MD software. Conversely, the US regulation diffuses a detailed list of MDs and seems to suggest that EHR are MD software. At first glance, the guidance document to qualify software as MD [4] provides clarity, but with a closer look it can become a battlefield of interpretations. In any case, in the end, the manufacturer is the one choosing. It is left to him to argue whether his software is a MD or not. It is also left to him to draw the boundaries and to argue that some modules are no MDs and others are.

2. Fear From Manufacturers that Regulation Stifle Innovation

The major requirement of the MDD is that MDs should be designed and manufactured so that they will not compromise the safety of patients and users of the device. This can be considered the first challenge for the developers of medical software. The MDD states that a device should be designed so that it adheres to patient safety principles and that state of the art methods are used. Currently, such a systematic patient safety based design is not common practice and state of the art methods are not articulated. The question arises whether the ISO standards should be considered as state of the art or whether additional research based recommendations are needed [5]. Some initiatives tend to provide this kind of supports such as the Standards Australia who published a handbook with requirements for the presentation of health data [6]. The Microsoft and the National Health Service have also developed guidelines for a common user interface for electronic patient record systems [7]. But these initiatives are perceived by manufacturers as "killers" of innovation because they would lead to the standardization of the design.

Moreover, manufacturers are supposed to publish sufficient information for an objective analysis about the trade-offs between safety benefits and harms of their MD. But manufacturers consider as confidential the knowledge about the design of their

MD, especially drawbacks and glitches. Not sharing the software problems is an industry implicit norm to keep competitors at bay. Manufacturers feel crashed with this "aggressive government regulations of health IT" [8] and constantly claim that regulations will cause an exodus of IT manufacturers from the field. In honesty, one can acknowledge that there is a high number of regulation requirements usually associated with onerous conformity assessment procedures.

3. Usability Requirement: Methodological Challenges

There is also the important question of whether software regulation is even feasible. Apart from evaluation, the MDD mentions explicitly the ergonomic factors that should be considered and integrated in the design and development cycle following a standard user-centred approach. The aim is to secure patient safety (as well as the safety of the users of the device) by preventing usage errors. But such approaches are still not universally applied in the development of medical software and it is an arduous challenge to overcome.

First of all, many methodological issues are raised by the required conformity assessment procedure. On the one hand, manufacturers should use published data on other devices that are sufficiently similar to the device at stake. But it is very difficult to see this applied to medical software. Let's take the example of Computerized Physician Order Entry (CPOE). Are different CPOE sufficiently alike that studies of benefits and potential harm can serve as proof that a particular CPOE is safe? On the other hand, software implementation is massively complex. It may imply many users with different goals and may lead to resistance, work processes reorganizations and/or frustration. It is difficult to predict all the scenarios in which software failures could result in patient harm and liability [9]. Finally, the medical specificities often request specific configurations and customizations. Medical rules and order sets, for instance, are almost always locally developed and extensively modified. These adaptations may improve the fit between software and the work processes and enhance patient safety. But, even an "innocent" modification may have negative repercussions on the use of the software. How to track and control all these post-hoc changes? Does one need to prove that the order sets are safe? And what if changes are made over time?

To conclude on usability methodological issues, the standard proving conformity with the ergonomic Essential Requirement [10] raises various problems and needs to be improved in its current version. It is supposed to guide manufacturers for the usability engineering process but it is almost impossible to understand and apply for non-usability experts. The major risk is that manufacturers interpret the standard in a wrong way. The usability process is a subpart of the risk management process (risk analysis focused on errors of use) that manufacturers often perfectly handle. They are also persuaded to have all the necessary information to document the usability file. But they often identify the risks related to technical problems of the MD and not the risks of errors of use.

4. A Brief CaseSstudy: A Mobile Application for Diabetics

A Small & Medium-sized Enterprise (SME) has designed an innovative mobile application for diabetic patients with insulin therapy. A Smartphone app helps patients

to manage their insulin treatment determining the right dose of insulin by analyzing ongoing treatments, glycemic index goals, previous and current days' results, and personal variables. A telecare platform enables physicians and nurses in the telemonitoring to support patients using physician-approved protocols. Usability specialists have accompanied the company in the validation phase of the usability process (*i.e.* evaluation of the achievement of the safety criteria for usability) and the documentation of the usability file, subpart of the technical file for CE marking. The usability study in still in progress, only partial results are presented in the paper.

4.1. Global Approach of the Manufacturer

The demonstration of the safety and efficacy of their product was a lengthy and onerous process for the company. But, the revised regulation brought the company a potential big benefit. CE marking allows the introduction on the market. The further step with additional assessments may allow their software to be registered in the list of products and services qualifying for reimbursement (LPPR) to be reimbursed by the National Health Insurance. The inclusion would give a competitive advantage compared to the others editors of this kind of software. Aware of this, the company had approached a large pharmaceutical manufacturer and a research team on diabetes to create a consortium enabling to face all the challenges to attain CE marking, and the reimbursement of their software MD.

First, a clinical study was conducted to show that the tool significantly improves metabolic control and effectively helps patients manage their care and maintain their desired lifestyle. Significant improvement in glycated hemoglobin levels was achieved in six months using the app. A second clinical study was planned to confirm these results and measure the medico-economic impact of the app on large-scale care management. The usability intervention was decided by the in-house person in charge of the regulatory affairs, because he realized that the validation phase for usability needed to be performed by usability specialists.

4.2. The Definition of the Medical Software

As it suited the manufacturer that his app was a MD, the MEDDEV guiding the qualification of standalone software [4] was interpreted in this way: the app (i) was a computer program, (ii) performing actions on data different form storage, archival, lossless compression, communication or simple search, (iii) its actions were for the benefit of individual patients, and (iv) its actions were for monitoring and treatment. The precise MD boundary raised different points of view. For the manufacturer, the MD was only the standalone software enabling the patient to manage his insulin treatment in his Smartphone. As the interface between the app and the telecare platform was not yet completely finalized, the manufacturer preferred that the usability evaluation focused on the app only. But for usability specialists, it was not acceptable in terms of patient safety: the app cannot be used by the patient safely without the telecare platform used by professionals to manage the monitoring. Professionals were mandatory to help patients in their decisions to adapt or not their treatment regarding the app suggestions. The software MD was also defined as the app integrated in the Smartphone and linked to the telecare platform to support interactions between professionals and patients.

4.3. The Usability Engineering Process

A standard user-centred approach was performed: some interviews with patients and professionals, a literature review of incidents related to errors of use reported with this type of apps, a usability inspection and usability tests. The results show that while the manufacturer was convinced he had identified and documented all risks related to the software MD, risks of wrong usage were obviously missing. Due to superficial usability problems, the main risk for patients is that they register wrong data without realizing. Another problem more related to a "loss of opportunity" is the feeling for patients of not being followed by a real professional (because the interface with professionals was not yet finalized). Several patients stressed the importance of not feeling isolated but feeling "*there is someone on the other side, a real person*".

5. Discussion - Conclusion

This study shows that cooperation with manufacturers within the regulation procedures is possible, provided that (i) there is a benefit to the manufacturer and (ii) for "simple" software MDs. The manufacturer here has a particular interest in following correctly all the procedures to be included in the LPPR. His software MD is not a complex one. It remains today a real challenge to test systems as they are implemented in highly networked and interfaced systems. Concerning the qualification of software as MD, the manufacturer is the one deciding regarding his interests. But it is also to market actors to require for instance that software has a CE marking to be sure that it was developed according to certain standard. One could imagine that hospitals, for instance, may buy only software MD with CE marking to reduce the risk of compromised patient safety. Another major challenge lies in maintaining innovation during the implementation of regulations. We have to think about a potential set of recommendations for how regulation could be implemented with minimal impact on innovation. Future innovations should not be stifled due to poorly thought out safety regulations.

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Nursing Informatics

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Developing National Level Informatics Competencies for Undergraduate Nurses: Methodological Approaches from Australia and Canada

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Abstract. Health information systems are being implemented in countries by governments and regional health authorities in an effort to modernize healthcare. With these changes, there has emerged a demand by healthcare organizations for nurses graduating from college and university programs to have acquired nursing informatics competencies that would allow them to work in clinical practice settings (e.g. hospitals, clinics, home care etc). In this paper we examine the methods employed by two different countries in developing national level nursing informatics competencies expected of undergraduate nurses prior to graduation (i.e. Australia, Canada). This work contributes to the literature by describing the science and methods of nursing informatics competency development at a national level.

Keywords. nursing informatics, health informatics, education, competencies, methods

Introduction

Internationally, we have seen a change in healthcare delivery with the introduction of health information systems (HIS) such as electronic patient records (EPRs), electronic medical records (EMRs) and electronic health records (EHRs). For example, EPRs are being implemented in acute care settings in order to streamline health care processes, improve the quality of healthcare and reduce the number of medical errors that arise during health care delivery. In response to this modernization of health care, nurses are being asked to use HIS in acute care, home care, long term care, and community settings [1]. With these changes there has developed an increased demand for nurses graduating from college and university undergraduate programs to have already acquired competencies associated with the use of HIS and other technologies before completing their program of study [1, 2]. Employers (e.g. regional health authorities) are placing demands on university and college schools of nursing to produce graduates who are able to use these technologies during patient care [2].

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There are few opportunities for nurses in their undergraduate studies to engage with EMRs, EPRs and EHRs [1]. Many countries around the world: (1) have not fully described the nursing informatics competencies that will be expected of nurses upon graduating from their undergraduate nursing programs, (2) have not developed a clear strategy for integrating these competencies into undergraduate nursing curriculums, and (3) have not invested in developing tools representative of real-world clinical settings that would help student nurses to understand the underlying theory and principles embedded within HISs in order to be able to use these technologies [1]. As a result, many student nurses are graduating without sufficient knowledge of nursing informatics to be able to work effectively and efficiently in clinical practice settings such as hospitals and clinics [1]. National governments, nursing educational organizations and nursing informaticians around the world have recognized this is an issue [2-4,6,8-11]. Two countries that are currently engaged in the process of developing and integrating nursing informatics into undergraduate nursing programs are Canada and Australia. In this paper we describe and compare the methods used to develop these competencies, and the strengths and limitations of the approaches in terms of work involving the science of developing national level competencies.

Methods for Developing Undergraduate Nursing Informatics Competencies

Although researchers have attempted to develop nursing informatics competencies at the undergraduate and graduate levels [7], there are few countries that have attempted to develop nursing informatics competencies for undergraduate nurses at a country level. Both Australia and Canada have attempted to do so. Although there are many aspects of undergraduate nursing informatics competency development that can be focused upon [4], we have chosen to focus upon the methods that are used to develop undergraduate nursing informatics competencies in this paper. For the purpose of this work, we have chosen to focus upon the following dimensions (which are contained in Table 1): the process of competency development, the types of background work that was done to develop the nursing informatics competencies, the type of stakeholder involvement, and the validation processes that were used (see Table 1). We have maintained a constant definition of **competency** in reviewing this work. A competency is a complex term that describes a professional's ability to combine knowledge, attitudes and skills with external resources and apply these to specific practice situations [4].There are many similarities and differences between Australia and Canada where nursing informatics competency development methods are concerned. For example in both Canada and Australia initial literature reviews were conducted followed by the development of draft competencies. There are differences as well: the validation process in Australia involved sending the competencies to **all** nurses in the country for comment [3]. In contrast, in Canada a forum of 50 participants that included individuals with diverse geographical representation from across the country and who were nurse educators, practicing nurses, representatives from national nursing associations, students, and other health professionals participated in competency development and validation. Many of these individuals had interest in nursing informatics, yet only a few were nursing informatics experts. These stakeholders were involved in the validation process, with the competencies being sent to Deans and Directors of Schools of Nursing for additional comments.

Table 1: Methods of Developing Nursing Informatics Competencies

Australia	**Canada**
Process of Development	
1. Review of literature 2. Survey all Australian Nurses using an online survey. 3. Develop draft competencies. 4. All Australian nurses review a draft list of the competencies. Nurse informaticians validate the competencies. 5. National focus groups are conducted for further validation of feedback 6. Changes are made based on feedback and a final draft is sent out to all Australian nurses and nurse informaticians 7. Further changes were made. 8. Final competencies are developed and validated by nurse informaticians. 9. Competencies are submitted for publication and acceptance into the National Registered Nurses Competencies Framework	1. Development of a Task Force and sub-task forces. 2. Review of the literature. 3. Draft a list of national nursing informatics competencies by the sub-task force. 4. Presentation to the full task force for review and refinement. 5. Presentation to stakeholders (nursing informatics experts and a diverse group of interested nurses and students from across the country) for review and refinement. 6. Presentation for review to Deans and Directors of the School's of Nursing for review and survey completion. 7. Refinement by the sub-task force. 8. Presentation to the full task force and refinement.
Background Work	
- Extensive literature review was conducted to ascertain existing competencies outlined in the research - Draft evidence based competencies were formulated from the analysis of the literature in consultation with the Project Advisory Committee, key stake holders and expert nurse informaticians - An on line questionnaire (34 questions) of all competencies was constructed from the literature review, and sent to all Australian nurses to identify NI priorities for the profession. - Draft competencies were developed from the outcomes of the questionnaire	Review of the literature that included: -A review of the national and international literature grey and academic literatures. -A review of nursing competencies at both the provincial and regulator levels.
Type of Stakeholder Involvement	
Project Advisory Committee - Oversaw all of project Key stake holders (Australian Nurses) and expert nurse informaticians - were consulted about the competencies (from draft through to completion) - Focus groups were conducted with nurses (8 questions)	A taskforce of nursing informatics experts was brought together to develop the methods and oversee the process: The findings were: -presented at a stakeholder forum to 50 nursing informatics experts and others -stakeholders reviewed and 20 competencies developed Draft competencies were also presented to Deans and Directors of Schools of Nursing, stakeholders and the Canadian Association of Schools of Nursing committee. This group of stakeholders was asked to complete an online questionnaire with the competencies.
Validation Processes	
Following draft competency list approval: - Competencies were sent to all Australian Nurses and nurse informaticians for validation - Focus groups were conducted - Changes were made to the competencies from feedback - A final draft was sent out to all Australian Nurses and nurse informaticians for final validation - Changes were made based on feedback [3]	Following draft competency list approval: - Competencies were presented at a stakeholder forum for 50 nursing informatics experts and other nursing groups. - Changes were made based on feedback - Competencies were presented to Deans and Directors of Schools of Nursing, stakeholders and the CASN committee. This group of stakeholders was asked to complete an online questionnaire with the competencies. [2]

Discussion and Conclusions

Healthcare is an information intensive industry that requires nurses to learn informatics competencies [5]. Yet, nurses have few opportunities to learn about nursing informatics within the context of their undergraduate programs [1]. Both Australia and Canada have taken the first step toward integrating competencies into undergraduate curricula- they have developed nursing informatics competencies. The processes undertaken by both countries have both similarities and differences. Similarities exist in terms of: (1) developing project groups/task forces to initiate work on the competencies, (2) using empirical literature to drive initiate competency development, (3) initiating the process using literature reviews, and (4) engaging in stakeholder consultation to improve the competencies through consultation. There are some differences between the countries. One country has chosen to use the research and grey literature as well as regulatory information to inform their work while the other has used the research literature as their primary source of literature. In addition to this, there are differences in the validation processes between countries. Although both countries consulted key stakeholders (e.g. nurses with informatics expertise), the countries differed in their decisions regarding whom to consult. Australia validated their work by sending out a draft version of the competencies to all nurses and nursing informatics specialists in the country, while Canada reviewed draft versions of the competencies with nursing informatics experts, nursing students in practice with particular interest in this area, students and other health professionals as well as Deans and Directors of Schools of nursing [3]. CASN taskforce members were involved in the development of these competencies. There are advantages and disadvantages to using these differing methodologies. There are advantages to consulting Dean and Directors of Schools of Nursing. Such consultations would enable the developers of the competencies to determine the feasibility of implementing them in Schools of Nursing. There are also advantages to consulting front line nurses who are currently working with the technologies that nursing students will be expected to be working with. It will be interesting to review the strategies of other countries developing national level competencies for undergraduate nursing students – to learn about the methods that were employed. For example, in the United States nursing informatics competencies at the undergraduate level were developed using a Delphi panel of experts in the field of nursing informatics [12]. More importantly, understanding the similarities and differences in competency development will allow for international comparisons in not only methods for competency development but will allow researchers to determine if methodology of development is a factor that influences the type of undergraduate nurse competency development.

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What Nurses are Talking About: Content and Community within a Nursing Online Forum

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Abstract. There is little research on the use of online forums by nursing professionals as a way of creating community and exchanging professional knowledge. The purpose of this study is to analyze the content of an online nursing forum to determine the potential of online forums to constitute a community of practice among nurses. We examined one month of thread topics from a nursing focused general discussion forum and categorized (294 discussion threads) according to content. The most frequent topics of discussion were advice regarding career planning and clinical/technical questions. The majority of posts dealt directly with the domain of nursing. The finding that nurses are seeking information about clinical tasks from unverified anonymous online sources raises concerns about the safety culture of health care institutions.

Keywords. online forum, nurses, communities of practice

Introduction

Online forums, defined as websites "that provide a venue of exchange of information between people about a particular topic" [1], allow multiple participants to contribute and/or respond to a comment or narrative in an asynchronous manner. As such, nursing focused online forums are potentially a rich source of information regarding the experiences, concerns, stories, and work-worlds of practicing nurses [2]. Existing empirical research addressing nursing and internet use has focused on issues such as the internet as a teaching tool for students [3], internet communication of health information from provider to patient [4], health communication using mixed samples of physicians, nurses, and consumers [5] and the privacy risks of forums use [6]. Less research has addressed the use of online forums by nursing professionals as a means to create community, share narrative, and exchange knowledge within their professional domain. The goal of this study was to analyze the content of threads within a nursing focused online forum to 1) better understand the topics and content of nursing discussions that occurred outside of the nursing workplace but within the nursing community and 2) discuss the potential of online forums to constitute a Community of Practice (CoPs) among nurses.

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1. Communities of Practice

The word community is used to mean a wide range of relationships based on such categories as: geography (neighborhoods, villages, towns, cities), culture (ethnic groups, religious groups), organizations (families, kinships, associations), identity (craft, trade), and physical/biological similarities (scientific organisms) to name a few. One particular type of community, connected through shared knowledge, is called a Community of Practice (CoP). A Community of Practice, in a basic sense and for the purposes of this study, can be thought of as a group of individuals who share a body of knowledge and work together to solve a common problem. Organizational and rhetorical scholars have argued that CoPs demand scholarly attention for their ability to increase effectiveness and reduce organizational costs [7,8,9]. In addition, CoPs offer possibilities to save lives (e.g., in high risk industries), and alter oppressive conditions by giving voice to personal and collective narratives of its members. For example, CoPs have developed in nursing and midwifery, firefighting, and the Armed Forces to serve as forums for practitioners who share a concern for what they do, and wish to improve effectiveness through regular interaction.

Although the theoretical parameters of CoPs are still being constructed [10], Community of Practice is traditionally viewed as a combination of three fundamental elements: domain, community, and practice [9]. Domain refers to the set of issues that bring individuals together. These domains may be based on a profession (cardiologists, teachers, nurses, etc.) or because members face similar problems in different contexts (handling paperwork, workplace motivation, etc.). The domain represents the topic with which CoP members are passionately interested. Community refers to the individuals who participate in the CoPs and the social context they create. Membership in CoPs is dependent on the idea of reciprocation; individuals trust that membership will be beneficial and mutual respect encourages willingness to share, expose, and provide empathetic feedback [9]. Practice is concerned with the exchange of knowledge that improves effectiveness in whatever domain the community shares, and creates a shared repertoire of tools, cases, and ideas. A defining characteristic of CoPs is that, although they utilize a variety of formats, members may come from diverse backgrounds a long as the interest in the domain is shared [9,10].

Tacit knowledge refers to knowledge that individuals have but cannot easily communicate. Unlike explicit knowledge, which is formally communicated through organizational processes such as training or orientation, tacit knowledge represents the unspoken but important knowledge that does not get formally relayed, or participants' intuitive knowledge of the domain [9,11]. CoPs have potential to give voice to members of a community who may not otherwise be heard within formal organizational structures, challenge oppressive ideologies through the expression of narratives that tell the story of their practice, and construct new worldviews.

Nursing work has historically relied upon both explicit and tacit knowledge to inform its practice [12]. Interestingly, the emergence of online asynchronous forums may provide a visual text of such knowledge transfer between participants. We argue that some online forums are an example of CoPs, and that these forums are worthy of our scholarly attention. Online forums offer a unique space for nurse dialogue because a) the internet provides a certain level of anonymity that may allow openness, b) personal story-telling in these forums often encourages others to share narratives and exchange tacit knowledge with an interest in the domain, and c) internet forums are becoming more common and further exploration is needed to investigate the

communication occurring in this relatively novel setting. We explored the scope and content of a nursing-focused community of practice, specifically a nursing asynchronous online forum, to more fully understand how and why it is being used. Results have potential to inform health care organizations regarding the domain and practice issues that are relevant to CoPs participants.

2. Methods

Data was collected from the General Nursing Discussion forum found on the website allnurse.com. This website was developed in 2003 as a resource for nurses, and provides information about job opportunities, nursing education, financial aid, and travel opportunities in addition to the asynchronous online forums addressing a number of respondent-initiated topic streams. As such, this site represents the everyday discourse of a community of practice in the domain of nursing. As a fairly new source for mining texts, online forums require several a priori decisions to be made before analysis. For this project, the particular site for study was chosen from among many nursing forums for three reasons; (1) the forum is public and does not require membership approval, (2) the forums are searchable, and (3) there is no warning to researchers that the site is off limits. Once the site was chosen, on-line forums were searched. We categorized respondent initiated threads within the online forum in terms of content and characteristics. The study was designed specifically to be exploratory in nature, and thus an open-coding method was employed to discover the topics addressed by participants. Categories were first developed by the first author, then reviewed, discussed, and refined through collaboration between authors. Each threaded post was assigned to a single category deemed to best fit the overall content of the thread. To set realistic parameters for this study, one month of thread topics (May of 2012) were examined. Thus, a limitation of this work is the potential emphasis on issues that occurred temporally close to the time of data collection. Future research would benefit from a more time representative design.

3. Findings

A total of 294 discussion threads were initiated during the time period of May 1-May 31, 2012. The most frequently noted category of discussion was advice regarding career planning within the domain of nursing. Examples of threads in this category include questions regarding employment (Should I send my resume if I haven't passed the NCLEX yet?), pay expectations (Can I live this lifestyle as a nurse?), interview tips (Should I speak of another offer during an interview?), and advice regarding career strategy (How did you know your specialty and when?). The second most frequent category included posts seeking answers to specific clinical questions or concerns. Interestingly, many of these questions requested information that is readily available in policy manuals or nursing reference materials (How do I flush a PICC line?), or cited actions taken in the clinical setting then asked, essentially, 'did I do it right?' Nearly all threads remained tightly linked to nursing-specific topics. The emergence of discussions regarding unjust treatment (21%), job-related emotional difficulties (4%), and sharing stories (4%) highlight the potential for internet forums to allow community narratives to develop. Additionally, practice tools in terms of technical advice and

resource sharing accounted for approximately 25% of posts, reflecting the potential of internet forums to allow for exchange of ideas applicable to practice change. Categories of forum thread content are noted in Table 1.

Because privacy concerns were an emergent theme in the existing literature addressing medical professional use of online forums [6], we also examined threads for information that would identify patients, identify a specific facility, describe a patient situation with enough detail that the patient could potentially identify themselves in the thread, and/or endorse specific products. Of the 294 posts none named or otherwise identified a patient, and only 4 posts named a facility (3 were in reference to potential employment or an employment interview). Specific patient situations (without identifying information) were highlighted in 11 posts; these 11 posts were contained within the categories of dissatisfaction with nursing, concerns/commentary regarding poor or dangerous care, technical questions, sharing stories, and ethic concerns. No thread overtly endorsed a product.

4. Discussion

The goal of this study was to analyze the content of a nursing focused internet forum to 1) better understand the topics and content of nursing discussions that occurred outside of the nursing workplace but within the nursing community and 2) discuss the potential of internet forums to constitute a Community of Practice (CoPs) among nurses. We discovered that within a single nursing focused internet forum the majority of posts dealt directly with the domain of nursing, nurses were willing to share information that included emotion-based content, and nearly half of the posts were contained within the two most frequent categories (advice regarding career planning and technical questions). Additionally, apart from the two most dominant categories, thread content varied considerably over a wide range of categories, indicating that nurses were engaging the forum membership for both professional interaction and information needs. Surprisingly, nurses frequently used the forum to ask information regarding the safety or procedural steps of clinical tasks such as IV line flushing and medication administration, information that should be readily available on a nursing unit or in an established nursing reference. The finding that nurses are seeking such information from anonymous online sources (there is no way for members to verify the identity, experience, clinical capability or qualifications of fellow members) is of concern, and may reflect poorly on the safety culture of health care institutions. Despite recent efforts to encourage nurses to openly question procedures, admit when further information is needed, and discuss situations where patient safety may have been comprised within their organizational settings, some nurses are instead seeking this type of support from internet forums.

The nature of a community of practice (CoPs) is one that encourages individuals to share their experiences in order to solve common problems. Some threads appeared in the form of questions, wherein nurses seek advice from other community members, while other threads were declarative in nature and made assertions regarding personal experiences and professional knowledge. The CoP framework draws our attention to knowledge "as communicatively constituted in practice" [10,p.193]. We recognize that not all nurses who participate in online nursing forums represent CoPs, but believe there is valuable information about how knowledge, especially tacit knowledge, is rescued and shared through this type of interaction. As theorists continue to examine

CoPs, they are realizing that the "enactment of CoPs can differ greatly as regards mutual engagement, shared repertoire, and negotiation of a joint enterprise" [10 ,p. 195]. If the benefits of CoPs are to be realized, we must also take the changing nature of community into account in order to include the explicit and tacit knowledge shared in online communities.

Table 1. Categories of Forum Thread Content

Category	n	%
Advice re: career planning (hiring, pay, interview, job choice, career strategy)	75	26%
Technical questions, clinical questions	51	17%
Advice re: formal education (course of study, coursework, schools)	24	8%
Perception of unjust treatment by administration or leadership	21	7%
Issues related to scheduling or shift work	14	5%
Handling job-related emotional difficulties	13	4%
Sharing stories (telling a story and/or asking others for their stories)	13	4%
Issues specific to nursing management	12	4%
Professional development or training/related readings/ instructional videos	11	4%
Licensure issues	9	3%
Interpersonal conflict with co-worker or colleague	9	3%
Dissatisfaction with nursing career in general	8	3%
General discussions of issues affecting nursing care	5	2%
General discussions of issues affecting personal health	5	2%
Discussion comparing practice settings without requesting career advice	4	1%
Concerns/commentary of poor or dangerous care	4	1%
Discussion regarding of public image of nursing	4	1%
Comments on forum use or the forum itself	4	1%
Questioning the ethics of a specific situation	3	1%
Using forum to gain employment or recruit nurses	3	1%
Event announcements	3	1%
Missing/unable to categorize	3	1%
Interpersonal conflict with patient	2	<1%
Using forum to recruit nurses for research studies	1	<1%
Asking where to find a specific resource	1	<1%

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A Framework for Leveling Informatics Content Across Four Years of a Bachelor of Science in Nursing (BSN) Curriculum

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Abstract. While there are several published statements of nursing informatics competencies needed for the Bachelor of Science in nursing (BSN) graduate, faculty at schools of nursing has little guidance on how to incorporate the teaching of such competencies into curricula that are already overloaded with required content. The authors present a framework for addressing nursing informatics content within teaching plans that already exist in virtually all BSN programs. The framework is based on an organization of curriculum content that moves the learner from elementary to complex nursing concepts and ideas as a means to level the content. Further, the framework is organized around four broad content areas included in all curricula: professional responsibility, care delivery, community and population–based nursing, and leadership/management. Examples of informatics content to be addressed at each level and content area are provided. Lastly a practice-appraisal tool, the *UVIC Informatics Practice Appraisal – BSN* is presented as a means to track student learning and outcomes across the four years of a BSN program.

Keywords Nursing informatics, baccalaureate nursing education, nursing curriculum

Introduction

There have been several efforts over the years to establish nursing informatics competencies for nurses, beginning with Staggers and colleagues work in 2001 and 2002 [1,2]. This work was followed in the U.S. more recently by the TIGER initiative (Technology Informatics Guiding Educational Reform) [3-5] and work in Canada supported by Canada Health Infoway and the Canadian Association of Schools of Nursing [6]. The resulting competency documents provide statements describing the knowledge, skills and attitudes needed for modern nursing practice and suggest that nurse educators must incorporate nursing informatics content into their curricula. In addition, the national accrediting bodies for nursing education in both countries suggest that graduating students should be prepared with basic nursing informatics competencies (6,7). Although these efforts indicate agreement that informatics content is required in undergraduate curricula, faculty has little guidance on teaching such

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content. For example, the TIGER initiative provides broad goal statements such as a beginning nurse should "access data and perform nursing documentation using computerized patient records" and should "recognize the role of informatics in nursing" (8, p 58] but does not provide concrete examples about *how* or w*here* to bring a wide range of nursing informatics competencies into undergraduate nursing curricula that are already challenged to cover a wide range of required content. In addition, prior work on leveling nursing informatics content has addressed competencies and outcomes across levels of nursing education (i.e. the undergraduate, masters and doctoral level)[1], not leveling content within undergraduate programs. The current paper presents a contribution to the literature as it describes how nursing informatics competencies can be integrated across BSN curricula.

The purpose of this paper is to present a useable framework, developed by the authors, suggesting ways that faculty can incorporate much of the needed material into content areas already being addressed in virtually all nursing programs within the four years of a baccalaureate nursing program. In addition, the authors present a practice appraisal tool that faculty and students may use to track exposure and achievement of nursing informatics competencies over the four years of a program.

Background: Organization of Nursing Curricula: Elementary to Complex

In baccalaureate programs, nursing curricula are designed to move the learner through course content and clinical experiences that ensure the graduate is ready for beginning professional practice. This means that in a four-year university program, the learner begins as a novice nurse (i.e., one without nursing knowledge and experience) and ends as a generalist ready for practice in any of nursing specialty areas. Nursing curricula have been widely influenced by the work of Benner [9] who has documented the development of nurses throughout their careers in her publication "From Novice to Expert". Though there are program and regional variations, nursing curricula take an approach of thinking about student learning and development over the four-year experience. Nursing curricula begin with content and experiences that are more elementary or foundational to the discipline and move the learner through experiences that build on that foundation to increasing levels of complexity. Thus, it is relatively common that students provide care first to individual adults and care for families and communities later; they build care management skills by taking responsibility for one patient, moving to take responsibility for a group of patients, and only then take on unit management/leadership experiences.

In order to incorporate nursing informatics awareness and competencies into nursing curricula, the authors have selected four content areas that are addressed in one way or another in all programs. These are: 1) professional responsibility, 2) care delivery, 3) community nursing and care of populations, and 4) leadership/management. These content areas are present in a BSN curriculum as illustrated in Figure 1 as four squares. Nursing informatics represented by the arrows moving from the centre out, depicting the integration of such competencies from elementary to advanced.

Figure 1: Nursing Informatics Competencies across a Four Year Nursing Curricula

In the sections that follow, the authors suggest specific informatics content related to each of these broad areas, provides examples of how this suggested content addresses published competency statements, and give examples of items that could be used in student practice appraisals to retrieve competency achievement.

Content Area 1: Professional Responsibility

The topics of professional responsibility, accountability for professional behavior, and the legal/ethical issues of nursing practice are always addressed in the beginning of nursing curricula. The learner must understand that nursing practice is based on a legal scope of practice, that the use of professional nurse title (Registered Nurse) is governed by a regulatory body, and that the nurse is legally and ethically accountable for all nursing actions. There is opportunity for faculty to address a wide range of informatics content in this introductory content. Privacy and confidentiality are two concepts the novice nurse must understand in a new, professional context. Topics such as access to digital records, password security, use of social media, cell phones, photographs, and text-messaging can and should be addressed early. In addition, for the novice nurse who has learned to rely on technology in his or her personal life, the possibilities of technology failures and e-iatrogenic errors/technology-induced errors can be incorporated into course content about use of records, decision supports and the nurse's accountability for all professional actions. Lastly, in the beginning courses, the topic of the professional and therapeutic nurse-patient/client relationship is addressed. Here, discussion of the challenges of developing appropriate supportive practice while using technology is an important consideration. Faculty understands that technology can readily become a focus for care and in some circumstances the technology impedes the development of a new nurse's ability to interact with the patient.

Addressing these areas of privacy, confidentiality, access to records, device use, technology induced errors and development of professional/therapeutic relationships attends to the competency requirements of the TIGER competency of "clinical management and care responsibility" with its related skills of assuring confidentiality

and system security in information[10] and the CASN informatics competency document [6] under domain of "professional and regulatory accountability" with indicators related to legal/ethical standards and use of professional judgment and accountability in all practice decisions; and under the domain of "information and communication technologies" with indicators related to use of technology that supports the nurse-patient relationship. Examples of performance appraisal indicators are listed in Table 1.

Table 1: Informatics - Professional Responsibility: Selected Performance Appraisal Indicators

Uses only those technologies that ensure the privacy and confidentiality of patients.
Posts, enters or saves files (including digital photo files, text and/or audio files) on only password protected, organizationally-sanctioned secure sites.
Reports any loss or theft of hardware, software breaches or presence of computer viruses.
Develops a practice style that incorporates technology use and positive nurse-patient relationships.

Content Area 2: Care Delivery

Students provide basic care in beginning nursing courses and most often learn clinical skills in a nursing laboratory before carrying out care in actual clinical situations. There are two areas of care delivery that require the learner to understand care in a technology-enabled practice setting: 1) documentation of nursing care and 2) medication administration.

In learning care documentation, the beginning nurse needs an understanding of the legal status of nursing notes, signatures (paper or electronic) that indicate personal knowledge/observation of the material for which the signature is given, and -- in digital records -- the differences between narrative language and use of standardized languages. Introduction to nursing and other standardized languages (such as the ICNP®, NANDA-I, C-HOBIC, ICD-10, DSM-IV-R) is essential content. The beginning nurse need not be an expert in all of these language systems, but needs to understand their development and use in recording in electronic health records systems. Providing a foundation early in a nursing curriculum with reinforcement of knowledge throughout the program gives students an opportunity to grow in their sophistication of use, critique, and, ultimately, improvement of digital documentation systems.

Medication administration cannot be taught without attention to paper systems, hybrid systems and electronic order entry systems. Nursing laboratories that simulate all three are best suited to teach the learner how to practice in current and future systems. Paper systems provide the basics for the learner to understand how a medication order is processed from initial writing to administration and recording. Electronic systems involving physician order entry, pharmacist and nurse receipt, pharmacy dispensing, and nurse administration are complicated and, when explained, help the student understand care processes and the nursing and interdisciplinary roles in safe practice. Decision supports related to medication dose and interactions between medications provide opportunity for learning related to system benefits, possible errors, need for professional judgment and vigilance in professional behaviours.

Addressing issues such as nursing documentation, standardized languages, decision supports, accountability for professional decisions and actions, and understanding of systems processes address the TIGER competency area of "clinical information management" and its related skills of maintain records, capturing data,

producing summary records of care and managing medication orders and care [10]and the CASN informatics competencies [6] under the domain of "information and knowledge management" with indicators related to use of nursing data using standardized languages, recording nursing data, use of hybrid and homogenous record systems, and under the domain of "information and communication technologies" with indicators related to understanding various components of health information systems. Table 2 provides examples of performance appraisal items of these competencies.

Table 2: Informatics – Care Delivery: Selected Performance Appraisal Indicators

Describes the underlying workflow that supports medication ordering, dispensing and administration when using an electronic health record that supports physician order entry, pharmacy information systems and medication administration systems.
Communicates with physician and/or pharmacist if there are questions about a medication order (demonstrates awareness of underlying rationale for a physician or prescriber bypassing an alert or reminder where the patient's health status is concerned).
Documents care according to the standardized language systems used in practice settings.
Describes which parts of the nursing record are codeable, stored, and retrievable.
Provides examples of how hybrid records could introduce opportunities for errors.

Content Area 3: Community/Population-based Nursing

Community nursing and care of populations most frequently comes later in a BSN curriculum – often in years three or four. The student must build on knowledge and practice experience with care of individuals to care of client groups to expand practice to the community/population level. Areas that the student must learn have to do with retrieval and interpretation of population-based data to determine needs, risks and surveillance activities as well as need to consider basic privacy/confidentiality issues in terms of transferal of data over wireless networks (from client homes to clinical record systems), protection of client/patient data when data are held on hand-held laptops or portable devices such as computers used in the home. The student will need to become acquainted with population datasets, interpretation of population-based statistics and new considerations for privacy and confidentiality. In addition, when providing care to clients in their homes, the student needs to gain an awareness of how clients obtain access to their personal health data and make use of personal health records. When this new content is delivered through classroom and clinical experiences, the faculty are addressing the TIGER competency of "management of patient groups or populations" and related skills of use of information to support epidemiological investigations and population health issues, and the CASN informatics competencies [6] under the domain of "information and communication technologies" with indicators related to care delivery to diverse populations, assisting patients and their families to use information and technologies to manage their own health, and critical evaluation of data from a variety of sources. Table 3 provides examples of performance appraisal items of these competencies.

Table 3 Informatics – Community Nursing/Population-based Care Selected Performance Appraisal Indicators

Describes how data can be transferred in the community via secure networks.
Ensures that hardware used is stored in safe and secure settings between home visits.
Teaches patients and their families how to access and use personal health information from digital records.
Accesses population-based information from available datasets.

Content Area 4: Leadership and Management

Courses in leadership and management come near the end of BSN curricula. Students need to understand approaches to leadership and to think about their own personal leadership styles. While a new graduate is rarely hired directly into a management position, BSN graduates will be in positions of leading teams and directing and supervising care soon after graduation. Further, many will move into supervisory positions without returning to school for additional formal education. There are two important informatics content areas that directly impact the nurses' ability to serve in supervisory and management positions: 1) access to data for assessments of quality and safety, and 2) evaluation of technology and its impact on workflow. Quality and safety have become essential parameters for evaluation of institutional performance. While each healthcare system will have related data identified and stored in varying ways, the BSN graduate nurse must have enough background to understand data collection, retrieval and interpretation for these purposes. Use of aggregate data to identify trends, 'change points', and progress toward institutional goals can be taught at the undergraduate level. Again the BSN graduate will not be the expert, but must have a basic understanding of the processes used to ensure quality and safety. Also, a nurse supervisor needs an understanding of the well-known fact that technology impacts workflow and behaviours [11]. Adding hand-held devices, personal paging systems, bar code identification, or new documentation systems will impact (positively or negatively) on the work of the nursing team. To fully participate in technology roll-outs, a supervisor must be in a position to ask questions related to workflow, time management and the results of pilot-tests of new technology. Courses can include this content with case-studies from practice experiences to help the graduate learn. Use of data for quality and safety and an understanding of technological impacts on workflow address TIGER competency of "clinical information management" and related skills such as data capture, information management in relation to clinical workflow tasks [10] and the CASN informatics competencies [6] under the domain of "professional and regulatory accountability" with indicators related to advocacy for use of information systems to support safe, quality care; and under the domain of "information and communication technologies" with indicators related to understanding the ability of technology to improve health systems and quality care. Table 4 provides examples of performance appraisal indicators.

Table 4: Informatics – Leadership and Management: Selected Performance Appraisal Indicators

Tracks data on unit performance for quality measurements.
Analyzes data collected to provide input to quality improvement activities.
Works with health informatics professionals to evaluate impact of technology on care processes.
Advocates for nursing staff where technology safety is concerned.

Practice Appraisals

Documenting student learning and tracking student learning outcomes are integral tasks for professional nursing programs. Practice appraisal forms provide both faculty and students the ability to document exposure to content and learning of content across the entire four years of a program. Such forms can be used as part of end of term student evaluations, incorporated into student portfolios of individual learning, and as measures contributing to overall program evaluation. The authors have developed a nursing informatics practice appraisal tool (see Appendix A) that is a form that could be used for each of these purposes. This tool, titled the *University of Victoria Informatics Practice Appraisal - BSN is* organized according to the four content areas addressed above and provides indicators of student learning. The authors present this tool for faculty or students who may wish to incorporate it into their own programs.

Discussion

Nursing faculty is often faced with the challenge of being asked to add content to their courses and curricula without being able to omit content already present. This need to add new and changing content is even more difficult when faculty themselves are not expert in the new content. Existing frameworks for leveling nursing informatics competencies provide information about how to integrate these technology-based competencies across differing levels of nursing education (i.e. the undergraduate, masters and graduate). In this work we outline a framework that can support faculty decision making when integrating nursing informatics competencies across a four year undergraduate baccalaureate in nursing program. The framework we outline illustrates a place in curricula where content and learning experiences can be incorporated into existing teaching plans and activities and provides a way forward for faculty addressing the informatics content required for practice in our future. We also present a practice appraisal tool for aiding faculty in their process of documenting and tracking student learning. Our future work will include testing the framework to determine whether it can be used to support faculty decision making in integrating such context in an undergraduate program context. In carrying out this work (i.e. integrating nursing informatics content into four year baccalaureate programs), faculty will be able to demonstrate that their curricula meet current published standards for informatics in BSN curricula and will be able to retrieve student learning of this content in practice appraisals.

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Appendix A

University of Victoria Informatics Practice Appraisal – BSN: A Template for Tracking Nursing Informatics Competencies

*Developed by Elizabeth Borycki, PhD, RN, School of Health Information Science and Noreen Frisch, PhD, RN, FAAN, School of Nursing**

Content Area 1: Professional Responsibility

- ***Understands the difference between public space, private space, and the need to maintain privacy and confidentiality when using differing types of software and hardware***
  - *Uses only those technologies that ensure the privacy and confidentiality of patients*
  - *Posts, enters or saves files (including digital photos files, text or and audio files) on only password protected, organizationally sanctioned secure sites.*
  - *Accesses patient information using organizationally sanctioned resources*
  - *Accesses only the patient information for those patients for whom one is responsible for*
  - *Accesses confidential patient information only during periods of medical crises*
- ***Recognizes limitations, potential errors, and errors in electronic systems.***
  - *Reports any loss or theft of hardware, software breaches or presence of viruses*
  - *Uses clinical judgment when confronted with decision support*
  - *Reports technology errors/failures and instances where the technology does not effectively support nursing practice.*
- ***Maintains relational practice and therapeutic communication within technologically-enhanced environments***
  - *Develops a practice style that incorporates technology use and positive nurse-patient relationship.*
  - *Identifies when technology is disrupting nurse-patient therapeutic communication and modifies communication style or technology use accordingly*

Content Area 2: Care Delivery

2a. Medication Administration

- ***Understands the underlying workflow that support medication ordering, dispensing and administration when using an electronic health record***

that support physician order entry, pharmacy information systems and medication administration systems

- ***Communicates with physician and/or pharmacist if there are questions about the medication order***
  - *Is aware of the underlying rationale for a prescriber bypassing an alert or reminder where the patient's health status is concerned*
  - *Questions if medication order data appears incorrect as it appears in the medication administration system (i.e. the wrong dose or if the medication is the incorrect medication)*

2b. Electronic Documentation

- ***Demonstrates ability to use electronic documentation for nursing documentation***
  - *Documents according to the standardized language systems used in practice settings*
  - *Documents accurately on checklists, assessment forms, and other computerized systems.*
  - *Accesses patient data from the record as needed to perform safe care.*
- ***Understands which parts of the nursing record are codeable, stored, and retrievable.***
- ***Understands how hybrid environments could introduce opportunities for errors.***
  - *Understands the communication and information access challenges of hybrid environments (i.e. where part of the patient record is paper based and part of it electronic) and develops strategies to overcome them*
  - *Reports errors or near misses arising from work in a hybrid environment to nurse managers, the information technology department, professional practice and to error reporting systems*

Content Area 3: Community and Population-Based Nursing

- ***Understands privacy issues related to community care and electronic documentation, transfer of information and information retrieval***
  - *Describes how data can be transferred via secure networks*
  - *Follows agency policies in all aspects of data collection, storage and retrieval.*
  - *Ensures that hardware used is stored in safe and secure settings between home visits.*
  - *Educates patients and families about the most appropriate communication channels between nurses, clients, and families to maintain privacy and confidentiality.*

- ***Is aware of technological supports available for use in home and ambulatory settings to manage chronic disease and/or to enable safe and independent living.***
    - *Demonstrates (articulates) ability to meet the issues and challenges of monitoring, independence and privacy in community settings.*

Content Area 4: Leadership and Management

- ***Has basic data and information literacy skills***
    - *Tracks data on unit performance for quality assurance and comparisons*
    - *Analyzes data collected via the electronic health record to provide inputs into professional practice and quality improvement activities*
    - *Uses analyzed data to undertake evidence-based, management decision making*
    - *Presents data to staff about units clinical outcomes*
- ***Understands how work is embedded in the technology and how the introduction of new technologies affects workflow (e.g. wireless IV pumps, smart beds, wireless vital signs monitors and the electronic health record)***
    - *Works with the health informatics professionals to optimize workflow arising from software and placement/use of the technology*
    - *Works with health informatics professionals to evaluate the impact of technology upon unit processes and clinical/organizational outcomes*
- ***Advocates on behalf of the nursing staff when issues arise when the hardware and software does not adequately meeting health professional needs.***
- ***Advocates for nursing staff where technology safety is concerned***

*****The authors would appreciate feedback from colleagues using this tool for further extension and development*

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Patient Safety Perspectives: The Impact of CPOE on Nursing Workflow

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Abstract. The purpose of this review is to explore the impact of Computerized Physician Order Entry (CPOE) systems on patient safety from a nursing perspective. The paper discusses the importance of safety culture within nursing, nursing perceptions of CPOE, and the impact of CPOE on nursing workflow. The findings indicate that the implementation of CPOE negatively impacts nursing workflow when CPOE systems are inadequately designed. Future work is necessary to explore the impact of CPOE on nursing workflow and the direct impact on patient safety.

Keywords. Patient Safety, Nursing, CPOE, Medication Errors.

Introduction

In 1999, the Institute of Medicine (IOM) released a report, *To Err is Human*, which predominantly focused on health care errors and revealed that between 44,000 and 98,000 Americans die from medical errors each year [1]. The report stressed the importance of using reporting systems to collect standardized information about adverse events for the purpose of improving patient safety. The report also recommended the use of voluntary reporting systems for systemic failures and near-misses to identify potential problems before harm occurs [1].

Almost 12 years later, in 2012, the Institute of Medicine produced a report on the impact of health information technology on patient safety [2]. The IOM reported that health information technology products are expected to improve patient safety only if the products are well-designed and strategically implemented. Incidences in which poorly designed health information systems caused medical errors were a concern, particularly due to the impact on patient safety. The report encourages collaboration between health information technology vendors, physicians, nurses, and hospitals to improve patient safety.

According to IOM reports, Computerized Physician Order Entry (CPOE) systems were identified as a means of improving patient safety by reducing hospital medication errors. CPOE systems are broadly considered an essential component for health information systems that helps improve patient safety by reducing medical errors. CPOE provides passive and active reminders, alerts and alarms that notify medical

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staff (such as nurses) of incorrect orders, and information about possible drug-drug interactions and missed medication doses that allow medical staff to correct, modify and rewrite incorrect entries[3]. A large number of serious medication errors occur every year and include prescribing the wrong drug, drug over-dosage or unobserved drug interaction and allergy. CPOE offers accurate drug information, dose auto-calculations and support for making the appropriate decision at the point of care. CPOE application helps decrease medication errors in multiple ways. For example, when a nurse inputs a physician's order into a CPOE system and there is a mistake on the order, the CPOE system will give him/her a warning alarm. As a result, the nurse is given the opportunity to review the prescribed medication with the physician and to correct and re-enter the order.

A study conducted by Bates et al. showed that CPOE application reduced the medication error rate by 55% [4]. A systematic review of 10 studies was performed: five of the studies indicated that the use of CPOE significantly decreased the number of medication errors, four of the studies concluded that the resulting decrease in medication errors was not significant and one of the studies showed no change in the number of medication errors with the use of CPOE [5]. Some studies have shown that the application of the CPOE system has a negative impact on medication errors. A study conducted by Koppel et al. reported that the CPOE system facilitates medication errors and identified 22 types of medication errors that can result from CPOE application [6].

The use of CPOE in hospitals is facilitating many changes to the processes of prescribing, dispensing and administering medications. These changes are becoming more apparent in the tasks of nursing staff, as more physicians are requesting nurses to enter orders into CPOE systems [7]. In 2009, Fields et al. reported that the total impact of CPOE on nursing can be determined by evaluating three aspects of nursing: process, relationships and operations. Moreover, nurses' concerns and difficulties with using the CPOE system may potentially affect nursing workflow [8].

Little work has determined nursing perspectives on the use of CPOE and its potential impact on nursing workflow and patient safety. In this paper, we discuss the importance of the patient safety culture within the nursing profession, the nursing perception of CPOE, and the impact of CPOE on nursing workflow.

1. Nursing and Patient Safety

Patient safety is defined by the IOM as "the prevention of harm to patients"[9]. There exists much concern regarding the healthcare system's ability to prevent errors and to facilitate learning from errors, which requires the involvement of the hospital administrator and medical staff [10]. Improving quality within hospitals has long been a goal of medical professionals, especially nursing professionals. For example, in 1855, Florence Nightingale played a major role in creating a patient safety culture when she gathered and analyzed the mortality data of British troops and then promoted hygienic practice [11]. In 1859, she was credited with initiating the implementation of the world's first hospital performance measures. Today, nurses play a major role in improving patient safety within hospitals. The impact of nurses on patient safety is greater than the impact of medication administration or injury prevention in health care settings .

2. Nursing Perceptions Towards CPOE

One of the benefits of using CPOE in nursing practice is that CPOE supports safe drug administration by promoting "the five rights of drug administration"; this can provide nurses more time to focus on the professional steps of medication administration, such as the monitoring of adverse events and the continuous assessment of patients [14]. However, nurses have resisted the introduction of information technology into hospitals. In 2003, Trimmons reported on a study that evaluated nurse resistance to the use of information technology [15]. The study revealed that nurses found that the use of information technology increased their dependence on technology and therefore undermined their critical thinking skills. The nurses in the study were also concerned with the reliability and security of health information systems. Additionally, nurses were concerned that they would be unable to access patient information during a system failure.

However, Ash et al. reported that nurses were comfortable in using CPOE systems that were well-designed. Nurses reported that easy-to-use systems improved their workflow and that badly designed systems actually hindered workflow, especially when they were not customized or implemented accordingly. The authors also reported that one major success of the project resulted from strong support and leadership from management [16].

The ways in which nurses interact with CPOE are also changing. CPOE systems were originally designed for physicians to enter medication and lab orders. However, a study conducted by Kazemi et al. (2010) showed that most of the CPOE systems implemented in hospitals are not used by physicians, but rather by nurses and other medical staff [7]. Physicians were found to be resistant to using CPOE systems and relied on nurses and other medical staff to input CPOE orders.

The studies conducted by Trimmons, Kazemi and Ash indicate that physicians are relying on nurses to enter CPOE orders and that, as long as the technology helps improve patient care and is designed to support workflow, nurses are more willing to use the technology.

3. CPOE Impact on Nursing Workflow

The full impact of CPOE on nursing tasks and patient safety has not been examined and, therefore, remains poorly understood. Small studies are available on this subject, but as more health information systems are implemented and used by nurses, the need to understand the impact of these systems on nursing workflow and patient safety is increasing. Ash et al. reported that nurses and other clinicians were willing to use CPOE systems if they were well-designed and implemented [14]. The study noted that CPOE implementation had a major impact on nursing, but it was unclear whether CPOE systems would decrease or increase the duration, number or type of nursing tasks, such as order processing and other patient care duties.

Another study, conducted by Bleich et al., reported that the implementation of CPOE increased the time nurses spent performing tasks on the system while reducing time spent performing patient care activities [16]. The authors recommended achieving a greater and more thorough understanding of the CPOE system and the effects on CPOE users, including nurses who interact with the system daily to retrieve and manage patient orders and improve patient care and safety.

When a CPOE system is implemented and physicians enter orders from other places within the hospital, nurses become dissatisfied with CPOE. Nurses must log into the system many times to check for new orders, which increases the time spent using the system rather than visiting bedsides. Therefore, this additional clerical task is imposed on already-burdened professionals and is also economically inefficient [15]. A study examining nursing time expenditure determined that nurses spend approximately 20% of their time on direct patient care, 9% on activities related to the unit, 25% on indirect patient care, 30% on documentation, and 15% on personal activities [17]. In fact, there exists a difference in the amount of time nurses spent on documentation before and after using the CPOE system, indicating that more time will be available for nurses to spend on direct patient care and improving the quality of work documentation [18].

Successful implementation and adoption of CPOE are more likely when the developers and implementers understand the complexities and unpredictability of the nurses' workflow. For instance, an inability to ensure the compatibility of the system with nursing workflow may lead to increased encounters of unintended consequences. Clearer guidance is required from hospitals on the use of CPOE systems by physicians, nurses, and other medical staff. Without clear policies, well-developed CPOE systems that are well-implemented and -designed may hinder nursing workflow and impact patient safety and patient care.

4. Discussion and Conclusions

CPOE with Computer Decision Support Systems (CDSS) can help health care providers achieve optimum care for their patients. Raebel et al. conducted a study to assess CPOE abilities in alerting prescribers of contraindicated medications during pregnancy. The trial included more than 11,000 women who were enrolled in urban Kaiser Permanente Centers. The study findings were statistically significant and indicated that CPOE with CDSS reduced potential medication errors [19].

Although CPOE systems can improve patient care, they can negatively impact organizational culture, workflow processes, and medical errors due to poor design. In 2006, Campbell et al. identified unintended consequences that resulted from CPOE implementation. The study made use of an expert panel by using an iterative process in which the list of CPOE adverse consequences was divided into categories. This study revealed that CPOE can generate new types of errors, which include, but are not limited to, organizational culture, workflow process, and order errors that occur when users accidentally select an item that appears beside the intended choice. This is a result of poor design [20].

As an increasing number of nurses enter physician orders into CPOE and administer such orders, more work is required to understand the impact of CPOE on nursing workflow and, in particular, the impact of these changes on patient safety and patient care. Kazemi et al. suggest that the involvement of nurses in entering data into CPOE serves as a form of collaborative effort between physicians and nurses that may improve patient safety and patient care [7]. This further highlights the need to study the impact of CPOE on nurse workflow and the direct impact on patient safety.

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Healthcare Modeling and Simulation

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Developing a Multivariate Electronic Medical Record Integration Model for Primary Health Care

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Abstract. This paper describes the development of a multivariate electronic medical record (EMR) integration model for the primary health care setting. Our working hypothesis is that an integrated EMR is associated with high quality primary health care. Our assumption is that EMR integration should be viewed as a form of complex intervention with multiple interacting components that can impact the quality of care. Depending on how well the EMR is integrated in the practice setting, one can expect a corresponding change in the quality of care as measured through a set of primary health care quality indicators. To test the face validity of this model, a Dephi study is being planned where health care providers and information technology professionals involved with EMR adoption are polled for their feedback. This model has the potential to quantify and explain the factors that influence successful EMR integration to improve primary health care.

Keywords. complex interventions, electronic medical record, primary health care

Introduction

Despite increased adoption of the electronic medical record (EMR) in primary health care reported in recent years, its impact on provider performance and patient outcomes has been mixed [1,2]. For instance, a systematic review by Lau et al. [3] of 43 EMR evaluation studies has shown only 51.2% had positive impact, while 30.2% had no effect. Given the recent attention to transform primary health care in Canada and the great expectations on EMR as the enabler [4], the lack of positive evidence to date is cause for concern. That said there are successful primary health care practices that have shown improved care thru innovative use of their EMR. Examples are the use of individualized decision support and reminder tools by Holbrook et al [5] to improve diabetes care in a Canadian community, and an EMR supported quality improvement project by Nemeth et al [6] in 99 primary care practices in the United States. Both studies had multiple interventions in which EMR was one component. In this paper we present a multivariate EMR integration model that is used to define, quantify and explain factors that may affect the successful integration of EMR systems to improve

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the quality of care in the primary health care setting.

1. Purpose

This study is to develop a multivariate electronic medical record (EMR) integration model for the primary health care setting. Our working hypothesis is that ***an integrated EMR is associated with high quality primary health care***. We postulate that an integrated EMR is one where its features are well adopted and used over time in the practice to support improvement of the care provided. Our assumption is that EMR integration can be viewed as a form of complex intervention with multiple interacting components that impact the quality of care [7]. These components include a set of contextual factors that influence EMR integration in a practice. Depending on how well the EMR is integrated into the practice, one can expect a corresponding change in the quality of primary health care (PHC) as measured thru a set of PHC quality indicators.

2. Methods

To develop this multivariate model, we defined the parameters, provided evidence to justify the choices where feasible, and described means by which this model could be tested. The model is built on the EMR adoption framework by Price et al [8] since it provides a means of rating the level of EMR adoption within a PHC practice. We also selected relevant PHC indicators from the Canadian Institute for Health Information (CIHI) since they are specific to the Canadian primary health care setting [9]. To establish the evidence base for the model parameters, we searched for published EMR literature and synthesized key concepts from relevant articles through an iterative consensus process among the three co-authors. Where feasible we used articles that focused on Canadian primary health care practices within the last 10 years when much of the PHC transformation occurred in Canada. In instances where the evidence for a model parameter is not conclusive we arrived at a consensus from our best judgment and what would be feasible in terms of the sample size needed for model testing. We acknowledged this model was tentative in nature and required validation by others.

3. Results

3.1. Model Parameters

First we define EMR adoption in terms of an adoption score based on the EMR adoption framework. Second we define EMR integration in terms of the EMR adoption score and the contextual factors that influence how well the EMR can be integrated. Third we define PHC quality index in terms of process and outcome quality indicators, which are derived from the PHC indicators from CIHI [9] and the Summary of QUality InDex (SQUID) algorithm by Nietert et al [10]. Fourth we model the relationship between EMR integration and PHC quality index. These definitions are as follows:

EMR adoption score from 0 to 5, defined as

$$EMR\ adoption = Health\ information + Medications + Labs + Diagnostics + Referrals + Decision\ support + Electronic\ communication + Patient\ support + Administration + Practice\ reporting \quad (1)$$

EMR integration = EMR adoption as a function of *the contextual variables*, as

$$EMR\ integration = EMR\ adoption\ score + (EMR\ product + EMR\ configuration + EMR\ data\ quality + Time\ since\ implementation + Provider\ type + User\ prior\ EMR\ knowledge + User\ satisfaction + Practice\ organization + Practice\ size + Practice\ improvement + Financial\ incentive) \quad (2)$$

PHC quality index = Summary PHC quality index as a proportion from 0 to 1, as the average of the patient level indicator targets, derived from below: (3)

E = Number of quality process and outcome indicators the patient is eligible

M= Number of quality indicator targets that the eligible patient has met; for process quality indicators the target has been met if the process has been performed within the specified time period; for outcome quality indicators the target has been met if the outcome has achieved the recommended guideline

Patient level indicator target = M/E

Association between EMR integration (2) and PHC quality index (3) to be determined by modeling PHC quality index as a function of EMR integration (4)

The parameters listed in the above equations are further defined in Table 1.

3.2. Evidence for Model Parameters

For each of the parameters in the model we searched for relevant literature to find out how others have defined them. We have included three such parameters to illustrate the source of evidence used. For example, our *Practice organization* definition is based on five published Canadian PHC organizational performance studies [4,10-13]. Our *Practice size* definition is based on five published studies from Canada, United States and Australia [1,14,16,17]. Table 2 shows the suggested *PHC indicators* for our model, which are drawn from PHC content standard development work by CIHI [9].

3.3. Model Testing

For testing, we need to collect data for the parameters identified in the model. We then conduct statistical analysis to test the model. These steps are described below:

Data Collection – We need to collect data for the parameters from multiple sources through environment scan, survey and data extraction methods. The variables, sources and tools are listed below. The tools are available via the UVic eHealth Observatory website (http://ehealth.uvic.ca/resources/tools/tools.php).

a) EMR adoption score – from care providers and support staff through face-to- face interviews using the EMR adoption survey tool
b) EMR products and configurations – from EMR vendor, jurisdictional and Infoway websites and published reports using the environment scan tool
c) User prior EMR knowledge and user satisfaction – from care providers and support staff through face-to-face interviews using the user assessment tool

d) EMR product, configuration, time since implementation, provider type, size, organization, practice improvement and financial incentive – from interviews with lead provider and support staff using the practice characteristics survey
e) EMR data quality – from anonymized EMR data extract or query report provided by the practice analyzed using the EMR data quality assessment tool
f) PHC quality index – from anonymized EMR data extract or query report from the practice analyzed using the PHC quality indicator assessment tool

Table 1. Definition of the parameters in the multivariate EMR integration model.

Legends: EMR-electronic medical record; ASP-application service provider; PHC-primary health care; CIHI-Canadian Institute for Health Information; SQUID-Summary of QUality InDex.

Parameter	Definition
EMR adoption	Level of EMR adoption achieved in a practice measured by EMR adoption score
EMR adoption score	User reported adoption level from 0 to 5 (0 as paper-based, 5 as fully integrated)
EMR integration	How well EMR has been adopted in terms of adoption score and contextual factors
EMR product	Number of EMR software product on the market
EMR configuration	Type of EMR instance installed in practice, e.g. local, single and multiple ASP
EMR data quality	Overall rating of data quality based on sensitivity/specificity of selected data elements in terms of accuracy and completeness; high ≥80%, medium ≥60%, low <60%
Time since implementation	Length of time since EMR went live, expressed as <1, 1-2, 3-4, ≥5 years
Provider type	Type of primary health care providers in practice, defined as solo physician practice, group/multispecialty physician practice, and interprofessional PHC team
User prior EMR experience	Average length of time that users have used EMR in the past, expressed as none, or yes with <1, 1-2, 3-4, ≥5 years
User satisfaction	Overall satisfaction rating from users toward the EMR, expressed in a Likert scale from 1 to 5, with 1 as highly dissatisfied and 5 as highly satisfied
Practice organization	Type of PHC organization/model in place, defined as fee-for-service, alternate payment plan, capitation and blended payments
Practice size	Number of PHC providers in the practice, defined as 1-3, 3-4, ≥5 providers
Practice improvement	Training and support activities in place that enhance practice management and clinical care, defined as none, EMR related, non-EMR related, and both activities
Finance incentives	Use of government funding to improve practice, defined as EMR support, practice support, and both
Indicator targets	The quality process and outcome indicators defined by CIHI summarized as a PHC quality index, calculated using the SQUID algorithm [x]
Quality process indicators	The subset of PHC quality indicators that relate to care processes performed within the specified time period as part of the recommended guidelines
Quality outcome indicators	The subset of PHC quality indicators that relate to care outcomes met as part of the recommended guidelines
PHC quality index	Adaptation of the SQUID algorithm based on a subset of PHC indicators published by CIHI, expressed as the average of indicator targets

Data Analysis - We need to conduct univariable testing of each pair of parameters, followed by multivariable testing while controlling for the parameter. We then use this multivariable model for prediction

a) Univariable testing – Determine relationship between PHC quality index and each variable separately, e.g., PHC quality index and EMR adoption score, PHC quality index and EMR product, etc.
b) Multivariable testing – Determine relationship between PHC quality index and EMR adoption score after controlling for the other parameters, i.e. Eq.5.

$$PHC\ quality\ index\ = \\ Adoption\ score\ +\ (EMR\ product\ +\ EMR\ configuration\ + \\ EMR\ data\ quality\ +\ Time\ since\ implementation\ +\ Provider\ type\ + \\ User\ prior\ EMR\ knowledge\ +\ User\ satisfaction\ +\ Practice\ organization\ + \\ Practice\ size\ +\ Practice\ improvement\ +\ Financial\ incentive) \quad (5)$$

c) Prediction – Use the multivariable model from (b) to do prediction

4. Next Steps

HIMSS Analytics has recently released an US Ambulatory EMR Adoption Model that measures adoption stages but it is focused on EMR functionality without any linkage to contexts [18]. Conversely, two recent PHC evaluation studies from Ontario and Quebec have identified many factors that influenced PHC performance but neither examined their relationship with EMR adoption in detail [19,20].

Table 2. Example PHC indicators from CIHI.
Legends: PHC# indicator reference number; + reviewed by author.[MP] as feasible to extract from EMR, *not part of prioritized CIHI list but reviewed as feasible

PHC Quality indicator	Eligibility criteria	Target	PHC#	Feasible+
Process Quality Indicators				
Influenza immunization	Age ≥ 65	Within last year	41	
Congenital hip displacement, eye and hearing problem screening	All	By 3 years of age	43	
Primary childhood immunizations	All	By 7 years of age	44	
Colon cancer screening (Hemoccult)	Age ≥ 50	Within last two years	48	√
Mammography and breast exam	Ages 50 to 69	Within last two years	49	
PAP smear	Ages 18 to 69	Within last three years	50	
Lipid profile screening (full fasting)*	Women, age ≥ 55	Within last two years	52	√
Lipid profile screening (full fasting)*	Men, age ≥ 40	Within last two years	53	√
Blood pressure measurement	Age ≥ 18	Within last two years	54	√
Fasting blood sugar Lipid profile screening (full fasting) Blood pressure measurement Obesity/overweight screening	Age ≥ 18 with coronary artery disease	Within last year	55	
Eye exam	Ages 18 to 75 with diabetes mellitus	Within last two years	58	
ACE inhibitors or ARBs*	Congestive heart failure	Active ACE or ARB treatment	60	√
Beta blocker	Acute myocardial infarction	Active beta blocker treatment	62	√
Outcome Quality Indicators				
Blood pressure control	Age ≥ 18 with hypertension duration ≥1 year	<140/90 mmHg	40	√

We presented this multivariate model as part of a panel discussion on complex eHealth interventions at the 2012 Canadian Association of Health Services and Policy Research Conference in Montreal. The model was well received as a potential way to quantify and explain the factors that influence successful EMR integration to improve primary health care. For next steps we are planning a Delphi study in fall 2012 to solicit feedback on the face validity of this model from stakeholders involved with EMR adoption in Canada and elsewhere. The Dephi study will consist of two rounds of feedback from stakeholders starting with the proposed model in this paper with revisions to improve the model after each round. The stakeholders will include jurisdictional representatives who are part of the Canada Health Infoway benefits evaluation forum, members of the UVic eHealth Observatory virtual community on eHealth benefits evaluation, and researchers and practitioners engaged in primary health care and EMR research. Then we need to test the model with the steps that have been outlined in section 3.3 of this paper.

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Towards Assessing The Socio-Economic Impact of VPH Models

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Abstract: Biocomputational modeling as developed under the European Virtual Physiological Human (VPH) and the US NIH program on "Predictive Multiscale Models of the Physiome in Health and Disease" is the area of ICT to most likely revolutionize the practice of medicine. The VPH is a framework of methods and technologies that, once fully established, will make possible the investigation of the human body as a whole. There is considerable demand for measurable evidences that such complex technology is actually worth the cost. How is it possible to quantitatively assess ex ante such technologies in terms of safety, efficacy, and socio-economic impact on our health systems? With the example of osteoporosis management, a socioeconomic assessment framework is presented that captures how the transformation of clinical guidelines can be evaluated. Applied to the clinical decision support system under development in the European Osteoporotic Virtual Physiological Human Project, a consequent cost-benefit analysis delivers promising results, both methodologically and substantially.

Keywords: Virtual Physiological Human

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The Use of Discrete-Event Simulation Modeling to Compare Handwritten and Electronic Prescribing Systems

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Abstract. Electronic prescribing (e-prescribing) is expected to bring many benefits to Canadian healthcare, such as a reduction in errors and adverse drug reactions. As there currently is no functioning e-prescribing system in Canada that is completely electronic, we are unable to evaluate the performance of a live system. An alternative approach is to use simulation modeling for evaluation. We developed two discrete-event simulation models, one of the current handwritten prescribing system and one of a proposed e-prescribing system, to compare the performance of these two systems. We were able to compare the number of processes in each model, workflow efficiency, and the distribution of patients or prescriptions. Although we were able to compare these models to each other, using discrete-event simulation software was challenging. We were limited in the number of variables we could measure. We discovered non-linear processes and feedback loops in both models that could not be adequately represented using discrete-event simulation software. Finally, interactions between entities in both models could not be modeled using this type of software. We have come to the conclusion that a more appropriate approach to modeling both the handwritten and electronic prescribing systems would be to use a complex adaptive systems approach using agent-based modeling or systems-based modeling.

Keywords. Discrete-event simulation model, Complex Adaptive Systems, Agent-based Model, Electronic Prescribing, Handwritten Prescribing.

Introduction

There are many benefits that are expected from an electronic prescribing (e-prescribing) system for Canadian healthcare. These benefits include greater efficiency and a possible reduction in medication errors and adverse drug events (ADEs) [1]. Canada Health Infoway (Infoway) has found some benefits from e-prescribing implementations in Canada, such as a reduction in ADEs, greater patient compliance, and greater productivity from providers [2]. However, since there currently is no functioning e-prescribing system in Canada that is completely electronic, the ability of the system to function at both a provincial and national level is not clear. As we are unable to evaluate the performance of a live e-prescribing system, a reasonable alternative would be to consider the use of simulation modeling for evaluation. Simulation modeling can be used to model a proposed system, making it possible to

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design and measure the performance of a system before it is actually built [3]. Simulation modeling of e-prescribing may be of benefit in identifying transition issues, key productivity bottlenecks and patient safety concerns that may disrupt or delay clinical adoption. Simulation modeling might also be able to demonstrate the potential impact that e-prescribing would have to Canadian healthcare. Others have developed simulation models of e-prescribing systems or closely related systems, such as computerized provider order entry systems (CPOE). Bell et al., with the RAND Corporation, developed and used a simulation model to predict how the implementation of different aspects of an e-prescribing system would affect variables such as process times and workflow efficiency [4]. Anderson et al. developed a simulation model to test how changing certain aspects of a CPOE system would impact variables such as medication errors, ADEs, and costs [5].

We set out to develop two discrete-event simulation models, one of the handwritten prescribing system currently used in the out-patient setting in Canada and one of a proposed electronic prescribing system for Canada, and then compare the performance of these systems to each other.

1. Methods

1.1. Building the Simulation Models

The modeling software Arena was selected for building our discrete-event simulation models. Arena has been selected by other researchers to develop e-prescribing simulation models, such as Bell, who were able to successfully develop their simulation models using this software [4]. Drug prescribing and dispensing processes for both handwritten prescribing and electronic prescribing were first mapped out in Arena using a standard modeling notation, Business Process Modeling Notation (BPMN). Both models included processes involved in drug prescribing and dispensing. The handwritten prescribing simulation model was built based on the clinical experiences of a member of the research team (KK). The electronic prescribing simulation model was inspired by a proposed e-prescribing system for Canada developed by Canada Health Infoway [6]. The models were reviewed by a pharmacist and two data modelers for completeness and accuracy.

Data values for both the handwritten prescribing and e-prescribing simulation models were estimated based on the clinical experiences of a member of the research team (KK). Data values were estimated for process times, number of prescriptions, and decision points. Minimum, maximum, and average values for each process were also estimated.

1.2. Testing the Simulation Models

Once the simulation models were built and populated with data, test scenarios were developed to test the models. Test scenarios were designed to test the completeness of the models and to check for any bugs present in the models. Sensitivity analysis was also performed.

1.3. Comparing the Simulation Models

After the models were tested, the handwritten prescribing simulation model was compared to the e-prescribing simulation model. This was done by running each simulation model and then comparing the output reports for the variables of interest.

2. Results

Both the handwritten prescribing simulation model and the e-prescribing simulation model were successfully built in Arena and were determined to be complete and accurate by the pharmacist and data modelers who reviewed the models. Figure 1 displays a condensed version of the handwritten prescribing simulation model. Figure 2 displays a condensed version of the e-prescribing simulation model.

Running test scenarios through each model revealed that the models were running properly and were complete. Small bugs in both models were corrected. We were able to compare the handwritten prescribing simulation model to the e-prescribing simulation model on several levels. We compared the number of processes involved in each model and were able to determine that the e-prescribing model clearly contained more processes than the handwritten prescribing model. The handwritten prescribing model contained 34 processes, while the e-prescribing model contained 60 processes. We found that we could compare workflow efficiency between the two models by comparing similar processes in both models for average process times. Finally, we were able to compare how the initial input of patients or prescriptions were distributed throughout the handwritten system and the e-prescribing system once the simulations were run. The results of the comparison between the two simulation models are displayed in Table 1.

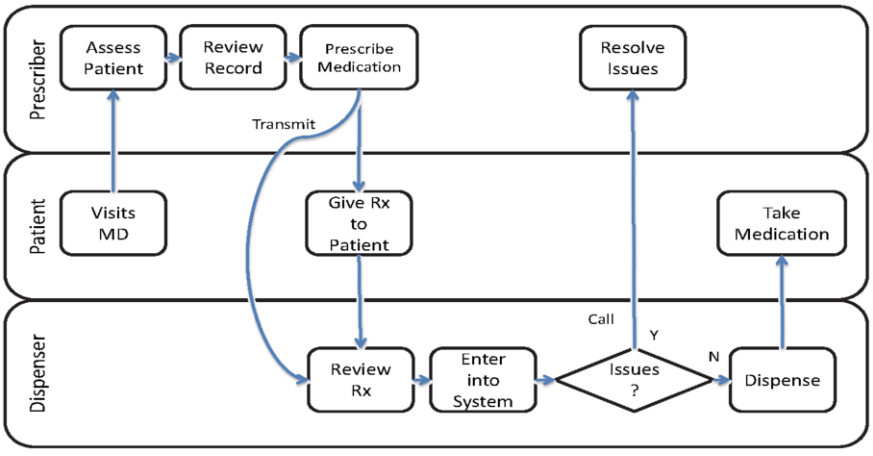

Figure1. Condensed version of handwritten prescribing simulation model.

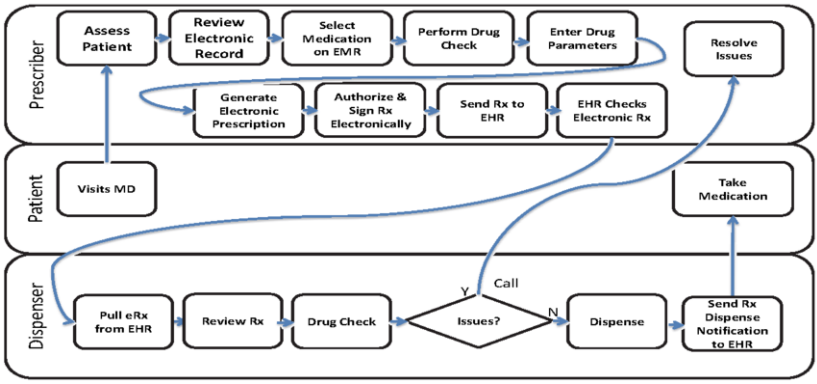

Figure2. Condensed version of electronic prescribing simulation model.

Table 1. Comparison of Process Number and Times for Each Model

	Handwritten Model	E-Prescribing Model
Total Processes	34	60
Time to Review Chart	Paper Chart –1.58 Minutes	E-Chart – 0.84 Minutes
Select Medication	0.23 Minutes	0.22 Minutes
Generate Prescription	Paper – 2.49 Minutes	Electronic – 0.44 Minutes
Pharmacist Manages Issues From Drug Check	0.97 Minutes	0.33 Minutes
Callbacks to Physicians	21.87 Minutes	28.86 Minutes

3. Discussion

Although we were able to build detailed simulation models of the handwritten prescribing system and the electronic prescribing system in Arena, using a discrete-event simulation modeling software to model these systems proved to be challenging. We were only able to measure workflow efficiency, using process times, in Arena. We could not also measure other important outcomes such as patient safety, which would be measured using the number of medication errors or adverse drug events. We initially viewed both the handwritten system and the electronic prescribing system as linear processes; however, when modeling both processes we came to the realization that there are processes in both systems that are non-linear. An example is a prescription that is not clearly written, which affects several other processes including the pharmacist reviewing the prescription, the pharmacist calling back the physician, the patient receiving the wrong drug, and then ultimately having to see the physician again due to issues with the medication. While it is possible to model non-linear processes like this using discrete-event simulation software like Arena, discrete-event simulation software is not the ideal choice for modeling non-linear processes [7]. Furthermore, we found that there are several feedback loops in both systems, such as call backs to physicians from pharmacists seeking clarification and the refill process. Again, while feedback loops can be modeled using discrete-event simulation software,

it is not the ideal choice for modeling feedback loops [7]. Finally, we found that while Arena was suitable for modeling both systems with a sufficient level of detail, it was not suitable for modeling the interactions between entities in both models.

In future, we plan to use a complex adaptive system approach to simulating the handwritten prescribing system and electronic prescribing system by using agent-based or systems-based simulations.

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A Model of Collaborative Agency and Common Ground

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Abstract. As more healthcare delivery is provided via collaborative means there is a need to understand how to design information and communication technologies (ICTs) to support collaboration. Existing research has largely focused on individual aspects of ICT usage and not how they can support the coordination of collaborative activities. In order to understand how we can design ICTs to support collaboration we need to understand how agents, technologies, information and processes integrate while providing collaborative care delivery. Co-agency and common ground have both provided insight about the integration of different entities as part of collaboration practices. However there is still a lack of understanding about how to coordinate the integration of agents, processes and technologies to support collaboration. This paper combines co-agency and common ground to develop a model of collaborative agency and specific categories of common ground to facilitate its coordination.

Keywords. Common ground, collaborative agency, coordination

Introduction

Collaborative care delivery is challenging due to the fact it requires the integration of multiple people, processes and information and communication technologies. Failure to properly integrate these different entities results in communication issues, medical errors, and poor information management [1].

Information and communication technologies (ICTs) can facilitate collaborative care delivery by supporting different types of interactions [2]. To date there has been limited research on ICT design to support collaboration with the more prominent focus being on individual ICT usage [3]. However before we can designing ICTs to support collaboration we need to fully understand the various interactions that exist as part of collaboration.

Co-agency, described as humans, technology and processes working together in the pursuit of jointly held goals [4], has been used to understand collaborative practices. A shortcoming with existing studies is that they have not studied the multiple ways in which collaborative agents, processes and technology integrate. It is these dynamic integrative processes that we need to focus on because that is where problems most often occur. Coiera's interaction design theory states that we need to look beyond

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individual agents or technologies to understand group interactions across multiple agents and technologies [5]. A key part of group interactions is common ground, the knowledge two or more agents need to share in order to collaborate. If agents do not have common ground about roles or processes it can impact how a task is conducted leading to adverse events or communication issues [6].

We suggest that co-agency and common ground can be combined into collaborative agency to refer to how collaborative agents (i.e. human and technological) and information and processes are integrated as part of collaborative care delivery. Collaborative agency considers the multiple entities that are integrated but also the process of integration.

This paper introduces the concept of collaborative agency and the role common ground plays in its development. Specifically we develop a model of collaborative agency that focuses on the integrative aspects of collaborative care delivery. We then identify categories of common ground that impact the development of collaborative agency.

1. Study Design

The authors studied collaborative care delivery in two different areas of medicine. First was a study of palliative sedation on an inpatient palliative care unit. Second was a study across three hospitals of a surgical information management system (SIMS) that is used in all areas of the perioperative process. Both studies had specific objectives related to studying aspects of collaboration. The findings from both studies were combined and reanalyzed to provide insight on collaborative agency and common ground

1.1. Data Sources

The palliative care study involved 76 hours of non-participant observation. The perioperative study involved approximately 90 hours of non-participant observations. Both studies also conducted follow up interviews to probe or gain insight into observation details.

1.2. Methods

Qualitative content analysis [7] was used to re-analyze the data from both studies. The analysis was not done with any preconceived themes other than wanting to identify components of collaborative agency and common ground.

2. Results

Our results are presented in two sections. First we develop a model of collaborative agency. Second we identify four types of common ground and describe how they influence the development of collaborative agency.

2.1. Model of Collaborative Agency

Fig.1 shows our model of collaborative agency. There are two main aspects to the model. First are the collaborative factors and second is the coordination of the factors as part of collaborative care delivery.

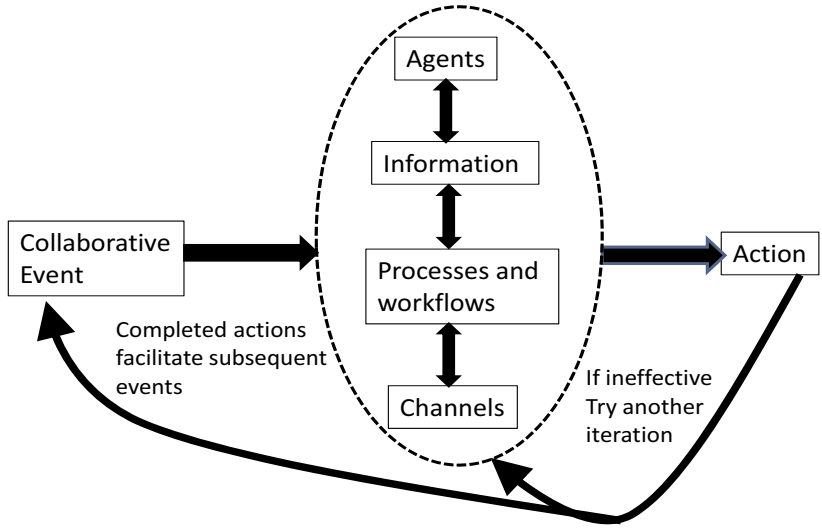

Figure 1. Model of collaborative agency (dotted oval is the collaborative cycle with four collaborative factors within it)

Collaborative agency is initiated with an event. The event then facilitates the integration of four collaborative factors: agents, information, processes and workflows, and channels. The integration of the different factors leads to an action. There are two aspects to the model that illustrates the complexity of collaborative agency. First is that collaborative agency is a dynamic process with multiple potential iterations. Although a collaborative event will use each of the four collaborative factors in the collaborative cycle (dotted oval in fig.1) the factors can be integrated in many different ways. There are also different variations of each factor. For example, channels that are used to communicate can include paper, electronic or oral means, while agents can be intra or inter disciplinary. Second, collaborative agency is not a one-time action but rather is an ongoing cycle of collaborative events and different integrations of the collaborative factors. A collaborative event may cycle back to form a new iteration of the collaborative factors if the action was ineffective and did not achieve the desired outcome. For example, if a communication action did not reach the desired recipient a new channel or different agent may be integrated into the event. Successful collaborative events will drive subsequent events as part of the continuum of care.

2.2. Common Ground and the Development of Collaborative Agency

Common ground represents the shared meaning that the collaborative factors need to have in order for collaboration cycle to work effectively and facilitates the coordinative aspect of collaborative agency. If there is weak common ground amongst any of the collaborative factors it will adversely impact the development of collaborative agency.

We identified four specific types of common ground: technology, information, process and personnel. The four types map to the four collaborative factors from section 2.1 (technology common ground incorporates channels and personnel common ground incorporates agents from section 2.1).

Technology Common Ground – If agents do not have common understanding about how to use technology they may use it in ineffective ways or develop workarounds. In the perioperative study an anesthetist was entering all her data in the Surgical Information Management System (SIMS) in real time and commented that the technology made it difficult to administer medications and monitor the patient. However, the system was designed to allow a clinician to tag certain events as a bookmark to enable them to go back and enter data during a quieter time in the surgery. The real time data entry that impacted patient care was not necessary but the anesthetist lacked common ground about how SIMS should be used.

Information Common Ground – Information is what is disseminated through channels as part of collaboration and lack of common ground about information will impact the agent's ability to collaborate effectively. One of the biggest barriers to information common ground was informal communication practices. In the palliative care study informal communication practices, both text-based and oral, were common. Informal communication may lead to inconsistent messages and may not be disseminated to all agents. Both of those issues prevent the development of information common ground.

Process Common Ground – If agents do not have common knowledge about processes and how they should be conducted it can impact integration with other collaborative factors. For example, in the perioperative study SIMS allows users to 'bring forward' a previous patient assessment. The anesthetist then simply has to update the patient assessment rather than entering in a whole new assessment. During observations we learned that it was common for anesthetists to not know about the 'bring forward' process and instead do a whole new assessment. Further they would blame SIMS for being the cause of redundant data entry. One anesthetist who knew about the 'bring forward' process commented '*That's a process issue and not a technology issue*'.

Personnel Common Ground – An essential part of coordinating collaboration is common understanding about what roles or tasks collaborating agents can and cannot do. Personnel common ground looks at the different roles that agents can play, the abilities they have, and their level of comfort at doing a task. Part of personnel common ground is differentiating an agent's ability to do a task with their willingness to do it. As one physician noted, "*it's not fair to ask [nurses] to nurse the patient if they're not comfortable with what you're asking them to do*".

3. Discussion

This study combined co-agency and common ground to introduce the concept of collaborative agency. We developed a model of collaborative agency and identified four collaborative factors that comprise agency. We have also expanded existing work on common ground by identifying four specific types of common ground and describing their role in the development of collaborative agency. Although the importance of co-agency and common ground has been previously described this is the

first study that has combined the two and identified specific collaborative factors and types of common ground.

The collaborative factors and common ground types can be used to design and evaluate ICTs to support collaboration. For example, while technology is often blamed for workflow problems, the description of technology and process common ground in section 2.2 revealed that people do not always use systems in an appropriate way. Although SIMS was blamed for workflow and redundant data entry issues it was actually a lack of technology or process common ground that caused the issues. Conducting in-situ evaluation studies, better training on system usage, and longitudinal evaluation studies would help the formation of process and technology common ground.

Collaborative agency and common ground can also help process redesign to support collaborative care delivery. One of the biggest barriers to common ground development was informal communication practices or processes. Informal processes (i.e. workarounds) make it difficult for collaborative agents to coordinate actions and may be an ineffective or even unsafe way of doing the process. Informal information reduces standardization which can adversely impact information exchange. Protocols that facilitate collaborative agency and support common ground development (i.e. formalized processes and information) should be developed as part of collaborative care delivery.

This study has illustrated the relationship between collaborative agency and common ground and their roles in supporting collaborative care delivery. While collaborative agency represents the integration of agents, processes, information and technology it is common ground that ensures that the collaborative factors are actually interoperable with each other.

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