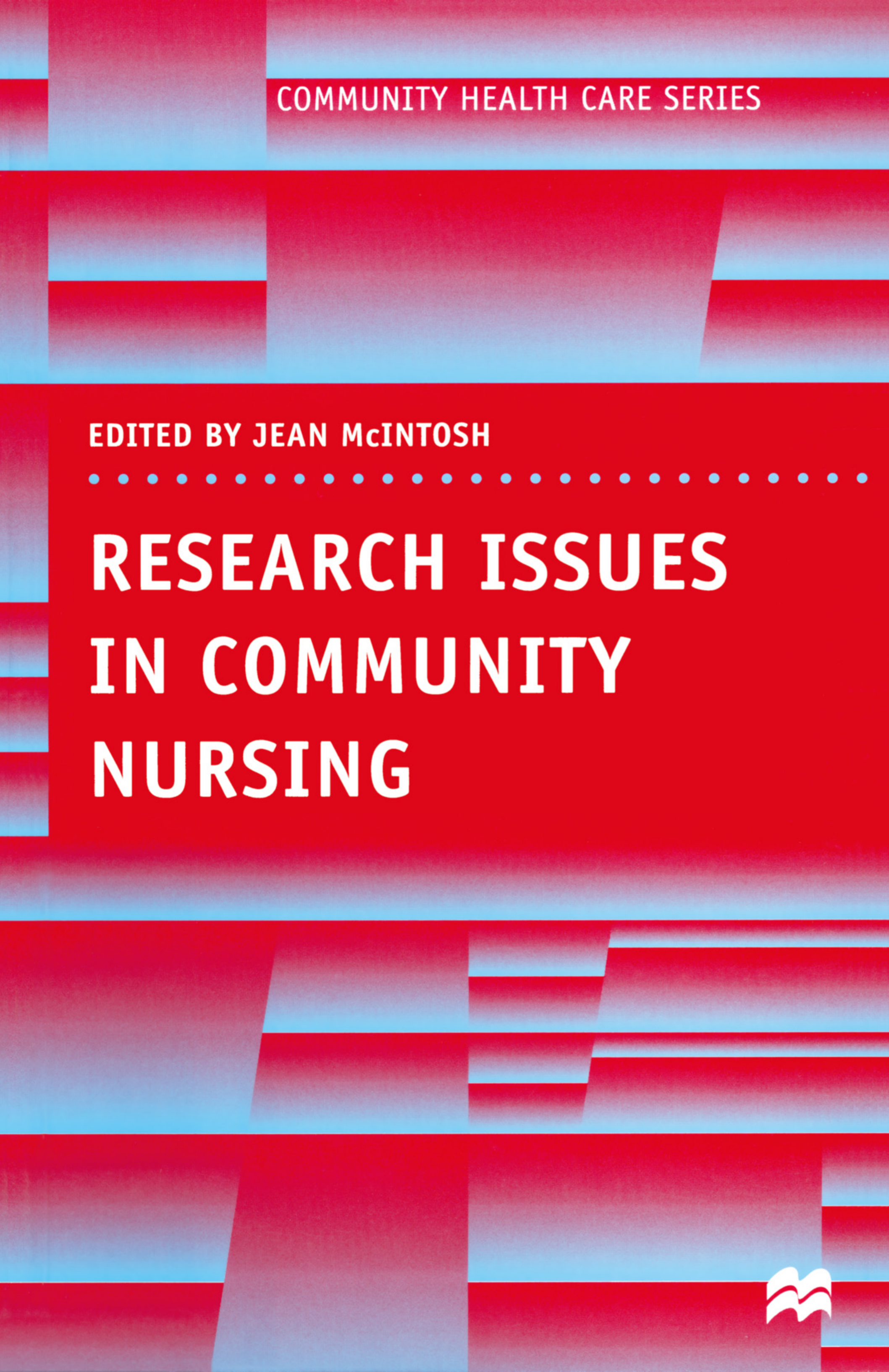

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Research Issues in Community Nursing

Edited by

Jean McIntosh

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FOREWORD

The current pace of change in primary care has an unstoppable momentum. The shape of health and social care services is being transformed as primary care groups evolve, the balance of care continues to shift into the community, and policies promote the involvement of users and carers. However, organisational change on this scale is more often influenced by politics than by research, and this primary care agenda is no exception. Jean McIntosh's book is welcome because it is a timely addition to the relatively sparse research literature on community nursing and because it gives space to the conceptualisation and elucidation of ideas that drive research questions. Theoretical development of this kind is highly important but, in the rush to appraise effectiveness and value for money, is rarely funded. However, if funded time is not given to understanding the concepts of, for example, vulnerability and carer stress, which define the questions and drive the method of empirical study, the quality of research will be diminished.

This book pulls together several important themes, the first being the analysis of the evolution of research questions concerning role definition, boundaries and deployment that have preoccupied both the profession and managers for the past 30 years. The overviews of district nursing and community psychiatric nursing put the contemporary versions of those earlier questions into an interesting and helpful historical perspective. Building knowledge from incremental research of this kind must be articulated and made visible to the research commissioners and policy-makers, who will continue to be preoccupied with these questions as the service changes and adapts to new demands, and as continued quests are made to match roles to service needs.

The second theme that emerges is the detailed discussion of method in some of the chapters. Jean McIntosh and her colleagues' clear exposition of the conceptual framework and methodological development in a study that sets out to explore district nursing skills is an unusual and helpful contribution to research knowledge and understanding. Alison While draws attention to the value of the multimethod approach in a complex field where there are inconsistencies in the definitions used, difficulties in follow-up and important ethical issues related to investigating the needs of and services for families caring for children with life-limiting illness.

The book's third major theme is the meaning of evidence, its value and its application to practice. It is not new for nursing to be exhorted to use research findings, but this view has been reinvented and clothed in different language in the evidence-based practice 'movement'. Sally Kendall and Ros Bryar tackle different aspects of this in a review of the constraints on the utilisation of research in practice and the strategies for overcoming these. This book makes an important contribution to this issue because it provides some of the tools of critical appraisal by its in-depth consideration of selected questions and by giving nurses the mental map containing its own (albeit small-scale) research history, which has been used to build increasing expertise and sophistication in theoretical development as well as the use of appropriate methods. This knowledge is vital if nursing is to enhance its credibility as an equal partner and stakeholder in primary care research and to help us to explore questions on, for example, the nature of nursing and health visiting interventions and whether or not they make a difference.

FIONA ROSS
PROFESSOR OF PRIMARY CARE NURSING

SERIES EDITOR'S PREFACE

Successive governments have indicated their commitment to enhancing the health of the nation and, in recent years, the focus of care delivery has shifted with escalating speed into the community. In so doing it has become evident that community nurses and health visitors provide the focus for the promotion of health gain, and for the maintenance of positive health status for individuals, groups and local communities. Community nurses and health visitors are destined, therefore, to become leaders in the design, delivery and evaluation of effective health care interventions, informed by academic discovery, and advanced practice skills and competencies.

The changes that confront the contemporary community nursing practitioner are characterised by the diverse nature of the context within which community care is transacted, with an increasing emphasis on inter-sectoral co-operation, interprofessional collaboration, community action and development, and reduced reliance on the acute sector and residential care provision for longer stay client groups.

The impact of change, pushed by a growing demand for flexible, high-quality services provided within local communities, will inevitably shape the NHS of the future. Resources have already been shifted to the community (although at a pace that is all too often criticised as being grossly inadequate to meet client need). Commissioners and providers are now required to demonstrate that the care they purchase and deliver is effective and responsive to the needs of local practice populations. To complement this, community nurses will be required to ensure that their activities make a significant impact on health gain for their practice population and, as such, must become seriously involved in structuring the political agenda that ultimately governs their practice environment.

In order for the community workforce to respond to these challenges, it will be necessary to ensure that community workers are equipped with the necessary skills and knowledge base to be able to function effectively in the 'new world of community health practice'. Nurses will be required to develop and change, drawing upon the very best of their past experience, and becoming increasingly reliant upon the production of research evidence to inform their future practice.

This series is aimed at practising community nurses and health visitors, their students, managers, professional colleagues and commissioners. It has been designed to provide a broad-ranging synthesis and analysis of the major areas of community activity, and to challenge models of traditional practice. The texts have been designed specifically to appeal to a range of professional and academic disciplines. Each volume will integrate contemporary research, recent literature and practice examples relating to the effective delivery of health and social care in the community. Community nurses and health visitors are encouraged towards critical exploration and, if necessary, to change their own contribution to health care delivery – at the same time as extending the scope and boundaries of their own practice.

Authors and contributors have been carefully selected. Whether they are nurses or social scientists (or both), their commitment to the further development and enrichment of health science (and nursing as an academic discipline in particular) is unquestionable. The authors all demonstrate knowledge, experience and excellence in curriculum design, and share a commitment to excellence in service delivery. The result is a distillation of a range of contemporary themes, practice examples and recommendations that aim to extend the working environment for practising community nurses and health visitors and, in so doing, improve the health status of their local consumer populations.

Research Issues in Community Nursing, edited by Professor Jean McIntosh, has been written by a team of expert researchers and practitioners that is representative of the context of contemporary community health-care delivery. Together they produce a rich tapestry to illustrate the scope and influence that community nursing research has exerted on the health care agenda. The book provides evidence of the potential role that exists for all community nurse practitioners to aspire towards excellence in their work, based on the synthesis and dissemination of expert evidence to inform clinical/client-focused decision-making in the workplace. The text is based on a vision of the achievable and recognition of the many challenges that confront community practitioners in the advancement of their primary care research role. As such, readers will be challenged to reflect and adopt a systematic approach to research enquiry while being encouraged to integrate theory with practice with the aim of improving client care.

DAVID SINES
UNIVERSITY OF ULSTER, BELFAST

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I would like to offer sincere thanks to the researchers who have contributed to this book. All of them have many other demands on their time, and their willingness either to write a chapter or contribute to a chapter for this book has been much appreciated. I would also like to thank David Sines, Series Editor, whose wise counsel, good nature and enthusiasm have helped me throughout the editing work.

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Introduction

Jean McIntosh

This volume aims to explore research in community nursing from a range of different perspectives, focusing on the way in which the research is developed, conducted and used. Rather than presenting a series of straightforward 'accounts' of research studies, the intention within the volume is to explore the context in which research takes place, to illuminate important aspects of the research process that present challenges to the researchers concerned and finally to highlight the knowledge-building potential that research in community nursing offers.

As nurses are now being exhorted to make their practice evidence-based, it is hoped that this volume will make a contribution to that process and also highlight some of the difficulties involved in both producing and using research as 'evidence' (DoH, 1993). It is also the intention to raise awareness of the nature and extent of the influence that government policies and current changes in the NHS have on research enquiry.

In order to set the context for an understanding of current issues in community nursing research, three chapters include reflections on the early pioneering work in the field, noting the genesis of the research questions that were being asked at that time and making connections between past and current preoccupations.

A broad view of the development of research in the field of district nursing is taken by Lisbeth Hockey in Chapter 3. Hockey discusses some of her early research studies, setting them into a historical context and then demonstrating a progression of content in her linked series of research investigations. Such an achievement of coherence and development is uncommon in the field of nursing research, and Hockey argues cogently in support of the benefits of taking such an approach. The chapter concludes with a review of more recent developments in district nursing research and identifies some of the key issues within practice and policy that need to be addressed in the future. The challenge posed for those contemplating research in the field of community nursing is to identify ways in which future studies can achieve both progression and coherence.

In Chapter 2, Sally Kendall adopts a slightly different stance and reflects on health visiting research through the lens of evidence-based practice. She explores the problems that health visitors may encounter in trying to decide what constitutes 'evidence', and her argument links well with that of Ros Bryar in Chapter 1. In discussing the context of some of the early work in health visiting research, Kendall echoes some of Hockey and McIntosh *et al.*'s points in Chapters 3 and 4 about the private nature of community nursing activity and the importance of research, which reveals the nature and quality of professional practice in this field. Kendall also considers the relationship of accountability to evidence-based practice in the context of current policy within the NHS and concludes her chapter with a detailed exploration of the way in which all these themes are expressed within the important issue of postnatal depression.

Edward White completes the reflective theme in Chapter 6 with an historical perspective that relates the development of the community psychiatric nursing service to the central themes of research investigation in the field. White discusses the seemingly perennial issues of role, role ambiguity and workforce planning, spanning decades of enquiry. He demonstrates how a misuse of research can be accepted uncritically and subsequently lead to faulty assumptions that may persist for a considerable period of time. These are still key issues today, given the relocation of mentally ill people in the community and the continuing debate about the appropriate focus for the work of the community psychiatric nurse.

Rosamund Bryar explores the very important issue of research utilisation in Chapter 1 and relates it to community nursing practice. She argues that the 'development phase' of research and development activity has been given scant attention in the past and goes on to explain the complexities involved in using research findings to achieve development and change in practice. One of the key issues is an understanding of the way in which contextual and other factors influence such change. Bryar rightly emphasises the importance of understanding those factors that militate against, as well as those that promote, the use of research findings. Such an understanding is central to any use that is made of the research reported in this volume and Bryar concludes with an account of an action research initiative offering useful examples of how some of the difficulties in development have been overcome.

In Chapter 5, Sawsan Reda gives a personal account of her doctoral research in the field of mental health. Personal accounts are useful in demonstrating one of the ways in which community nursing research can be accomplished, and this research differs in important respects from other doctoral work, that is more often conducted in isolation from funded research. It is interesting to note how Reda's study dovetails with a concurrent grant-supported investigation, and she offers a range of useful references identifying in more detail how the studies complement each other. Reda reports on the important issue of resettlement in the community of people with mental health problems and identifies a number of challenges facing researchers in this field. There are important lessons contained within this chapter regarding the process of seeking ethical approval for access to research sites and participants, and Reda's experience resonates with comments made by Hockey in Chapter 3.

A complementary account of a national Department of Health funded study is offered by Alison While in Chapter 8. While offers a valuable insight into the difficulties associated with identifying a specific group of individuals, namely children with life-limiting disorders, and the problems encountered in estimating the size of this target population. She explains the strategies that had to be used to recruit research participants and demonstrates the benefit of using modified versions of existing research instruments. The chapter will be of value to researchers undertaking similar studies on either a national or a local basis.

The three remaining chapters each take an in-depth look at an area of key importance to the practice of community nursing. Jane Appleton, in Chapter 7, offers a comprehensive picture of the challenging and contentious issue of vulnerability, exploring problems of definition and interpretation. Appleton draws on a wide range of examples and argues that the concept of vulnerability could have important applications in community nursing, albeit with the use of different terminology. She then refers to her own research in order to explore the dimensions of vulnerability within health visiting practice. Her discussion raises important issues for practice, knowledge development and further research, and these should be capable of being applied across the community nursing specialties.

In Chapter 4, Jean McIntosh and her co-authors discuss a research study on the important issue of district nursing skills in the context of grade mix and the current climate of cost containment. They first consider the concept of skill and identify the problems that have stemmed from the overemphasis on practical skills as opposed to cognitive, interpersonal or managerial skills. The chapter goes on to discuss these skill domains in the light of work from the field of social psychology on skills acquisition, relating this to experiential learning. The authors highlight the fact that it is those skills which are 'invisible' that might best exemplify the differences between nurses of different grades, and they then discuss some of the challenges involved in undertaking research in this field. The authors conclude with some early findings from their Scottish Office supported study.

Finally, in Chapter 9, Mike Nolan and his co-authors identify the principles that could be used by community nurses as a foundation for their support of family carers. Drawing from their considerable research experience in this field, the authors put forward an assessment and intervention model for practice. Although the chapter refers to work with frail individuals, it will undoubtedly have relevance for all the specialties within community nursing. It is of particular note that the transactional model of stress developed by Lazarus (1966) forms a core part of the authors' work and links with some of Appleton's discussion in Chapter 7. Nolan and his colleagues carefully spell out the application of Lazarus' work to the support of carers, including the all-important coping strategies that might be employed, and outline the application to community nursing.

There is still a relative lack of research on practice, education and policy relevant to community nursing, in comparison with hospital nursing. The situation is gradually changing, as the balance between primary and secondary care alters in favour of health care in community settings. However, with the inception of primary care Trusts, there is added incentive, and a continuing urgent need, for practitioners and researchers to embark on investigations that can demonstrate the complex interrelationships between patient need, 'context', skills in use and community nursing practice (DoH, 1997; Scottish Office DoH, 1997). This book aims to show some of the progress that has been made in the research field and also to highlight some of the challenges that remain.

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CHAPTER ONE

Using research in community nursing

Rosamund Mary Bryar

Increasing the use of research in community nursing will only be achieved through a better understanding of the factors inhibiting the use of research and through investment in the different processes that have been found to enhance utilisation. In the report of a workshop on evidence-based nursing, Normand (1998, p. 22) comments: 'In many spheres of activity, and in most industrial settings, the development of products and services is a larger and more expensive process than research.' In contrast, in health care, the emphasis has been on undertaking research rather than on gaining an understanding of research findings, and facilitating the process by which they are adopted into practice, education and policy. The lack of attention paid in the wider health-care arena to the development side of research and development, and the utilisation of research is mirrored in the field of community nursing. For example, in *Nursing in Primary Health Care. New World, New Opportunities* (NHSME, 1993, p. 39), primary health-care nurses were exhorted to 'ensure that their practice is based on valid up-to-date research evidence and that they initiate, facilitate and participate in innovation and research programmes wherever feasible and appropriate', and it was stated that 'Nursing research should be integrated into primary care nursing practice. Existing practice should be continuously evaluated to ensure that every nursing activity is demonstrably beneficial to individual patient outcome and population health gain.' How these 'keys to progress' were to be achieved, however, is not elaborated.

It is the purpose of this chapter to explore those factors that inhibit the utilisation of research and to identify ways in which the use of research in community nursing practice, education and policy can be developed.

Nursing research has grown rapidly over the past 30 years, as is shown in Chapters 3, 4 and 7. This expansion has been encouraged by reports such as the Briggs Report (DHSS, 1972) and changes in nurse education, including the growth in the number of degree courses and the move of nurse education into universities (Hopps, 1994). Community nurse researchers, such as Lisbeth Hockey, Jean McFarlane and Charlotte Kratz, were among the early pioneers of community nursing research in Britain providing a basis for much of the later research in community nursing. Today, the Culyer mechanism, which has required the development of clear research programmes within the NHS, provides new opportunities for community nursing research (Brooker, 1998). However, this process is again focused on the generation of new knowledge through research rather than on the utilisation of the knowledge that is already available.

What is meant by the utilisation of research in community nursing? Tierney (1996) makes the interesting point that research utilisation is not only about the adoption into practice of research findings: utilisation also involves the use in practice of research methods, such as pain assessment tools. It is also concerned, Tierney suggests, with the process of enlightenment. While research findings may not be directly applicable to practice, or while the adoption of particular findings may be inhibited by organisational constraints, nurses may, by reading research reports, find that 'at least their own thinking had been extended, and become more enlightened' (Tierney, 1996, p. 394). A belief that the use of research includes the process of enlightenment and use of tools that are familiar elements of everyday practice may help to reduce the still-common responses among nurses to the word 'research' of fear, anxiety, distrust or indifference.

Utilisation is not, however, simply a function of the awareness or interest of the individual community nurse in research. As the International Council of Nurses (1996) and many researchers, including Closs and Cheater (1994) and Kenrick and Luker (1996), have commented, there is a need to consider the context within which nurses work in order to appreciate why they do or do not utilise research in practice. The community nurse is part of a complex system, and whether or not the care that the nurse provides is research based is determined by a number of factors, including the interrelationship between attitudes towards and support of research at the national and international levels, the organisational ethos in which the nurse is working and the attitudes of the individual nurse, which are in turn a function of the nurse's experience and education (Figure 1.1).

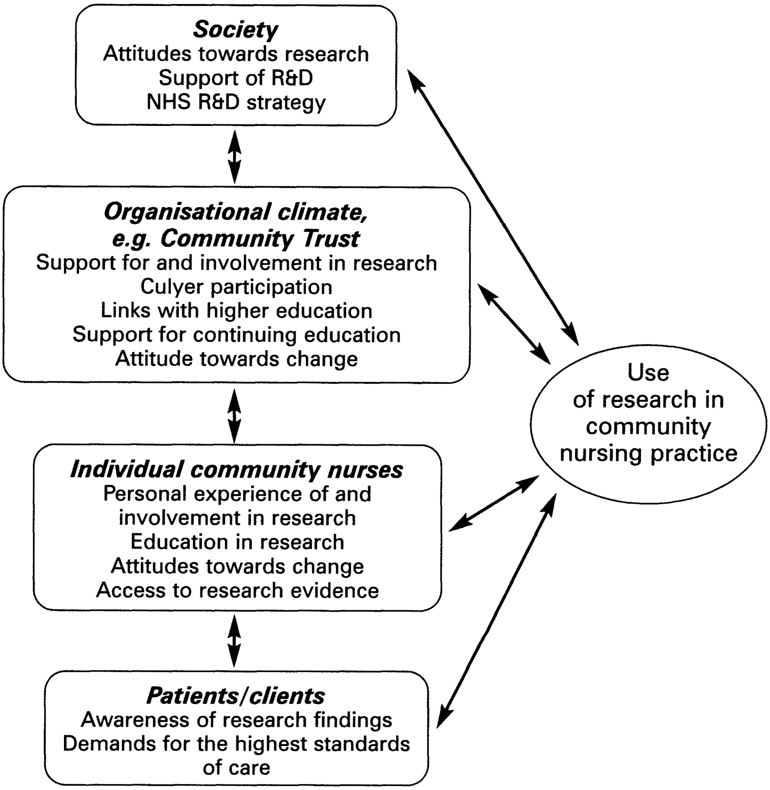

Figure 1.1 Aspects of the system of care influencing the utilisation of research in practice

The first part of this chapter considers three issues that are concerned with this wider context: the development end of research and development (R&D), change and the nature of research knowledge. Evidence of barriers to research utilisation is then discussed, followed by an examination of methods to overcome such barriers. The chapter concludes with a description, drawing on my own experience, of a development project that sought to increase research utilisation through a number of different methods using an action research approach.

DEVELOPMENT: THE CINDERELLA OF R&D

As noted at the beginning of this chapter, development has received less attention than research: 'No one owns the problem of getting research evidence into practice' (Normand, 1998, p. 19). Until recently, the general approach taken to development and research utilisation, as part of that process, has been low key. There has been an expectation that the trickle-down effect (which has been so singularly unsuccessful in tackling poverty) will see the gradual adoption into practice of research findings. However, this process can take a considerable amount of time and, in terms of the health of individuals, means that many people do not benefit from available knowledge of the most effective treatments. As a consequence, they may suffer avoidable pain, morbidity and death.

Research has received more attention than development as research is seen as the prestigious end of the R&D spectrum (Eve *et al.*, 1997). Research and development are often viewed erroneously as being at either end of a continuum, but Eve *et al.* (1997) suggest that, in reality, a chasm exists between research and development. In seeking to achieve a greater utilisation of research, local circumstances need to be understood, and multifaceted approaches may be most effective in bringing together the everyday world of practice with the world of research (Meerabeau, 1995; Eve *et al.*, 1997; Thomson, 1998). However, this process is not easy:

> The bad news is that there are no magic bullets, no quick-fix tool boxes packed with nifty tricks to achieve this [change]. Instead there is the much more complicated business of listening to people, solving the real world problems they tell you are inhibiting them and inspiring them to change. (Eve *et al.*, 1997, p. 34)

A number of methods have been described that illustrate the complexity of the process of development or research utilisation. Edwards-Beckett (1990) undertook a review of methods of facilitating research utilisation and identified nine issues needing attention at the level of the individual, group and organisation or profession. For example, the organisational promotion of research may be achieved through individuals having access to traineeships in research, in groups developing policies based on research and by the organisation or profession requiring evidence of research utilisation in departmental goals and statements. In the UK, the appointment of R&D co-ordinators is one approach that has been employed in altering the climate and developing research awareness and research skills (Fenn and Harries, 1990). Alternatively, in some research centres, emphasis is placed on researchers working with practitioners to utilise both deductive theory, developed through research activity and for example distilled into clinical guidelines, and inductive knowledge, developed from practitioners' descriptions and understanding of practice (Kitson *et al.*, 1996).

Rolfe (1994) argues for 'a new model of nursing research' that is concerned with changing practice. Using the experiential learning cycle, familiar to practitioners from reflective practice, Rolfe suggests that nursing research should move from observation and reflection, conceptualisation and generalisation to a third level involving the application of research to practice, the testing of applicability and further data collection and testing. This process, he suggests, will result in nursing being driven by research. While this process may be described more commonly as action research, this model provides an accessible approach to development.

Luker and Kenrick (1992), in their study of district nurses' knowledge and practice in relation to the care of people with leg ulcers, provide something of an illustration of the process described by Rolfe (1994). These community nurse researchers undertook a study of the sources of influence on district nurses' clinical decisions. Having identified a lack of awareness of research regarding leg ulcers, they developed a clinical information pack that was found to increase nurses' knowledge and change their reported practice (Luker and Kenrick, 1995). These findings, and the evidence of a lack of clinically relevant research literature in other areas of district nurses' practice, led to the publication of *Clinical Nursing Practice in the Community* (Kenrick and Luker, 1995). This aims to provide community nurses with research and other evidence that they may then utilise in their practice. Research could now be undertaken to complete a second cycle to evaluate the effectiveness of this publication in supporting change in clinical practice.

Nurses are now participating to a much greater extent in evidence-based health-care initiatives. For example, Jones *et al.* (1996) describe an ongoing project in the Northern and Yorkshire Region that involves primary health-care team members. The project focuses on a number of clinical areas, including asthma and coronary heart disease. Practitioners undertake critical appraisal skills training to enable them to evaluate the clinical guidelines that they introduce into their work following an audit of their current practice. The effects of the guidelines are then audited at a later date. This project, in addition to developing practice, is evaluating the effectiveness of the facilitation provided to the teams in introducing change in clinical practice. This project will therefore provide evidence, as does the work of Eve *et al.* (1997), about methods that are successful in supporting the development of primary health-care practice.

Finally, Thomson (1998), in a review of methods of supporting change in practice, identifies strategies that are consistently effective, have mixed effects or have been shown to have little or no effect. Education outreach visits, reminders, interactive educational meetings and multifaceted interventions have all been found to be consistently effective, whereas, for example, audit and feedback and didactic educational events have been found to be less effective in developing the use of research in practice.

CHANGE

The utilisation of research in practice is essentially about the process of change. Even for those community nurses whose initial education was research based and whose initial practice is thus research based, new findings during their professional careers will involve them in reappraising and changing their practice. New research findings challenge our previous practice, the quality of that practice and its effectiveness. It may be disturbing to be aware that the advice or care we have given may have been less effective than it might have been or have even contributed to poor health. For example, midwives and health visitors may have felt threatened in this way by the 'Back to Sleep' campaign, which advises that babies should sleep on their backs, in direct opposition to the advice previously given that babies should be placed to sleep on their fronts.

Change threatens our picture of ourselves and our relationships with others. Marris (1986) has likened the process of change to that of bereavement and suggests that, in participating in change, individuals may have to work through the various elements involved in the process of loss. Thus, in relation to the introduction of new research findings to practice, individuals may respond initially with anger, followed by denial and other feelings. They should ultimately be able to integrate the new knowledge into their new understanding of themselves and their practice. For example, I was able to observe this process taking place in a project concerned with introducing care planning into midwifery, and this process has similarly been observed in relation to the introduction of primary nursing (Mead and Bryar, 1992).

The introduction of new research into practice therefore needs to be sensitive to these issues. If anger is expected, it can be dealt with in the context of the nurses' practice and not seen as a personal threat to the change agent. Such an awareness of the individual work that has to be achieved may help to contribute to the successful introduction of change, although factors outside the individual may also inhibit change (see Figure 1.1 above).

RESEARCH KNOWLEDGE

This chapter starts from the position that it is important to strive for the utilisation of the best evidence in practice, education and policy-making. It may be suggested that this is not a position that is self-evident, and that, in reality, the use of research in all aspects of practice, education and policy is a long way from being achieved. Within nursing and medicine, personal experience and learning from the experience of colleagues has been extremely important in guiding practice. The oft-quoted statistic that only 20 per cent of medical practice is based on research evidence indicates the continuing importance of experience. Descriptions of clinical practice, for example women's experiences of birth (Editorial, 1996) or the use that general practitioners make of patients' descriptions of their lives and everyday problems (Editorial, 1995), demonstrate that one of the key issues for the practitioner is the mechanism of bringing together knowledge of the personal experience of people's lives with the research evidence. Carper (1978, p. 22) describes the complexity of nursing as the integration of the varieties of knowledge available to nurses: 'Nursing thus depends on the scientific knowledge of human behavior in health and illness, the esthetic perception of significant human experiences, a personal understanding of the unique individuality of the self and the capacity to make choices within concrete situations involving particular moral judgements.'

Assuming that the community nurse is aware of current research findings (an issue to be discussed later), the question for the nurse sitting in someone's front room is how to incorporate into the care of that person research evidence that is congruent with that person's life. This problem may be particularly acute in community as opposed to hospital nursing practice. In the community, the nurse is very aware of the lives of patients and their families, and is usually working alone. In the hospital, the ward team may more easily be able to incorporate research findings into care through reinforcement by team members and the different power relationship that exists in the hospital ward.

Community nursing practice is informed by knowledge from different sources: personal experience, the experience of colleagues, the experiences of patients and their families, initial and continuing education, and research. Nursing care is concerned with integrating these different types of knowledge in the best interests of the patient, client, family and community. Research knowledge is only one type of knowledge that is used in practice. Here, the reflective process cycle is important as a mechanism for bringing together research and practice knowledge (Rolfe, 1994; White, 1997). The challenge to community nurses, educators and policy-makers concerned with community nursing is to find ways of increasing the use of sound research in community nursing.

BARRIERS TO RESEARCH UTILISATION

In the British nursing literature, Hunt (1981, p. 192) was the first to identify factors inhibiting the use of research in practice, concluding that nurses do not use research findings because:

- They do not know about them.
- They do not understand them.
- They do not believe them.
- They do not know how to apply them.
- They are not allowed to use them.

Closs and Cheater (1994), in a review of the utilisation of research, categorised the mechanisms for increasing utilisation under the headings of culture, interest and support. Culture refers to societal and organisational support for research (see Figure 1.1 above). Interest is concerned with stimulating the interest of practitioners in research through education about research, through researchers writing in ways that are interesting to practitioners and through making research findings accessible. Support is concerned with the mechanisms for helping the adoption of research into practice. Closs and Cheater (1994) conclude that nursing in the USA has been much more active in tackling the problems of getting research into practice and they identify 10 strategies that could be used to facilitate utilisation (see Figure 1.2), many of which are referred to in this chapter. Bassett

(1992) classifies the barriers to research utilisation as educational, communicational and organisational. MacGuire (1990) supports the view that many of the factors inhibiting research utilisation are organisational and, in a paper originally addressed to senior nurse managers and educationalists, identifies 10 areas needing attention if research utilisation is to be advanced. These may be summarised as making judgements about the applicability of much nursing research to practice, managing the growing amount of evidence and managing the process of change.

Figure 1.2 Closs and Cheater's mechanisms for developing the use of research in practice

1. Funding for research utilisation initiatives
2. The investigation of barriers to research utilisation in specific areas, for example community nursing
3. The evaluation of different models of research utilisation in different contexts
4. Narrowing of the practice–research divide, for example through a career structure for researchers in nursing
5. Increased liaison between academic departments and practice settings
6. The development of explicit links between quality of care programmes, audit and research
7. The integration of research teaching in all pre- and postregistration nurse teaching, with an evaluation of such teaching
8. Access for nurses to research publications, with the provision of time and training in skills to use these resources
9. Researchers producing more systematic reviews and meta-analyses of research literature
10. Researchers presenting their findings in ways that are relevant to nurses in clinical areas

More recently, Hunt (1997, p. xi) has identified additional barriers to 'research mindedness' in nursing:

- time wasted debating whether qualitative rather than quantitative methodology should be the foundation of nursing research
- the slower growth of research into nursing practice – the fundamental core of nursing – compared with that of research into nurses and nursing education
- the lack of co-ordinated, clinically based nursing research programmes

- the lack of sufficient skilled researchers and teachers of research
- the association of research with academic élitism.

Webb and MacKenzie (1993), in a study using a convenience sample of 94 hospital nurses, found that few read nursing research journals (although 42 of the 94 read *Nursing Times* weekly). In observing nursing practice, the research team found little evidence of the application of research findings and concluded, 'It is therefore hard to avoid the conclusion that nursing, at least in the area studied, is still far from being a research-based profession and that research mindedness is not an approach that has been adopted' (Webb and MacKenzie, 1993, p. 132). Hicks *et al.* (1996) report a study concerned with the development of a tool to identify research training needs among members of the primary health-care team and, for this reason, included only 24 participants. The findings therefore need to be treated with caution, but it was found that the majority of the sample considered research and the utilisation of research in their practice to be unimportant and that they had negative attitudes towards research, as well as having a poor understanding of the research process.

Together, these authors identify the following factors as potential barriers to the use of research: researchers themselves and the research they undertake, clinical nurses and their attitudes and knowledge, nurse education and its content and expertise, and finally the policy/organisational context and its support for research and its utilisation.

A considerable amount of research has been undertaken investigating the perceptions of clinical nurses about the barriers they experience in making use of research. Much of this research is based on the work of Funk *et al.* (1991a, 1991b). These researchers developed an instrument to measure the barriers to research utilisation, the BARRIERS scale, from an examination of the literature on research utilisation. The scale has 29 items grouped into four factors that are shown in the literature to affect research utilisation (Funk *et al.* 1991a):

1. characteristics of the adopter: the nurse's research values, skills and awareness
2. characteristics of the organisation: setting barriers and limitations
3. characteristics of the innovation: the qualities of the research
4. characteristics of the communication: the presentation and accessibility of the research.

Walsh (1997a) reports a study in which community nurses undertaking the Royal College of Nursing BSc Health Studies (Nurse Practitioner) course were asked to complete the BARRIERS questionnaire. Of 58 nurses who completed the questionnaire, 13 were district nurses, 9 were health visitors and the remainder were practice nurses. This study found that a lack of clarity in communicating research findings, difficulties in understanding statistics and a lack of perceived ability among nurses to evaluate the quality of the research rated most highly as barriers to research use. In a second study, Walsh (1997b) compared the findings from hospital and community nurses attending postregistration courses. No statistical differences were found in this study between those barriers ranked highest by the community and hospital nurses. In contrast to the first study, in which problems related to understanding research were ranked highest, in this study both groups ranked problems in the work setting as providing the greatest problems in using research. Walsh (1997b) comments on this paradox – of nurses being urged to implement research findings but being inhibited in so doing by the very organisations within which they work – and stresses the important role that managers play in facilitating the adoption of research into practice.

The part that management structures play in supporting research use has been investigated by Kenrick and Luker (1996). In a study of district nurses' knowledge and practice of leg ulcer care in five health districts, they found no district nurse-related variables associated with their awareness or use of research following the use of a training pack on leg ulcer care. In the district that had a flat as opposed to an hierarchical management structure, however, the district nurses were found to have the highest knowledge scores and highest scores of reported use of the knowledge in practice. With current changes in the organisation of community nursing, this is clearly a research finding that demands further investigation.

In a third study, also using a convenience sample of nurses attending post-basic courses, Dunn *et al.* (1997) found that factors related to the organisation and the presentation of research were identified as the greatest barriers to research utilisation. In a study that had as its sample all therapists in three Trusts, issues associated with the organisational climate and the presentation of research were also ranked most highly (Closs and Lewin, 1998). These authors make the observation that one of the questionnaire items, on 'authority to change practice', was ranked much lower by therapists than by nurses in the studies by Funk *et al.* (1991b) and Walsh (1997b). Closs and Lewin (1998) suggest that this issue may be of less concern to therapists than nurses because of the greater autonomy of therapists. Interestingly, although this item was ranked as the second greatest barrier by hospital and community nurses in Walsh's (1997b) second study, in his first study, of experienced community nurses, this issue did not appear within the top 10 perceived barriers. Given the autonomy of practice among community nurses and the findings relating to managerial arrangements (Luker and Kenrick, 1996), this is clearly an issue requiring further investigation. A number of studies using the BARRIERS scale are currently being undertaken, involving large samples of community and hospital nurses. This may help to provide more information on the key barriers to research utilisation in the community.

CHALLENGING THE BARRIERS

In the preceding section, a wide range of barriers to research utilisation reported by researchers and practitioners has been identified. In community nursing, some of these barriers may be particularly difficult to overcome, but there is evidence that national strategies, the use of new technology and other approaches are helping to surmount some of the difficulties.

Access to current research findings continues to be a problem for many community nurses because of the distance of their bases from libraries. The growing number of systematic reviews, and the publication of Effective Health Care bulletins on topics including the prevention and treatment of pressure sores and the prevention and treatment of obesity, is helping to provide practitioners with research evidence presented in a manner that is more applicable to practice (Cullum, 1998). The interest of some primary health-care teams and innovative schemes between universities and primary health-care sites mean that an increasing number of community nurses have access to on-line data-searching facilities and the Internet. The promise in the NHS White Paper (DoH, 1997) that all surgeries and hospitals will be linked to the NHSnet holds out the possibility that all community nurses will, in time, have access to wider sources of information.

However, access to information needs to be complemented by skills in the analysis of research and research findings. Much energy has been put into research awareness courses over the past 15–20 years, although, as Mander (1998) comments, what these courses have achieved has been very variable. It may be that the complexity of the process of understanding and critiquing research is only just beginning to be understood. Books aimed at developing skills in research appreciation, for example that by Parahoo (1997), manuals providing guidance on undertaking systematic reviews (NHS Centre for Reviews and Dissemination, 1996), new journals, for example *Evidence-Based Nursing*, as well as critical appraisal courses all have the potential to increase the community nurses' awareness of research, a prerequisite for utilisation.

A second barrier that may have significantly affected community nurses' use of research has been the lack of research that community nurses may have seen as relevant. The lack of research in community nursing is a consequence of the lack of attention that community nursing has been given at a policy and resource level over many years (NHSME, 1993). It is only comparatively recently that attention has focused on community nursing as the move to relocate services from the hospital and to establish primary care-led health care has gathered pace. Interestingly, all eight topics listed by Cullum (1998, p. 17), in a presentation to a mixed group of nurses, as having been reviewed in Effective Health Care bulletins directly concern the work of community nurses (Figure 1.3).

Figure 1.3 Effective Health Care bulletin topics

- The prevention and treatment of pressure sores
- Preventing falls and subsequent injury in older people
- Preventing unintentional injuries in children and adolescents
- The management of primary breast cancer
- Preventing and reducing the adverse effects of unintended teenage pregnancies
- The prevention and treatment of obesity
- Mental health promotion in high-risk groups
- Compression therapy for venous leg ulcers

A third major barrier to research utilisation in the community results from the lack of research skills among community nurses, which also reduces the amount of research undertaken into community nursing practice. The lack of research skills in primary health-care practice has been identified as part of the Research Capacity Strategy (DoH, 1998). Stange (1996) categorises problems that researchers in primary health care face relating to a lack of primary health-care research investigators, the lack of a supportive primary health-care research environment, the generalist focus of primary health care as contrasted with the reductionist approach of much scientific research, problems with methods that may not be applicable to primary health-care and finally the limited funding available for primary health-care research. Brooker *et al.* (1997) have also identified the process of applying for research funding and managerial support as important factors affecting the development of research skills.

Over the next 5 years, the amount of the NHS R&D budget spent on primary health-care research is to double, from £25 million to £50 million (DoH, 1996; NHSME, 1997). At the same time, a strategy is being put in place to develop the research culture in primary health care (NHS Executive, 1997). Throughout the country, there are a growing number of primary health-care research networks that provide community nurses, as well as other primary health-care practitioners, with opportunities to develop their research skills and understanding (Evans *et al.*, 1997). Such networks develop partnerships between practitioners and between practitioners and researchers, partnerships that Wilson-Barnett (1998) considers vital for the advancement of nursing research.

The Centre for Community Nursing at the University of Hull provides an example of a mechanism for developing such relationships. As the membership leaflet states, 'The Centre was established in January 1997 to provide for the exchange of ideas and information about community nursing and to promote evidence-based community nursing practice. The Centre's aim is to network practitioners, managers, researchers and educators with interests in primary health care and community nursing.' The Centre provides opportunities for members to meet at seminars and conferences, and it runs a community nursing research group. The Centre web pages enable members to establish more distant partnerships and research activities. Joint appointments in district nursing, mental health, learning disabilities and health visiting, between the university and the local Community Trusts, also help to ensure that practice and research are brought together in a meaningful way.

A fourth factor that may have inhibited the utilisation of research into practice may be the piecemeal approach that has generally been taken to developing the use of research in practice, education and policy. Educational initiatives may take place, which are isolated from practice development activities, which may be unrelated to policy developments. Meerabeau (1995) suggests action research as a means of bringing together the practical problems of practice with research knowledge. In the following section, an illustration is provided of an action research project that sought to influence the organisational research climate and individual primary health-care practitioners' knowledge of research, use of research and skills in undertaking research.

TEAMCARE VALLEYS: CHALLENGING THE BARRIERS

Earlier in this chapter, it was suggested that research utilisation is dependent not on a single factor but on the interaction of a number of different elements (see Figure 1.1 above). Based on the premise that change is a multifaceted process, a primary health-care development project, Teamcare Valleys (TCV), sought to develop primary health-care services through a multifaceted, multilevel strategy aimed at stimulating research understanding, research utilisation and the development of research skills. This project, funded by the Welsh Office, was based in the South Wales Valleys and was concerned with the development of primary health care in the 157 practices in the area (Bryar and Bytheway, 1996). Through a number of different initiatives, the aim was to support the development of a culture in primary health care in which practitioners questioned their practice and sought answers to their questions either through undertaking research investigations or through seeking evidence from research that had already been undertaken.

A multidisciplinary team drawn from research, general practice, nursing, health visiting and other backgrounds supported the development of this research culture in a number of ways (Figure 1.4).

Undertaking research

Community nursing research is of quite recent origin (see Chapters 3, 4 and 7) and there is frequently a lack of information about current practice or the best methods of providing care. Descriptive research is therefore very important and a prerequisite for research utilisation: if the extent of a problem is not understood, research utilisation to address that problem is difficult.

Figure 1.4 Teamcare Valleys and research utilisation

Undertaking research

- Description/developing understanding of a problem
- Testing research evidence
- Developing research skills

Access to research findings

- Library resource
- Newsletter
- Roadshows: local/potential projects

Dissemination of research findings

- Educational activities
- Project reports/chapters

Influencing policy

- Doing projects
- Discussion papers – policy-makers

A number of TCV projects were concerned with describing the current situation: what were the training needs of practice nurses? (Davies, 1996); how do community psychiatric nurses and general practitioners define depression? (Proctor *et al.*, 1996); and what are the views of women on continuity of care from community midwives? (Marx, 1996). These projects used interviews, questionnaires and other methods to describe the present situation. Other projects tested research evidence and its application in this particular setting. For example, a general practitioner and a practice nurse tested the effectiveness of group education versus individual education with people with asthma (Thapar, 1996), and a general practitioner worked with practice nurses and other general practitioners to implement best practice guidance in diabetic care (Wallis, 1996).

Through undertaking these projects, individuals and teams of community nurses, midwives and health visitors developed skills in the process of research project management, defining research questions, designing data collection tools, collecting and analysing data and the dissemination of research findings (Bryar, 1996). These people thus provide an ongoing research resource in the area and contribute to strengthening the research culture.

Access to research findings

A number of mechanisms were used to increase community nurses' access to research findings. A library was developed containing current journals relevant to primary health care, a range of books and research reports. The library was open to all primary health-care practitioners in the area, who were able to borrow books and other material from the library. Primary health-care practitioners could also undertake database searches, from the TCV offices, on research topics.

The TCV team itself was a source of knowledge about research findings across a very wide spectrum. Primary health-care practitioners' enquiries could be referred to a number of team members to provide references and research contacts. Research findings were included in a newsletter and in roadshows held in a number of venues in the area. A conference enabled primary health-care practitioners from the Valleys to meet and discuss their research issues with primary health-care researchers from different areas throughout Britain.

Dissemination of research findings

Research findings were disseminated through the activities mentioned above. The results of projects undertaken in TCV were disseminated via project reports and other publications, which continue to appear (see, for example, Bryar and Bytheway, 1996; West and Slater, 1996).

Another major mechanism for the dissemination of research findings was via educational activities. Study days, short courses, distance learning and video material were developed on such topics as child protection, audit, immunisation and presentation skills, and were all based on current research information. One course in particular, 'Community and Public Health in the Valleys', sought to challenge practitioners to explore research literature in order to expand their understanding of health and illness in the Valleys (Middleton, 1992). For example, Module Three 'examines the interaction between work, wealth, and health. Using both official statistics and academic reports the module looks at what is meant by "work", the health implications of different types of work including accidents, illness and stress' (Middleton, 1992, p. 3). The evaluation report of this course shows that exposure to this research literature led to fundamental changes in the thinking of many of the participants and a realisation that the reality of the problems of their everyday practice was part of a bigger research picture (Slater, 1993).

Influencing policy

A number of projects within TCV were directly concerned with policy issues. For example, the study of continuity of care for child-bearing women was concerned with examining the applicability of the policy of 'Changing Childbirth' in a local context (Marx, 1996). A project on teamwork was initiated at the request of policy-makers who wanted to know, prior to their further investment in team-building workshops, how effective such workshops were in developing teamwork (Brown, 1996).

Discussion papers generated within TCV, or by TCV and people in the area, were another mechanism used to engage policy-makers. These papers were on topics such as behaviour management (Pritchard and Bytheway, 1992) and the role of health needs assessment (Thomas, 1991) and were distributed widely to health authorities, the Welsh Office and academic departments, in addition to practices.

Project reports were also disseminated widely to policy-makers and were requested by them. For example, multiple copies of a report on the establishment of a community health house were requested by one health Trust interested in setting up similar services (Fisk, 1992). In her report on a project on leg ulcers, Rees (1996, p. 135) comments on the problem of turning research findings into practice and the need for training strategies to be established by policy-makers, commenting 'As this study has demonstrated, quality care at the present time is not assured within primary health care for patients with a leg ulcer.'

Teamcare Valleys summary

Research utilisation requires action at different levels: there is a need for good-quality research and for skills in reading and undertaking research; practitioners need access to research, which should be written in a manner that is understandable and relevant to their practice; education needs to be based on research; and policy-makers need both to seek out and be presented with research information. TCV provides an illustration of an action research approach to change that was able to use a number of different mechanisms to influence the primary health-care practice culture to increase research awareness, skills and utilisation.

CONCLUSION

The use of research in community nursing practice, policy and education is affected by many different factors, which may relate to the research and researchers, to the individual community nurse, educationalist or policy-maker, to the context of care or to the influence of other practitioners. There is currently available a considerable body of research that is applicable to community nursing. At the same time, there is growing evidence of effective methods of facilitating the use of that research in practice, education and policy-making. A number of initiatives, referred to in this chapter, also provide encouragement for the use of research in practice. Other developments will also have a longer-term impact on the use of research in community nursing. For example, the provision of research training opportunities to nurse educationalists, such as the scheme provided by the Welsh National Board for Nursing, Midwifery and Health Visiting (1998), will help to develop the abilities of nurse teachers in relation to undertaking research and in supporting its use, which will be reflected in the educational courses available to community nurses. The National Primary Care Research and Development Centre (1996) will be providing increasing amounts of research evidence over the next few years that will help to inform community nursing. The appointment of a Professor of Nursing Research and Development by the Department of Health and the testing of mechanisms for getting nursing development and research issues onto the policy agenda (Kitson *et al.*, 1997) should support more research relevant to community nursing and the testing of methods of facilitating use. The challenge for all community nurses, educationalists, researchers and policy-makers with an interest in community nursing will be to ensure that the R&D issues of concern to community nurses, their patients or clients and communities are high on these agendas.

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CHAPTER TWO

Evidence-based health visiting – the utilisation of research for effective practice

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The essence of this book is about the research base of community nursing and the need to enhance and utilise the evidence upon which community nursing practice is based. I would like to turn this around and to ask, from a health visiting perspective, where does evidence come from, and what evidence do we need for health visiting practice? I would like to explore some themes that are contemporary to professional health visiting practice, which will, hopefully, lead to discussion and debate to put an end, once and for all, to the question why do we need research in health visiting? We might more fruitfully be asking, why *don't* we need research? Could the profession of health visiting survive in the current climate of emerging Primary Care Groups (DoH, 1997a) *without* research? It seems not, and in this chapter I intend to explore conceptual and practical issues surrounding the need for evidence-based health visiting.

It is always helpful to start a discussion with some definitions. There are many definitions of research, some of which have been drawn on already in this volume. I am using the International Council of Nursing (ICN, 1996) definition of nursing research, which, I believe, adequately covers health visiting issues:

> Nursing research focuses primarily on developing knowledge about nursing and its practice, including the care of the person in health and illness. It is directed towards understanding the fundamental mechanisms that affect the ability of individuals and families to maintain or enhance optimum function and minimise the negative effects of ill health.

I find this definition helpful from a health visiting perspective because it relates to both health and illness (many health visitors being involved with families in which there are sick children or disabled adults), and to both individuals and families. It also refers to maintenance or enhancement, which provides scope for health promotion work as well as prevention.

In order to conceptualise and reason about the issue of evidence-based health visiting, I have considered such questions as:

- Without research, how can health visitors:
  - provide the best possible care?
  - be accountable for their practice?
  - demonstrate the value of health visiting?

PROVIDING THE BEST POSSIBLE CARE

It is not within the scope of this chapter to discuss the nature of health visiting. Suffice it to say that it has been argued at length in the literature that the practice of health visiting is essentially about promoting the health of individuals, families and communities (see, for example, Campbell *et al.*, 1995). It has equally been argued that health promotion is not unique to health visiting and that the concept itself is open to interpretation. For example, is advice from your own mother about child health the same level and quality of health promotion as support from a health visitor? I would argue that health visiting combines the qualities of support and advice, and that what makes this a *professional* practice, as opposed to a lay practice, is that health visitors underpin their care with knowledge, expertise, skill and wisdom that goes beyond the experiential base of lay support; in summary, they base their practice on evidence. The person seeking professional health visiting care might therefore reasonably expect to obtain the best possible care. In the 'new speak' of the NHS, we now refer to this as clinical effectiveness, but can health visitors be clinically effective without being able to identify the evidence on which to base their practice?

For many years, the health visiting profession claimed that tried and tested, experientially based practice had enabled them to pass on techniques of caring that benefited the client. We now laugh at some of these techniques – applying egg white to prevent cracked nipples, test-weighing babies and the overzealous checking of children's heads for nits. The reason we laugh is because these techniques have been shown, by research, not to be clinically effective. As Mary Wollstonecraft argued in 1792, it is no good doing today what you did yesterday merely because you did it yesterday. In order to provide the best possible care, health visitors have to examine their practice and ask the right questions. We need to translate these questions into audit, into systematic reviews of the literature and into research topics, and to develop skills in critical appraisal that will enable the utilisation of research findings in practice.

For example, when I was a practising health visitor, we knew that women suffered from postnatal depression (PND) and that health visitors were well placed to identify and support women in the postnatal period. We also knew from Hennessey's (1986) work that PND was frequently overlooked. Health visitors were arguably not being clinically effective where women were left with small babies feeling unsupported, isolated and unhappy. More recently, health visitors started to ask questions about how they could more easily identify PND and to investigate acceptable ways of measuring it. The Edinburgh Postnatal Depression scale (EPNDS) (Cox *et al.*, 1987) was developed and tested, and there are many examples of health visitors using this tool in practice. Counselling is offered to women scoring over 12/13 on the scale. Clearly, the acid test of the best possible care is whether or not women are being appropriately identified and whether or not the counselling works. Important questions we also need to ask are, what are the most effective counselling techniques, does the incidence of PND change over time and what general guidelines should health visitors be adopting to ensure that clinical effectiveness is universal? I will return to the theme of PND and these questions later in this chapter. Suffice it to say that the questions raised by research are endless, and there is never room for complacency that the best possible care has been achieved, only that the best possible evidence available to us at that time has been implemented.

EVIDENCE-BASED HEALTH VISITING

So what is evidence-based health visiting? It is argued above that clinical effectiveness relies on the best possible care being provided, based on the best available evidence. Evidence-based practice may simply be a new phrase for research-based practice. If this is the case, the idea is certainly not a new one for nurses. The Briggs Committee on Nursing (DHSS,1972) recommended that nursing should develop as a research-based profession, and numerous papers have been written since on the need to implement research in practice and on the barriers and opportunities that exist in taking this forward. This has all been re-endorsed by the ICN (1996), and, in a recent policy document from the National Health Service Executive, *Primary Care: The Future* (NHSE, 1996a), research is clearly on the agenda.

Wollstonecraft, in her treatise on the 'rights of woman' (1792, p. 8) argues the following:

> To do everything in an orderly manner is a most important precept which women who, generally speaking, receive only a disorderly kind of education, seldom attend to with the degree of exactness of men, who in their infancy are broken into method, observe. This negligent kind of guess work, for what other epithet can be used to point out the random exertions of a sort of instinctive common sense, never brought to the test of reason? prevents their generalising matters of fact – so they do today what they did yesterday, merely because they did it yesterday.

Mary Wollstonecraft lived and wrote in the age of enlightenment, a period when scientific discovery and our understanding of the physical world was growing exponentially. However, I see at least two issues for the case for evidence-based practice within her statement. First, and most obviously, common sense is not enough on which to base practice if we wish it to be effective; second, we need to bring ideas, treatments and practices to the test of reason in a systematic and orderly way so that some generalisable knowledge can be gained from it. In other words, we need sound evidence on which to base practice. Where I depart from Wollstonecraft is that, in my belief, such evidence can take a variety of forms and be drawn from a range of sources, not merely the generalisation of matters of fact.

If we are to believe some of the figures cited, around 85 per cent of medicine has been practised on the basis of 'a negligent kind of guess work'. For example, Mead cites the Office of Technology Assessment (1978) figure of only 15 per cent of medical practice being based on evidence. Sackett *et al.* (1996) have argued the case for basing medical practice on sound evidence but also found that doctors thought they needed to read one or two articles a week to keep up to date. In fact, through observation of their practice they found that they needed as many as four new pieces of information on which to base clinical decisions in just one half-day of patient consultations. Only 30 per cent of these information needs could be met directly,' and much of the rest, rather than being sought from journals and texts, was sought from colleagues, thus perpetuating the custom of doing things the way they were done yesterday. I have not come across a similar analysis of health visitors' journal reading habits in relation to decision-making, but I suspect that the findings would be similar.

Evidence-based practice appears to mean more than research-based practice as it implies an evaluation of the evidence, rather than just the blind acceptance of research findings. The *Oxford English Dictionary*'s (1964) definition of evidence is: 'Clearness, obviousness, consciousness'. While the dictionary definition also alludes to types of evidence (such as circumstantial used in the legal system), it could be argued that the raw definition of evidence provides us with scope for interpretation of what we need in order to improve practice and deliver the best possible care, both in terms of the type of evidence we seek and the ways in which we produce it. The use of evidence in the legal system is to enable a judge and a jury to arrive as near to the truth as is 'beyond all reasonable doubt' in order to ensure justice. In health care, we also need to be beyond all reasonable doubt in the treatments and practices that we offer the public, and we too must weigh up the evidence with which we are presented to arrive at the truth – however that is interpreted. We need not only to be able to distinguish the clear, obvious and conspicuous from the inconspicuous, confused and muddy, but also to recognise that evidence is not always black and white. Sometimes it is greyish, and it is at these times that it is particularly important to use the skills of critical appraisal to make judgements about its admissibility.

Sackett *et al.* (1996, p. 71) have defined evidence-based medicine as:

> the conscientious, explicit, and judicious use of current best evidence in making decisions about the care of individual patients. The practice of evidence-based medicine means integrating individual clinical expertise with the best available external evidence from systematic research.

How do health visitors decide what is the best available evidence, what is the *truth* about the best possible health care? It is feasible to survey a range of evidence, drawing on different philosophical standpoints, and to draw some conclusions, through a process of critical appraisal of the evidence, about the way in which health visiting knowledge and practice might be enhanced in order to achieve clinical effectiveness. I will return to this process of critical appraisal later in the chapter.

AN HISTORICAL PERSPECTIVE ON HEALTH VISITING RESEARCH

Historically, the evidence for health visiting practice was derived from a stream of research investigating the ways in which health visitors interacted with clients (Clark, 1973; Sefi, 1985; Montgomery

Robinson, 1987; Kendall, 1991) and client satisfaction with the health visiting service (Foster and Mayall, 1990). This type of research was necessary at this time because of the nature of health visiting practice. It was (and to some extent still is) very much a private activity, carried out in the home and very much out of the public gaze, unlike traditional hospital nursing, which was conducted in the open ward. Not only is it a private activity, but it is also difficult to define in narrow terms as health visitors are often faced with unpredictable and ambiguous situations. As such, it was recognised by researchers in the 1980s and 90s that, in order to ensure that families and communities were to receive a high standard of health visiting care, it was necessary to describe in depth what health visitors were actually doing and how they were doing it.

Many of the early studies on health visiting practice drew on qualitative or survey research designs. This resulted in an evidence base that was largely descriptive and did very little to advance our understanding of the relationship between health visiting practice and outcome. It became evident, through the various analytical techniques applied to the observation of health visiting practice, that there were shortcomings in the ways in which health visitors interacted with clients (usually mothers). For example, my own study (Kendall, 1993) revealed, through a process of conversation analysis of health visitor – mother interactions, that there was little convergence between the health visitor and client agenda, and that through the way in which health visitors controlled the interaction, there was little opportunity for mothers actively to participate in the discussion. This had implications for the important health promotion work that health visitors were trying to achieve. For example, in the field of child health, it is not difficult to see why a mother would be reluctant to listen to advice about mixed feeding when her own priority was a chronic lack of sleep.

This observational type of research was corroborated by the surveys carried out on client satisfaction. For example, Foster and Mayall's (1990) work found that mothers felt that health visitors did not understand their needs and that they were acting as agents of social control. As a foundation for the future of health visiting practice, this type of evidence was crucial as it provided the basis on which to build the educational curriculum for health visitors and identified where practice and professional development should and could occur.

However, more recently, it has become even more important in terms of clinical effectiveness to look more closely at not only the general way in which health visitors practise, but also the specific evidence base for particular aspects of health visiting work. In these times of skill mix reviews, cost-efficiency savings and budget cuts, health visitors often feel that they are not equally valued by their managers or the commissioning organisations. There is an obvious managerial response: if you think your service is a valuable one that should be retained, prove it – and prove it in cost terms, in clinical effectiveness terms and preferably in public health terms as well.

Hereby hangs a problem, and it is a problem of how far professional activity and its outcome can be measured. Hutchinson and Fowler (1992) reported on a study carried out in primary care in which practitioners were asked to identify and rank clinical problems in which outcome measures could be identified. A total of 20 such problems were prioritised, the first three being asthma, diabetes and hypertension. Clearly, it is relatively straightforward to demonstrate the outcome of care where there are measurable indicators such as lung function and blood pressure (although even these depend on the reliability and validity of the measuring tool and the person observing the measurement). However, there are no such indicators in other areas of work.

It was noted earlier in this chapter that the profession of health visiting is teneted on the concept of health promotion. If this is the case, and it appears to be well supported in the literature, health visitors have to grapple with the problem of what health promotion is, how it can be measured and how outcomes can be demonstrated. It has been argued elsewhere that this is a very difficult task, at least in quantifiable terms (Kendall, 1997). By its very nature, health promotion is a quality rather than a technology; it is a process through which people come to realise their health potential and feel reassured, comforted, healed and restored. These are neither outcomes in the same sense as blood pressure or serum glucose level, to which a numerical scale can easily be applied, nor public health gains monitored. Stange (1996) summed this up in his paper when he argued:

> This conflict between isolating as opposed to embracing the patient perspective and context is at the core of the uneasiness felt by (primary care) researchers who are trying to achieve methodological rigor while still asking the right questions and addressing the context of the patients' environment and values. (p. 195)

Health visitors should be trying to achieve methodological rigour in order to demonstrate the value of health visiting through research. However, there continues to be a considerable amount of work to do to convince the authorities that it is possible to be systematic and rigorous through the application and utilisation of alternative research paradigms that are more appropriate to the qualitative characteristics of health visiting, such as the reassurance that may be given to an exhausted first-time mother or the confidence that may be generated in a group of single, teenage parents. The report of a Department of Health working party (Hopkins *et al.*, 1993) referred to the notion of appropriate health care where emphasis is placed on patients' perceptions of outcomes and their involvement in decisions and the acceptability of treatment. This concept of appropriate health care is useful in the context of interventions that may not change the outcome of a disease but may contribute to a client feeling less anxious or more in control of his or her health. However, a caveat needs to be added here. There are obviously many 'health technologies' within health visiting that are readily open to measurement and *should* be measured: examples include immunisation uptake and smoking cessation. The problem with trying to assess the value of, or health gain from, these outcomes lies in the isolation of the independent health visiting variable that could usually be attributed to process and is therefore difficult to separate from outcome. However, there is certainly a degree of value added to appropriate health care through experienced health visitors carrying out such technologies, and we need to be able to demonstrate this through the isolation of significant factors.

I have indicated above that it is necessary to decide, usually at the outset of a research study, how outcome is to be defined – for example in terms of health status, health behaviour or client perceptions – if the concerns raised by Stange (1996) are to be taken into account and the appropriate paradigmatic approach taken to providing a systematic evidence base for health visiting. The question of outcomes in health visiting has been thoroughly reviewed by a Health Visitors Association working party (Campbell *et al.*, 1995), the report concluding that:

> Realisation of the potential value of outcome measures, however, relies on the development of outcome studies which reflect the presence of uncontrollable, confounding variables; which recognise the unpredictable ; which do not see changed health status as essential, and which recognise the validity of, and can analyse, the soft data. (Campbell *et al.*, 1995, p. 34)

This is an important issue for practising and academic health visitors to take forward. It is most likely to be fruitful where there is true collaboration and partnership between practitioners and researchers to ensure that evidence is developed for practice rather than just on practice simply for its own sake. This must be of particular interest to health visitors, and to the whole primary health-care team, in the context of the new NHS (DoH, 1997a) and the implications that this policy will have for the public health work of health visitors and their role in the commissioning process.

ACCOUNTABILITY FOR PRACTICE

To be accountable for practice means that health visitors have to take responsibility for, and be able to justify, their practice in terms of both clinical and financial effectiveness. As argued above, clinical effectiveness depends on the utilisation of sound evidence. According to Mead (1996), there is recent evidence that nurses still face real obstacles in the utilisation of research in practice. Is professional accountability a fair notion if research, as defined by the ICN, is not an integral part of professional health visiting practice? If it is the case that nurses and/or health visitors are (Mead, 1996):

a. Not enabled to implement effective research by their employers
b. Not encouraged to undertake research training
c. Not finding/being given time in their practice to follow up research issues
d. Not demonstrating personal commitment to the value of research for practice

then it is difficult to establish a clear argument for professional accountability on the grounds of clinical effectiveness. It has already been argued that health visitors need research in order to provide the best possible care. However, they cannot be held to account for that care if they are charged with neither the responsibility nor the authority to scrutinise practice and advance practice through the rigorous investigation of research findings. It is particularly important to emphasise the point here, paraphrasing Manthey's (1980) words that responsibility for practice is commensurate with authority, that is, the empowerment to act. Health visitors are so often given the responsibility for a job without any authority to act, which may mean that research cannot be put into practice and be shown to make an improvement in health.

Many recent policy documents have made reference to research and development in health visiting, not least of which was the Task Force Report on a strategy for nursing research published by the Department of Health (DoH) in 1993 (DoH, 1993a). Recommendations within this report related to improvements in practice, funding initiatives and collaborative partnerships. One of the key recommendations was the setting of a nursing research agenda, and this exercise is currently under way (Kitson *et al.*, 1997), with nurses from across the UK taking part in the review of research priorities. However, while it is admirable, and indeed crucial, that practitioners themselves set the agenda, without the authority to take this forward the health visiting profession will be endangered. Health visitors must be accountable for their practice, but equally they must be empowered to enquire and discover the best possible evidence for practice. This does not just mean research funding; it implies research training, time away from clinical care and recognition that the full range of research activities is valued by the various organisations in which health visitors work.

THE POLICY CONTEXT OF EVIDENCE-BASED HEALTH VISITING

Recent policy developments and reports from the DoH have had important implications for the future of primary health care, so the future of health visiting can be analysed in this context. All recent documents (NHSE, 1996a, b; DoH, 1997a, b) emphasise the significance of clinical effectiveness and evidence-based practice. The need to develop research awareness and research skills in primary care is also emphasised, particularly in Mant's report on *Research and Development in Primary Health Care* (DoH, 1997b). The DoH White Paper, *Primary Care: The Future* (NHSE, 1996a) also stressed the significance of this:

> The development of a good research base in primary care should also be encouraged. This would provide more information on effective treatments and interventions in primary care as well as offer wider career opportunities. ...opportunities could be expanded if research groups of general practitioner practices, community nursing teams, primary care therapists, pharmacists and others were established to take forward projects and proposals, perhaps in association with academic departments and on a network basis. (p. 53)

It is noteworthy that the DoH sees the future of primary care research emerging as a collaborative endeavour. While health visiting must be represented within this team approach, it also imperative to isolate health visiting variables that contribute to health gain.

Interestingly, all of these documents were preceded by a report on the development of primary health-care nursing – *New World, New Opportunities* (DoH, 1993b). This publication outlined the key areas in which primary health-care nursing should develop in order to ensure the place of effective nursing in the primary care setting for the future. The mnemonic ON-STREAM was used to indicate opportunities for nurses in Teamwork, Research, Education, Audit and Management. The new opportunities for primary health-care nurses were not, apparently, seized with any vigour as the same messages for the whole primary health-care team are being repeated 4–5 years on with little evidence that much has changed on the nursing front. Indeed, recent work by Sapsford (1998) suggests that nurses working in integrated teams are still struggling for autonomy and empowerment to act in relation to the key components of *New World, New Opportunities*. This, it appears from Sapsford's study, is because of the continuation of medical dominance in primary care and the structural and procedural barriers that are imposed on nursing from within the hierarchical management system within the NHS. Such structures have been reinforced through the introduction of general practitioner fundholding and commissioning groups that have limited nursing input.

The most recent legislation from the DoH (1997a) provides a framework for dismantling general practitioner fundholding and creating new Primary Care Groups (PCGs) that will have responsibility for commissioning health care at a local level, based on health needs assessments of populations of about 100000 people. Each PCG will work with the local health authority to meet the needs identified through the Health Improvement Programme (HIP), and the PCG will have 'control of a single unified budget which will give maximum choice to general practitioners and community nurses about how best to meet individual patient needs' (DoH, 1997a, p. 9). In theory, this will mean that nurses working in primary care will have a voice in the commissioning process and should be able to demonstrate the value of effective care through the targets set in the HIP. This would be a significant development for health visitors so that health interventions with less easily measurable outcomes could be identified, where they are relevant to the health needs of the population. Therefore, skills in health needs analysis, an area in which health visitors have always had a role and are demonstrating their effectiveness (Adams, 1995; Cowley *et al.*, 1995; Thomas, 1996) will be paramount if health visitors are, in reality, going to be part of the 'third way' NHS.

This is also central to the proposals set out in *Our Healthier Nation* (DoH, 1998). In this document, the government sets out the principles for improving public health, the health targets and possible approaches and mechanisms for achieving them. In terms of the health action zones, healthy schools and healthy neighbourhoods described in the document, the public health role of health visitors will be vital, especially as health visitors have traditionally been the fulcrum of assessing community health needs.

Counterproductive to this would be the possibility of continued medical dominance in the PCGs, supported by the reluctance of general practitioners to lose control of fundholding and the PCG budget. In this scenario, health visitors would continue to have responsibility for assessing need and meeting the HIP targets without the authority to implement evidence-based changes in practice. It therefore seems critical that health visitors are able to recognise the need for clinical effectiveness and also to utilise evidence both to improve practice and to develop arguments that will convince health-care commissioners of the value of health visiting.

The next section takes the example of PND in order to demonstrate how a critical analysis of existing data can support health visitors in their utilisation of evidence.

A CRITICAL REVIEW OF THE EVIDENCE ON THE SCREENING AND IDENTIFICATION OF PND

Ridsdale (1995) has provided a useful framework with which critically to appraise the literature in a specific field from the point of view of a practitioner so that conclusions drawn from the overview may have some significance for practice. In this section, I have used Ridsdale's framework to review a selective sample of the literature on PND. The aim is both to demonstrate the process of critical appraisal and, ultimately, to show how the ability to summarise and argue for resources on the basis of sound evidence may be useful to health visitors in the commissioning of services and the provision of the best possible care.

Is the problem important?

Even before starting to review the evidence in a particular field, health visitors should ask themselves how important the problem is. In so far as resources are concerned, there is little to be gained by spending a great deal of time on a topic that has little importance for either the population, the family or individual, or the health visiting service. The government has outlined the targets for improvement in mental health in its consultation paper *Our Healthier Nation* (DoH, 1998). While the Green Paper acknowledges an unequal distribution of mental illness between men and women (women experiencing a higher incidence of mental ill-health), there is little specific detail about the nature of mental illness among women and no attention given to postnatal depressive illness. The paper sets out targets for mental health in terms of a reduction in the rate of suicide as this is seen as the most readily available measure of mental illness. However, the majority of women with PND do not go on to commit suicide. In broad terms, mental illness is acknowledged as sufficiently important by the government to receive political attention, and PND can be seen in this context. However, as the Green Paper itself states, changes in mortality cannot be the only measure of improvements in mental health, and this is an area where health visitors should consider what indicators of improvement among women with PND could be utilised. As far as PND is concerned, the main indicator of its 'importance' is probably the prevalence, that is, the proportion of women (sometimes expressed as the number per 100 000) who are experiencing PND at a given time. This can be determined from epidemiological studies, which can be carried out either retrospectively or prospectively. A further indicator of 'importance' is the short-term and long-term effects of PND on both the parents and the children in the family. Finally, its importance to individuals who are experiencing the illness is significant in terms of both treatment and prevention.

Prevalence of PND

PND is characterised by irritability, sadness, lack of confidence, fatigue and feelings of failure (Sheppard, 1996). Prospective studies conducted during the 1980s (Cox *et al.*, 1982, 1984) have suggested that as many as 10–15 per cent of postnatal women experience depression, and up to 50 per cent have transitory mood changes known as 'the blues'. A prospective study that follows women through the course of childbirth and the postpartum period is more reliable than retrospective studies that rely heavily on people's recollections of experience, medical notes and other sequelae that may or may not have been influenced by a depressive illness. A later study (O'Hara and Swain, 1996) confirms the prevalence at 13 per cent, having been based on a meta-analysis of a range of epidemiological studies. Assuming that the statistical techniques have been correctly employed, this type of pooling and secondary analysis of data is useful for confirming the findings of a number of studies and bringing greater validity and reliability to the knowledge drawn from such analyses. In other words, there is more credibility in the known prevalence of PND based on such a study than on one study alone, and the findings can be applied to practice with greater confidence. It would be fairly safe to assume that up to 13 per cent of mothers in any primary health-care population would be likely to experience PND. In terms of prevalence, the evidence therefore suggests that PND is a relatively important problem.

Effects of PND

The effects of PND are reported to be wide ranging, with short- and long-term effects documented for both the mother herself, the baby, other children and the other adults in the family. Such reports clearly add to the significance of PND as an important area for health visitor intervention. However, in order to put the consequences for the family into perspective with other, perhaps equally distressing, experiences, it is necessary to critically evaluate the evidence that describes these other effects. The ability to assess the robustness of the evidence enables health visitors to prioritise their interventions and to provide the most appropriate care. For example, a study by Sheppard (1996) investigated a sample of 701 women during the postpartum period, of whom 11 per cent were stated to be experiencing depressive symptoms. Sheppard found that child abuse and behavioural concerns were significantly more likely to be associated with depression and that these were three times as frequent among depressed mothers with children over the age of 1 year compared with women in their postnatal year. This finding suggests that health visitors should continue to be vigilant beyond the postnatal year. However, there may be other indicative factors, not discussed in this paper, that the health visitor should also take into account, including vulnerability factors identified in seminal work by Brown and Harris (1978), such as loss of the women's own mother before the age of 11 and the lack of a partner whom she feels she can trust. In order to make full sense of these findings, questions should be asked about the way in which PND was measured and the strength of association between child abuse, child behaviour and PND.

Another recent study (Murray and Sinclair 1998) has suggested that sons of mothers experiencing PND went on to display high rates of behaviour problems at school. The researchers screened 700 first-time mothers with healthy babies at 6 and 18 months, and 5 years, postpartum using the EPNDS (Cox *et al.*, 1987). Teachers were asked to comment on child behaviour at school using a questionnaire. They found that 70 per cent of boys whose mothers experienced PND displayed symptoms of hyperactivity and distractibility, boys from a lower social class being more affected. Interestingly, daughters were not apparently affected in this way, which the authors explain in terms of boys being more reactive to external influences than girls. Clearly, the implications seem to be that health visitors have an important role in identifying and supporting mothers with PND since the effects can last long into the school years and ultimately affect child development. This study used a well-validated instrument to measure PND (the EPNDS), and the large sample of women selected means that one can have confidence that the sample of children identified with behavioural problems did not occur by chance and that such attributes were in fact strongly associated with maternal depression.

However, there may be some uncertainty about the responding teachers' interpretations of behaviour problems for boys and girls. Another study that explored the impact of PND on infant outcome was conducted by Murray *et al.* (1996). They found that depressed mothers were less sensitively attuned to their infants and were less affirming and more negating of infant experience than were well women. They were able to establish that such disturbances in the early mother–infant interaction were associated with poorer cognitive development in children at 18 months, thus indicating that early detection and intervention could help to reduce later problems in childhood.

Mothers' experiences of PND

There is less evidence of mothers' own experiences and perceptions of PND. However, a qualitative study by Nicolson (1998) involved interviews with 24 women over a period towards the end of pregnancy up until 6 months after birth and is a useful example of research looking at the importance of a phenomenon from the clients' point of view. Nicolson wished to uncover the women's perceptions of the transition to motherhood and to explore with them the emotional changes that they experienced. As a result of her interview data, she was able to produce a feminist critique of PND that challenges the established view of its origins in the biology of pregnancy and childbirth, and places much more emphasis on the social and psychological changes that could be said to be normal for most women who become mothers.

Barclay *et al.* (1997) have also examined the general experiences of early motherhood. The researchers in this study adopted a grounded theory approach to understanding the factors that impact on early motherhood and were able to define six categories from their in-depth focus groups with 55 mothers. The mothers in the study found the process of becoming a mother overwhelming, including feeling physically, mentally and emotionally drained, and a further category identified was a feeling of being alone, unsupported and anxious. So while this study was not focusing on PND, it clearly identified the feelings of a group of new mothers that could be characteristic of women who go on to be depressed. In particular, the study supports Nicolson's work as it helps to clarify the social and relationship issues that many new mothers face and the need to develop health visiting practice to support them through this period.

Such studies do provide reasonable grounds for assuming that PND is an important enough health issue to consider both screening and prevention, as well as early intervention. Health visitors have seen this as legitimate work as all mothers are still seen by a health visitor at least once postpartum, providing opportunities for prediction, identification and intervention.

Are the questions already answered?

While there is considerable literature on the identification and prevention of PND (a search on Medline alone found 111 reports since 1995), it does appear that there is considerable scope for critical evaluation and review of the evidence that relates to health visiting practice. Although there has been considerable evaluation of the EPNDS across the world, there are no systematic reviews or meta-analyses of clinical effectiveness and very little qualitative evidence of how women experience nursing practice in relation to PND.

Is the location relevant to health visiting practice?

The majority of the UK studies carried out with depressed mothers have been community or primary care-based, suggesting that the location, or sites, would be similar enough to apply to health visiting practice in general. For example, Cullinan's (1991) study of health visitor intervention in PND was conducted among 874 women across one community Trust and Hearn *et al.* (1998) conducted their survey of identification of PND across the populations of 7 general practitioner practices in the Bolton area, involving 185 women.

Are the methods appropriate?

The design and methods of studies of PND are critical to the evaluation process and to the decision on whether research findings, the evidence, are sufficiently robust to utilise in practice. This process of critical appraisal is based on questions about the type of research design – for example survey, observational, experimental or qualitative – and whether the methodology answered the research questions. For example, Hearn *et al.*'s (1998) study aimed to determine whether the use of the EPNDS at the postnatal examination would detect women not recognised as having PND by the primary health-care team. To meet this aim, they conducted a survey of 176 women attending for postnatal examination. The EPNDS was administered, and primary health-care team members who were consulting with the mothers were asked to assess the mother's mental health prior to completing the EPNDS. The researchers found that 30 (17 per cent) of their sample scored 12 or more and were therefore classified as depressed; of these only 13 were perceived as being depressed by the primary health-care team. This survey design therefore helped to identify whether or not the EPNDS could identify women with PND who would not otherwise be recognised.

A study by Hickey *et al.* (1997) set out to determine whether early discharge after childbirth increased the risk of PND. They used the criterion of less than 72 hours to define early discharge. The study design was a prospective cohort design consisting of an initial interview with 425 women delivering over a 3-month period, followed by assessments every 6 weeks over 24 weeks using the EPNDS and a self-report questionnaire. The researchers found that women discharged early did have a higher risk of PND than those who had a standard period in hospital (14.4 per cent compared with 7.4 per cent scored 13 or more on the EPNDS, giving an odds ratio of 2.12). This question could not have been answered with confidence using a qualitative approach, although it could be argued that both the studies cited could have been enhanced by qualitative interviewing to find out more from the mothers themselves about their experiences. It is important to note that studies vary in the level that they set for the identification of PND – between 12 and 13 on the EPNDS was suggested by the two studies cited. This could obviously produce variable estimates of prevalence. In any study in which a state such as depression is being measured, there must be some evidence of the validity of the measuring instrument, in this case the EPNDS. This will be discussed further below, but suffice it to say that the EPNDS is now well validated, and studies not utilising this scale should be scrutinised for their validity.

Experimental studies set out to answer questions of cause and effect, and to give evidence on which to predict the health outcome for, or behaviour of, a person (at least in health research) in relation to a given variable, known as the independent variable. This is the most often used design in intervention studies when there is a need to establish the effectiveness of a certain treatment. The classical design is the randomised controlled trial, in which people are randomly allocated to either a treatment group (intervention) or a control group that maintains the usual conditions. Randomisation reduces the degree to which the treatment effect could have happened by chance, and the larger the sample, the more confidence one can have that the effect is a real one. An example of this type of study is one by Holden *et al.* (1989) in which a counselling intervention by health visitors was found to be more effective for women with PND than the usual health visitor input in the control group. This was supported by a later study conducted in Sweden using the same design (Wickberg and Hwang, 1996).

Cullinan's (1991) study is described as an intervention study and was conducted over one Community Trust involving 874 women and 58 health visitors who were trained in the use of the EPNDS and Rogerian counselling techniques. However, while counselling was offered to those women scoring 12 or more on the EPNDS, and 87 per cent of these improved, there was no control group described and therefore no randomisation into the intervention group. Thus, while Cullinan claims that the study demonstrates the effectiveness of health visitor intervention, this cannot be ascribed solely to the counselling intervention because the study is neither sufficiently well designed nor statistically powerful enough to determine whether these women would have improved anyway or indeed whether some other extraneous variable (for example a change in the environment) was responsible for the improvements.

Research questions that are more concerned with people's perceptions or experiences, or are aiming to develop theory, are more likely to be answered using qualitative designs. It is not appropriate in this chapter to discuss at length the range of qualitative methods available. However, they are all concerned with producing a rich description of the phenomenon under consideration that cannot be achieved using standardised questionnaires or measuring scales. Thus the qualitative evidence that they provide would tend to have more explanatory power, although it may not be predictive or generalisable. An example of this type of evidence is the study by Nicolson (1998) described above. The strength of this evidence is in the depth and breadth of the data, the systematic analysis of the interviews to produce a rich account of mothers' experiences and the theoretical challenge that it presents to health-care professionals with respect to PND being problematised. The logical argument when confronted with Nicolson's evidence would be to reject the PND scale (such as the EPNDS) and just talk to women and listen to their experiences. Therefore, the value of this type of evidence lies in its capacity to deconstruct accepted views and to provoke us to challenge our own notions of what being postnatally depressed means.

Other, traditionally regarded elements of critical appraisal include sampling, response rates and measurement of outcomes. Such criteria fall largely within the positivist paradigm of quantitative research and are important when judging the robustness of evidence produced by surveys and experimental studies. In these contexts, not only the size of the sample should be considered, but also the strategy to acquire the sample. For example, is it representative of the population under discussion in terms of criteria such as age, gender, occupational group, housing, ethnicity, geographical location, severity of disease if appropriate and so on? For example, in a prevalence survey of PND, it would be of little value if half the sample were over child-bearing age or if the sample was skewed towards a particular social group as it would be impossible to generalise from such data what the real extent of the problem is. So, for example, while Hearn *et al.*'s (1998) paper provides some interesting evidence about the prevalence of PND in their practice population, the description provided of the sample is inadequate for readers to judge its generalisability and therefore its utility for their own purposes. In qualitative designs, the sample is often small as the aim is to produce not generalisable results but thick descriptions and explanations that help to develop theory. Thus Nicolson's (1998) study of women after childbirth involved 24 mothers, each of whom was interviewed on three or four occasions. Barclay's (1997) study of becoming a mother involved 55 women in nine focus groups. The validity of these studies lies not in the size of the sample but in the explanatory and theoretical power of the analyses.

Measurement of outcome is a critical indicator of the validity of intervention or experimental designs, or surveys that measure the incidence and prevalence of a particular phenomenon. The EPNDS was developed by Cox *et al.*, and its validity was reported on in 1987. The need to develop a self-report depression scale was based on previous evidence which found that women with depressive symptoms following childbirth were not being identified in primary care and that other measures of depression such as the General Health Questionnaire (Goldberg *et al.*, 1970) and the Beck Depression Inventory (Beck *et al.*, 1961) were not sufficiently sensitive to depression in the postnatal period. There was also a need to develop a scale that was acceptable to women who might not regard themselves as unwell, which was simple to complete and for which the health professionals concerned need not have any psychiatric knowledge. The EPNDS was designed by Cox *et al.* (1987) by combining some factors from existing scales with some statements of their own based on knowledge and experience. Through a process of elimination, they reduced the scale to 10 items, this then being validated on a group of 84 women in Scotland.

It was found that a threshold score of 12/13 was found to identify women with PND when compared with diagnostic criteria for depression. The sensitivity of the scale was found to be 86 per cent, the specificity (the proportion of non-depressed women who were true negatives) 78 per cent and the predictive value 73 per cent. These measures of validity are described by the authors as being high enough for the scale to be usable in other community settings, especially as other criteria such as ease of completion were also met. The EPNDS has been extensively tested world wide since its development, and many researchers have found that it is a valid instrument in other contexts. However, one difficulty has been in the screening for PND among Asian women (see, for example, Hearn *et al.* 1998) where the somatisation of depressive symptoms within their culture makes completion of the scale difficult. This is of particular significance given the government's plans to reduce the mental illness level among ethnic groups (DoH, 1998). A further difficulty, in the light of Nicolson's (1998) study, is the temptation by health professionals to rely on the EPNDS to identify and problematise postnatal changes that may be largely of a social origin. This does not imply that health visitors should not be supporting women postnatally, but rather that by creating a situation in which some women, by virtue of a score, are seen to be more 'at risk' than others, it is possible that other professionals skills will be eroded, for example the ability to listen to and empathise with women as they become mothers without categorising them. There is clearly a careful balance to be found between missing women in need of specific help and problematising a normal reaction to change after childbirth.

CONCLUSION

In this chapter, I have attempted to outline the features considered essential to a basic understanding of evidence-based practice and clinical effectiveness for contemporary health visiting and to use the example of PND to illustrate the process of critical appraisal and synthesis that may be necessary in order to make decisions about the utilisation of research evidence. This type of approach could be used to address any topic that is of importance to health visiting in order to inform not only individual practitioners, but also the public health arena and decision-makers. The utilisation of evidence to provide the best possible care is not a choice: it is an imperative if health visiting is to be a major part of improving public health in the future. It is therefore the professional responsibility of individual health visitors, their managers and colleagues to ensure that practice can be based on robust evidence.

While this chapter has focused necessarily on research evidence and critical appraisal, the logical progression towards clinical effectiveness is continuous quality improvement through clinical audit. In relation to PND, for example, the utilisation of evidence surrounding the screening and measurement of the condition, followed by the implementation of interventions to prevent or allay PND, should be followed by audit in terms of the identification of its prevalence, the identification of groups that may need to be targeted (for example, Hearn *et al.*, 1998, found that Asian women were underrepresented because of the insensitivity of the EPNDS to the somatisation of symptoms) and the effectiveness of interventions, supported by patient satisfaction audit. Such an array of 'administrative' tasks can seem daunting to the practising health visitor, but they form a critical part of the progression towards providing the best possible care and being accountable for it. The new PCGs will have no choice but to function in this way if the ultimate aim of clinical governance is to be achieved. Research currently being completed by the author in collaboration with Yerrell, Kitson and Hughes (Yerrell *et al.*, 1998) has shown that, through the development of a 'tool-kit' approach to clinical effectiveness, primary health-care teams can work together, utilising intelligence and expertise from within the whole team, to identify priority areas within the practice population, to collect and appraise evidence, to implement innovations and to conduct audit to measure progress. While health visitors need to demonstrate their value to public health and secure their place within PCGs, this is probably more likely to happen, ultimately, through team work than through isolation of the health visitors' contribution.

Dedication

This chapter is dedicated to the memory of Sue Sefi who inspired some of my earliest thoughts on research in health visiting.

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CHAPTER THREE

Research questions and themes in district nursing

Lisbeth Hockey

This chapter has two main parts, followed by a brief section on conclusions and glimpses into the future. In the first part of the chapter, the background to the early development of research in district nursing is traced. A programme of research, undertaken by the author of this chapter, is outlined and some concurrent research alluded to. The programme of research is presented for four main reasons;

1. It constituted some of the groundwork in district nursing research.
2. It showed a progression in content as well as in methods.
3. It provides an early example of coherence of studies, illustrating some benefits of such a coherence.
4. It offers some examples of problems and weaknesses in research, from which important lessons can be learned.

The second part of the chapter is concerned with the main questions and themes that occupied researchers in the past 25 years or so. Some parallels between the early research and recent issues are highlighted. The literature cited is by no means exhaustive. It has not been selected on the basis of a judgement of quality: the studies mentioned are used merely as examples of the points made.

EARLY DEVELOPMENT OF RESEARCH IN DISTRICT NURSING

There can be little doubt that the choices and directions of nursing research in general, and community nursing research in particular, are to no small extent influenced by contextual factors, such as the type of research base, economic, political, social and professional pressures, and, not least, public demands and the profession's request to respond to them.

District nursing, possibly more than institutional nursing, is very much a community enterprise with a strong interplay between professional and societal factors. The research undertaken tends to mirror this. It is not surprising therefore that research in the field of district nursing had its root in the organisation responsible for the education of district nurses and thus, albeit indirectly, for the standard of service provided. In the early 1960s, this organisation was the (then) Queen's Institute of District Nursing, now The Queen's Nursing Institute.

On the author's appointment as tutor to the Queen's Institute in 1963, the first question demanding an answer related to the appropriateness of the traditional training syllabus for the current needs of district nursing staff. This apparently simple question generated a long-term research programme, each study within it arising from the results of the previous one. It became clear that a structure was urgently needed, and a foundation on which to build such a structure was sought without success. The only two studies that could be traced at that time were, first, a report of a national survey of patients with cancer being nursed at home (Joint National Cancer Survey Committee, 1952), and second, a study of Home Nurses' activities in a small English community (Brewin, 1963). These two studies, although limited in size and research design, epitomised the duality of purpose that was to direct district nursing research for some time to come. The duality relates to studies about patient care on the one hand, and to those exploring staffing and organisational matters on the other.

It was encouraging to identify such an early study with a patient-centred focus. It attempted to identify the needs of patients suffering from cancer who were being nursed at home. Studies related to the assessment of needs have continued since and seem to be on the increase. The early work had been initiated by the Marie Curie Memorial Foundation, a voluntary agency committed to the care of such patients. It can thus be seen again that organisations with a specific brief raise questions related to that brief.

The other study mentioned above, which predated The Queen's Institute's research programme, attempted to provide a basis for staffing by examining the activities performed by district nurses. It must be remembered that local health authorities were, at that time, responsible for the provision of an appropriate district nursing service, and the Medical Officer of Health, in whom that responsibility was vested, had initiated the work. It is significant that the study was published in the journal *The Medical Officer*. It is only in the past three decades or so that community nurses themselves have begun to ask pertinent questions about their work and about the care of their patients or clients – questions that led to their own independent research.

Simpson (1971), a pioneer in British nursing research – traced the development of nursing research in Great Britain and advanced the following speculative reasons for the slow beginning:

- submissiveness of the nurse to the system, resulting in an unquestioning acceptance of the *status quo*
- an inadequate educational background, affording little or no opportunity for the acquisition of research expertise
- a lack of financial and other resources
- difficulty in defining the content and ambit of nursing.

Simpson's first assertion, although entirely speculative, had been generated by her own and her colleagues' experiences. Later, submissiveness of nurses found its way into the growing volume of gender studies. As a predominantly female labour force, nurses worked in a male-dominated system, submissive to the largely male medical profession (Davies, 1995; Rafferty, 1996).

To compare Simpson's assessment of 25 years ago with the present situation is a salutary exercise. It seems that submissiveness prevails to a large extent, although the reasons for it may have changed. Many nurses today seem to accept the *status quo* for fear of unsettling their own position. In addition, the increasing pressures in their work situation, combined with more complex patterns of family life, leave little time or energy for exploring.

As far as the second reason advanced by Simpson is concerned, considerable optimism is justified. Educational opportunities have increased remarkably and, with them, the availability of research competence.

The last two points identified by Simpson, namely a lack of resources and difficulty in defining the nature and boundaries of nursing, seem to remain. For the district nursing service at the time of the present author's early research, these problems were particularly pertinent. The administrative units, the local health authorities, were smaller than the regional hospital board, which controlled the hospital services. They were independent autonomous structures and would have had to provide their own research resources, which they would have been unlikely to use for research outside their own boundaries. For each local health authority to set up its own research mechanism would have been unreasonable and possibly also counterproductive. Moreover, whereas the hospital services were financed directly by central government revenue, payment for the community nursing services came from local rates determined by the local authority. Although this system might in principle have increased or restricted expenditure, it was obvious that research ranked low in order of priority for financial resources. Research takes time and is not easily recognised as being of immediate and direct benefit to the consumer, who, as rate-payer, was also the paymaster. Local authorities, being politically orientated organisations, are influenced by prevailing party priorities. As alluded to above, community nursing was and continues to be difficult to define in terms of its content and boundaries. Even more difficult, was the identification of community nursing as a scientific discipline with its own professional content amenable to research.

The functions of community nurses are wide ranging as they have to be responsive to the often unpredictable physical, emotional, social and economic conditions of patients and their carers. In the early 1960s, many community nurses combined the functions of district nurse and midwife and some undertook health visiting in addition. It is not easy to study such a diffuse workforce in a systematic manner.

The fact that The Queen's Institute was able to consider a long-term research programme had its main reason in the voluntary nature of the organisation. However, before embarking on such a major commitment, reflections on the possible reasons for the delay in community nursing research were necessary in order to assess feasibility. It was considered that the anticipated difficulties were not insuperable and that, providing finance could be made available, there was no serious reason why research should be further delayed. Because of its voluntary status, the Queen's Institute was free to pursue its own interests, and, because of its delegated powers for education and standards, it was able to operationalise its interests in relation to the real world.

QUEEN'S INSTITUTE'S PROGRAMME OF RESEARCH

The Queen's Institute was also free to respond quickly to matters requiring urgent attention. Thus when concerns about aseptic techniques in the hospital service were made public, the Institute lost no time in examining comparable situations in the district nursing service. This was a complex enquiry requiring the help of governmental agencies to test the sterility of instruments and dressings used by district nursing staff. The results provided evidence for the need to introduce presterilised equipment to the district nursing service (QIDN, 1963). The relevance of such research was freely and universally acknowledged and there were no problems in using the research findings to change district nursing practice – an effect that few, if any, studies have achieved since. It also changed domiciliary midwifery and some aspects of health visiting practice.

After completion of this urgent work, the intended long-term programme was to be set in motion. The foundation on which it was built was a national study of district nurse training establishments and an enquiry among district nurses 1 year after completion of their training. The purpose was to discover whether their training had been appropriate for current practice needs. One important methodological problem soon came to light. It was difficult, often impossible, for many nurses to distinguish between the influence of their training and the influence of their year's experience since completion of training. However, the work provided pointers that helped with the design of the baseline study to underpin the research programme (QIDN, 1963).

This was a totally descriptive study of district nurses in six local health authority areas. It set the scene by showing who the district nurses were in terms of demographic and educational characteristics, what they did in their capacity as district nurses and what types of patient they cared for. The six health authorities were carefully chosen; two were industrial areas, two were retirement areas, and two areas were rural in character. The respondents were mainly district nurses, but district nurse managers and general practitioners were also included. Many different aspects of the district nursing service were explored. The first most striking result was that the professional qualifications of the district nursing staff did not seem to be fully utilised, thereby supporting the opinions and views that prompted the research programme in the first instance. Another important finding concerned the poor or non-existent communication between district nurses and the general practitioners who, ostensibly, shared the care of their patients. A further notable set of results suggested that district nurses' work patterns were related not only to the needs of their patients, but also to organisational issues and constraints. Moreover, the individuality of district nurses, who at that time worked largely in isolation, played a large part in the type of care provided.

Weaknesses in communication between district nurses and general practitioners have been alluded to. This finding was endorsed by Carstairs (1966), who undertook a similar but totally independent study of district nurses in Scotland. This was encouraging and lent credence to the Institute's research (Hockey, 1966).

From her experience as a district nurse, the investigator realised that there was a functional connection between the district nurses' work and their communication with general practitioners. At the time of the study, the district nursing service was, to a large extent, dependent on general practitioners for the referral of patients. Only those patients for whom the general practitioners considered nursing intervention to be needed became the concern of district nursing staff. Therefore, any assessment of domiciliary patients' needs by focusing on district nurses' workloads has inherent weaknesses.

Although most patients cared for by district nurses were referred by the general practitioner, some nursing intervention could be requested by hospital medical or nursing staff for those who had been inpatients or outpatients. In order to complete the picture of the nurses' actual or potential workload, the second study in the programme was generated from two specific questions and was planned to test two specific hypotheses. These had been formulated in the course of the pilot work. The hypotheses were:

1. Patients are recalled to hospital as outpatients for treatment or care that could be provided by the district nursing service in their home.
2. Patients are discharged from hospital after inpatient care without appropriate community services, especially district nursing, being organised on their behalf.

The second study was, again, limited in size. A small number of hospitals of different types and geographical location were selected. Although the hypotheses were confirmed within the limits of the study, and pointers to weaknesses in communication were provided, generalisation of the findings was not possible (Hockey, 1968). As was the case with the earlier study of the district nurses' profiles and work patterns, so it happened in this instance that a similar, although not strictly comparable, study was published in the same year (Forsyth and Logan, 1968). Again, the findings of both studies supported each other. Research published 2 years (Skeet, 1970) and 5 years (Roberts, 1975) later further corroborated the findings by showing continued gaps in the continuity of patient care between the hospital and community services. In spite of the fact that the findings were supported by similar work undertaken independently, they were not, in themselves, adequate to form the basis for a change in policy on a national scale.

As Simpson (1974) argued, research cannot take decisions but only provide information on which decisions can be made. Research available at that time, although amenable to professional interpretation, did not provide the type of information on which far-reaching decisions could be made. Description rarely, if ever, warrants prescription without intervening experimentation, and, as a result of this awareness, a *quasi*-experiment was conceived as a prudent next stage in progressing the programme of work. It was an experiment in that a situation was artificially created for the study of the effects of an experimental variable. It was described as a quasi-experiment, as there was no attempt at a scientifically rigorous control of variables. (In hindsight, it might more appropriately be referred to as an evaluated intervention.) The experiment consisted of attaching a district nurse to the surgical department of a general hospital. It was an attempt to forge a synthesis between two types of care – hospital and domiciliary nursing – each of which operated under its own bureaucratic administrative structure. Hospital care was supported within the gigantic hospital system financed from national taxation, and the provision of district nursing was the responsibility of local health authorities and financed from local rates. General medical practitioners had yet another administrative machinery controlling the organisation and delivery of domiciliary medical care.

The 'experiment' was based on the following assumption:

> If a patient's total care embraces both hospital and home care, nursing in both settings must be synthesised into one system, whose successful functioning will depend on mutual understanding and collaboration. Before such a synthesis could be recommended as a matter of policy, it seemed necessary to establish:
> a. descriptively, what the result of such synthesis would be
> b. evaluatively, whether such synthesis would be desirable or not.

The progression in the design of the research programme lay in setting up the 'experimental' situation and attempting a simple evaluation of it. The findings of the study suggested that an extension of community care by an earlier planned discharge of patients might seem a rational proposition (Hockey, 1970). The feasibility of such an extension was seen to hinge, to no small extent, on available nursing manpower in the domiciliary nursing service.

At the time of the study, district nurses in the UK were either registered, having had a basic professional preparation of 3 years, or enrolled, with a basic professional programme of 2 years. Some of both types of nurse had taken an additional course in district nursing, although such a course was not a legal or professional requirement for a licence to practise district nursing. Recruitment for enrolment courses had overtaken that for the register. It was therefore a logical next step to examine carefully the deployment and work of the enrolled nurse *vis-à-vis* the registered nurse in the district nursing service.

As far as the research method was concerned, it can be argued that it was a retrograde rather than a progressive step to proceed from an experiment to a descriptive survey. However, it was a national survey whose design warranted the claim for nationally applicable findings. This is one of the two respects in which this national survey showed progression. The other respect was the tool used for the collection of the data. For the first time, *one* document linked information about the nurses' work activities throughout the 24-hour period with information about their patients, including the place at which the care was given. Although the main benefit of that study lay in its applicability over the UK, the government department responsible for health in England was anxious to isolate that part of the country which came under its auspices. As the national sample of local health authorities had been stratified by region and by type of area, it was possible to undertake further, more sophisticated analyses of the data for district nurses in England. A sophisticated database had been established, from which further work could be developed (Hockey, 1972).

Reflections on the programme

Attempts to analyse the work of district nurses continued and still occupy the attention of researchers. Different emphases were used in those continuing analyses. McIntosh and Richardson (1976) focused on the duration and content of the various district nursing activities, while Olver and Buckingham (1997) used the diseases and conditions of patients as their main classification variable.

The research programme had led from a limited descriptive case study through a series of intermediate stages to a national database, which encompassed details about not only the nursing staff and every aspect of their activities, but also their patients. As alluded to above, it included the patients' age, sex, type of condition and degree of mobility, as well as the place at which the nurses gave the care. Such information, linked with demographic predictions and morbidity trends, can provide a basis for long-term planning and decision-making.

The programme also led to the construction of a conceptual model of factors influencing district nursing care. The programme had been initiated by service needs and pragmatic questions. It had no academic direction in terms of a theory to be tested, and it did not set out to postulate a theory. However, some theories emanating from the discipline of sociology as well as nursing were used to seek explanations of unexpected findings. As a rough guideline, the criteria used to accept a theory as having explanatory potential were those suggested by Glaser and Strauss (1967): that it should 'fit' the situation, that it should 'work' and that it should be understandable to the layman. An example was Mauksch's theory of the hospital as a social system (1966), which explained, at least in part, why nurses felt attracted to work outside it. Blau's work on the differentiation of power (1964) helped to explain further the preference of some nurses for working in the homes of their patients. Many other theories were invoked to explain certain aspects of teamwork and other findings (Hockey, 1979).

Some years after the completion of the research programme outlined, a report of a seminar on social care research was published (Barnes and Connelly, 1978). It was encouraging to note that, although it had been concerned with research into the local authority social services, many of the emerging points were equally applicable to nursing research. Indeed, the case made for the benefits of a long-term research programme with a clear progression of studies within it was echoed by Rutter (1978, p. 107) who said:

> there has to be a recognition that research is a process and that almost any policy question will require a series of studies each of which progressively takes the matter a little further

It is in progressively taking the matter a little further that the benefit of a long-term coherent research programme lies. It could be argued, of course, that individual studies might be so designed that they can reap the benefits of progression. In practice, however, it seems that researchers tend not to build directly on each other's work. They tend to go back to information-gathering instead of thinking about the 'why'. Rutter (1978) gave examples from social care research, but the same is true for nursing research. Any systematic review of the literature bears witness to it. There is a great deal of information available about the working day of district nurses, about the organisation of general practitioner and hospital attachment schemes, about communication problems, about role conflicts and about a range of other issues. The same themes have been studied with almost monotonous regularity, but with just enough difference in design to make them unsuitable for direct comparison. In spite of the large amount of data on certain subjects, little has found its way into policy, probably because the matter was not taken far enough (Rutter, 1978) to warrant its implementation. The regret about the lack of research-based policy or practice has continued. At the social care research seminar quoted above, it was concluded that:

> what is NOT required is a strategy which sprinkles research around like drops of water in a desert. What IS required is planning which identifies particular problems or issues and translates them into researchable questions, followed by programmatic research. (Rutter, 1978, p. 107)

The identification of so much commonality between community health and social care research 20 years ago should, perhaps, lead to a realisation that a jointly conceived and planned programme of research might tackle some of the current problems relating to the health care–social care interface.

RECENT DEVELOPMENTS IN DISTRICT NURSING RESEARCH

Developments in district nursing research during the 11 years from the beginning of 1974 to the end of 1985 are well documented in *Community Nursing: Research and Recent Developments* (Baker *et al.*, 1987). The authors emphasise the importance of the context in relation to research development. The boundaries defining their period of study were linked to legislative changes. Thus the NHS reorganisation in 1974, which resulted in the creation of local health authorities with responsibility for both hospital and community nurses, provided a clear pointer to an urgent need for research. The significant event that 'marked' the end-point of their review period appeared to be the government's decision to implement the recommendations of the Steering Group on Health Services (Körner, 1984), which related mainly to the creation of information systems by 1984/85. The period under review by Baker *et al.* (1987) was also influenced by the UK's membership of the EEC and by developments in nursing education. Although these events seem discrete, they are related to each other. The reorganisation of the NHS raised issues of management of the nursing services, including the more effective use of resources. It is not surprising therefore that a great deal of attention was devoted to various analyses of district nurses' work in attempts to find appropriate guidelines for the delegation of some work to less-qualified staff.

The early methods of attempting to describe a district nurse's working day were simplistic, a structured work record being used (Hockey, 1966). More advanced and sophisticated research approaches and new methods for the analysis of complex qualitative data are now available and put to good use.

Thus Rapport and Maggs (1997) attempted to 'measure' care given by primary health-care professionals, using a qualitative design. The fact that the mere listing of tasks performed does not reflect the knowledge base underlying district nursing care had been recognised and explored by McIntosh (1996). She attempted to demonstrate the covert knowledge used by district nurses in their decision-making by making that knowledge explicit and clearly visible. This is pertinent and important work in view of the government's pronouncement by the Secretary of State for Health in the White Paper (DoH, 1997) that professional decisions should be knowledge based.

Principles of good primary care presented in Chapter 1 of the White Paper (DoH, 1997) provide clear directions for research. It seems fairly certain that the shift from secondary care to primary care will continue to be promoted. Therefore, research exploring issues related to such a shift is gaining momentum. Because of the increased workload for district nurses that such a shift must cause, studies of skill mix must be included. Jenkins-Clarke and Carr-Hill (1991) attempted to measure skill mix in primary care, focusing their attention on dilemmas of delegation and diversification. Such considerations are bound to be related to role recognition and role boundaries. Advances in nursing education, including its shift into the tertiary/higher education sector, increase manpower costs. Added to the existing budgetary constraints within the NHS, the urgency to identify a suitable skill mix becomes obvious. Thus such studies have increased in tandem with needs assessment research. Worth *et al.* (1996), in their study of assessment of need in district nursing, recognised that the role of the district nurse, especially in relation to preventive and rehabilitative aspects, was far from clear. They also demonstrated that social workers did not rate district nurses' assessment skills very highly, but this may be associated with their acknowledged lack of understanding of the district nurse's role. It can be seen that studies of need assessment impinge on those of role boundaries, teamwork and communication. Although these issues are closely related, they are often studied in isolation, which tends to reduce their usefulness. At the same time, it is readily recognised that the prevailing economic climate militates against comprehensive research programmes.

Needs assessment has been the focus of a great deal of research over the past 6 or 7 years, with different methods being used for the purpose. For example, Ong (1991) used an ethnographic approach but stressed the complexity of the problem. No claim for a blueprint is made. More recently, the study by Worth *et al.* (1996) used the general practitioner referral system, case finding and interviews in their attempt to design at a needs assessment formula. They, too, were unable to arrive at a foolproof method, largely because of a variation in the perception of district nursing roles. They also stressed that the concept of need itself is not clear cut and is subject to many interpretations.

An exploration of profiling in community nursing is described in a study by Wright (1997). It had a related but different objective in that it set out to evaluate current practice and determine community nurses' perceptions of 'ideal' practice. Implicit in that exercise were needs assessment, quality monitoring and decisions regarding manpower requirements.

Another theme involving the district nursing service, which has been studied intermittently since the 1970s, is the discharge of patients from hospital into the community. Again, the early work consisted largely of basic structured interviews (Skeet, 1970; Roberts, 1975). Since then, a variety of more complex methods have been used to collect the relevant data. Examples of studies are those by Bowling and Betts (1984) and Tierney *et al.* (1994). Yet the transfer process is still far from seamless, as concluded by Nixon *et al.* (1998), who hope to develop an audit procedure from the research literature on discharge planning.

Within the Scottish Needs Assessment Programme, Miller *et al.* (1997) set out specifically to study and understand the shifts between primary and secondary care. The study makes a special contribution to the search for an appropriate method to identify shifts using routinely held data. The authors contend that, while a programme budgetary approach is useful in monitoring broad policy objectives, aggregate data cannot pinpoint whether specific services have shifted. They made three recommendations:

1. NHS policies should be constantly monitored against objectives.
2. Shifts of service between care settings should be properly evaluated on a case-by-case basis.
3. Further research needs to be conducted into the changes in costs and benefits of shifts in primary care.

As can be seen, each of the above recommendations requires a research basis, and the quest to develop techniques for monitoring, evaluating and assessing benefits is likely to continue.

CONCLUDING COMMENTS, PROBLEMS AND CHALLENGES

Many complex issues for research are emerging. For example, it is becoming increasingly evident that the working domain of district nurses is enormously variable. The emphasis on community care, resulting in much earlier discharges, as alluded to above, from hospital after surgery, confronts district nurses with situations demanding advanced technical skills, often using new sophisticated devices. At the same time, increased longevity adds more long-term elderly patients to the caseload, calling for a knowledge of multiple pathologies and considerable pharmacological expertise. Nurse prescribing is also likely to increase. Yet the conventional responsibilities of district nurses will remain, although skill mix can be expected to dilute the expertise available to some patients. The bases on which delegation to less qualified staff is operationalised require further study.

On another level, the district nurse's relationships with practice nurses, community psychiatric nurses, palliative care nurses and other nurse specialists, as well as social workers, community occupational therapists and physiotherapists in addition to other domiciliary health and welfare personnel, are becoming more convoluted and intertwined. In the interests of patient care, it seems important to explore and clarify such relationships. Research must address some of the above issues by unidisciplinary as well as inter- and multidisciplinary approaches. The effects of legislative changes on the workforce, as well as on patients and carers, must be established. The complexity of the knowledge base required by district nurses, both explicit and implicit, has begun to attract research interest, powerfully pinpointed by McIntosh (1996). The range of decision-making by district nurses, still largely obscure, calls for urgent study in order to secure appropriate care for future patients and their formal as well as informal carers.

There is also tremendous scope for research in the field of patient education, for research on patient outcomes in relation to different patterns of management and to different forms of patient information systems, and for research and evaluation of nurse-led diagnostic, caring and rehabilitative regimes. Patient satisfaction studies in relation to different interventions and new nursing roles will be needed, as will studies of nurses' job satisfaction in an era of change.

There is also a growing interest in clinically orientated studies in district nursing. To give just two examples: Freak (1996) added to the research-based literature on the care of leg ulcers, a regularly recurring topic, and Nolan (1996), recognising the importance of the informal carers' contribution to patient care, set out to explore the circumstances surrounding family care; Nolan's contribution in this field is well exemplified in Chapter 9 of this volume. There is likely to be a need to design research-based models of excellence taking account of such work and the context of a seamless service. The possibilities are endless. It will be important, however, to work towards a cohesive overall pattern, a research programme, which has an agreed direction and purpose. Only then will the results be able to provide realistic and valid pointers for a dependable and acceptable NHS.

Although the repertoire of available research, as well as the possibilities for complex data analysis, has increased enormously in recent years, some difficulties remain. The robustness of large, randomised controlled trials designed to seek answers to cause and effect questions cannot be disputed. However, it is becoming ever more difficult to identify comparable situations where the effects of independent variables can be measured. With the establishment in the UK of health-care Trusts and a multitude of small administrative units, patterns of work show greater variability than ever, especially in the community. Added to this variety was the mixture of fundholding and non-fundholding general medical practices in the late 1990s, with their own individual characteristics. Although fundholding by general medical practices is being phased out (DoH, 1997), some of its inherent individual features are likely to remain.

There are other difficulties in mounting large trials, such as costs in terms of finance as well as time. With regard to one aspect of time management in a research study, NHS Trusts have their own ethics committees, which are, rightly, powerful in their ability to facilitate or prevent research access. Ethics committees are not always predictable regarding decisions, do not always work to an agreed protocol and may set different conditions for the planned research.

Complex qualitative studies are not always understood or appreciated by quantitatively orientated committee members, many of whom come from an epidemiological medical tradition. Qualitative research in medicine is relatively new and it is likely to take some time for its value in answering certain questions to be widely recognised. Despite these potential problems with seeking ethical approval, mutual agreement is usually reached.

Finally, the plea for a cohesive research programme through a declared strategy, made by Rutter (1978), attempted to a small extent by Hockey and reinforced by Rothchild (1972), has been operationalised (although no connection between these events and statements is claimed) by the establishment of a UK Centre for Policy in Nursing Research. From this centre, a national initiative to establish a co-ordinated and systematic method for identifying priorities for research and development has been designed and piloted (Kitson *et al.*, 1997), one not confined to community nursing.

Most, if not all, research tends to generate more questions than it answers, and the studies cited above are no exception. Questions are raised regarding the role of the district nurse, his or her education, role boundaries with other community personnel, such as social workers, teamwork and many other areas. Most of the questions are not entirely new, but they may require new, possibly more sophisticated, methods to answer them. For example, cost accounting is likely to be a necessary component of most community nursing research. Yet this expertise is not widely spread among community health nurses. Therefore, collaborative studies with other disciplines such as health economists are likely to become increasingly important.

Reviewing the development of district nursing research over the period discussed in this chapter, it seems that the strongest influences can be attributed to progress in education and the ongoing almost constant changes in NHS organisation. It is impossible to predict the future with any measure of certainty, but history, linked with experience, can be a powerful pointer.

The British government has committed itself to the concept of community care through a primary care-led National Health Service. At the time of writing, the opportunities for obtaining government funds for community nursing research appear favourable. There seems to be no dearth of topics requiring research. Therefore, backed by research, interest and expertise, there should be no limit to the research enterprise resulting in a truly evidence-based community nursing service.

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CHAPTER FOUR

Exploring district nursing skills through research

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This chapter discusses the early stages of a study that was planned in response to a Scottish Office call for research proposals in the field of community nursing. The invitation to tender identified a number of areas of interest, most of which were of significance to policy or service provision. In selecting the area of district nursing skills and skill mix, the authors hoped to be able to make a contribution to a contentious topic that is underresearched and has important implications for patient care and nurse education. The chapter will therefore examine the policy context of skills and explore the meaning of the term 'skill'. It will go on to identify the challenges of setting up a research study designed to explore the use of district nursing skills and will then outline some early results from the study.

THE POLICY CONTEXT OF SKILLS

The nursing service has, for many decades, operated successfully on the basis of a workforce with different levels of professional qualification designed to develop different levels of nursing knowledge and skill. In parallel with this, the clinical grading of nursing posts reflects different degrees of responsibility, which are to a considerable extent, but not exclusively, linked with different qualifications. Until relatively recently, the balance of grades within the district nursing team – the grade mix – was seldom challenged across the UK. However, when more rigorous financial management principles were introduced into the NHS during the 1980s, the position changed. Alterations in grade mix became a key tool in achieving cost containment and revenue savings because the grading system is linked directly with remuneration (DHSS, 1983). Redefining appropriate spheres of activity for the different grades of community nurse thus became the means of justifying and achieving an increasing dilution of grade mix in an effort to contain costs.

The 'value for money unit' (VMU) research on district nursing in England was a prime example of this mode of thinking (Kelly and O'Leary, 1992). There were a number of flaws in the approach taken by the VMU research team, the most significant perhaps being the misinterpretation of the activity of assessment within the domain of nursing care. While assessment was correctly regarded as a key skill of G and H grade nurses, it was taken to include only the first assessment visit when it is in fact integral to much of the care given to patients on a day-to-day basis. The activity sampling that formed the mainstay of this study was undertaken in such a way as to demonstrate that assessment constituted a meagre proportion (3.5 per cent) of the working day. These results were then used to provide a basis for proposing a drastic reduction in the numbers of G and H grade district nurses and their replacement with nurses of a lower grade. The resultant cost savings were considerable.

The ethical argument about the appropriate use of public money must of course be acknowledged. However, when the recommended scale of grade dilution is as extensive as that suggested by the VMU team, questions need to be asked about the evidence base for such a change. If there is to be greater emphasis on care in the community, as successive government reports have urged, it follows that there will be many more frail and sick people being cared for at home (DoH, 1989, 1997). The need to ensure that such care is given by nurses with knowledge and skills sufficient for the identification of patients' needs, and the planning and giving of care, therefore has economic, policy, educational and moral dimensions.

At the present time, grade mix remains a powerful tool in the armoury of managers and directors of finance. Unlike the recommendations of the research study just outlined, it tends to be used in an incremental way in the form of a gradual move towards increasing dilution. This change is occurring at a time when the nursing care of patients at home is becoming more intensive. In parallel with this, the specialist preparation of community nurses has acknowledged the unique demands of working autonomously in an unpredictable and complex environment and is moving increasingly towards first and Master's degree-level study. Thus there is a potential paradox of securing a highly educated group of specialist practitioners who may eventually become an insignificant part of the workforce.

The exploration of community nursing skills in the context of grade mix and with reference to the meeting of patients' and clients' needs is thus an issue of great importance.

DEFINING TERMS – WHAT IS A SKILL?

The first task of any investigation of nursing skills is to ask two key questions:

1. What is meant by the term 'skill'?
2. What broad categories of skill are relevant to district nursing practice?

The most straightforward definition of the term 'skill' states that it is either a 'special ability to perform a task' or an 'ability conferred by training' (*New Collins Dictionary*, 1990). Given the statement above regarding the different levels of educational preparation for community nurses, one would thus expect to identify different levels of ability and what could be described as a 'hierarchy of skills'. The professional and academic discourse suggests that this is indeed the case. However, many researchers and commentators refer not only to a hierarchy of skills, but also to a corresponding and related hierarchy of tasks;

> staffing the task system requires a hierarchy of skills. (Gibbs *et al.*, 1991, p. 243)
>
> care should be given by the person with the most appropriate skills for that particular task. (Cahill, 1995, p. 357)

The notion that nursing skills can be appropriately linked to, or associated with, certain nursing tasks is an attractive one to service planners and managers because it opens up the possibility for evidence-based manpower planning. Computerised recording systems can identify and quantify the range of nursing tasks undertaken, and managers can then link these with a hierarchy of skills. Thus changes in the balance of grades could be justified on the basis of a perceived need for certain skills. This is particularly pertinent for cost containment if the nursing tasks that are linked specifically to the skills of G and H grade community nurses can be narrowly defined.

However, this notion that different levels of skill are required for different types of task contains a key assumption: that each nursing task requires either one skill alone, or one or more skills, all of which fall neatly within the capacity of the nurse undertaking the task. Before examining this assumption further, it is useful to identify why it might have arisen. It has already been noted in Chapter 3 that much earlier research focused on the work activities of community nurses. Given the invisibility of much of the care that is undertaken in people's homes, it is not surprising that the role of community nurses and the nature and scope of their work has remained a fruitful area for investigation. However, as Hockey has stated in Chapter 3, because many of these studies relied on questionnaires, the self-reporting of activity has been the principal source of data (Carstairs, 1966; Gilmore *et al.*, 1974; Kelly and O'Leary, 1992). In large-scale studies of nursing activity, questionnaires are designed to reduce error and minimise recording time in order to ensure accuracy and a high response rate. Such a method of recording has a major disadvantage, namely that often only the main procedure or nursing task is noted. Thus district nursing care in earlier research studies was mostly rendered visible through the medium of its practical tasks. Furthermore, nursing care was presented in such a way as to suggest that one main practical task dominated the home nursing visit. This may have served to promote the belief, particularly among managers, that district nursing care is predominantly practical, is relatively uncomplicated and can be safely given with minimal numbers of staff prepared at the specialist level. Such beliefs are no doubt further supported by the recognition that many thousands of lay people are taught to perform practical nursing tasks safely. The unfortunate consequences of this focus on practical skills are:

- a misunderstanding of the nature and range of skills used in district nursing practice
- a lack of evidence on the use of skills by different members of the district nursing team.

It is therefore clear that an in-depth investigation of district nursing skills is long overdue. The first step, however, is to gain a better understanding of the categories of skill that are likely to be a feature of district nursing practice.

TOWARDS A CONCEPTUAL UNDERSTANDING OF DISTRICT NURSING SKILLS

So far, we have noted that some researchers have tried to establish an association between particular skills and tasks, that skills are perceived to exist in some kind of hierarchy and that practical skills are regarded as the mainstay of district nursing activity. In order to gain a better understanding of the range of skills, it is useful to turn first to the expectations held by the UK statutory bodies of the competencies that should have been achieved by nurses by the time they become registered (National Board for Scotland, 1990). In addition to a range of practical skills, these competencies include interpersonal, observational, managerial and cognitive skills. Before considering some of these domains of skill in more detail, it is important to distinguish between competency and skill. In a review of the literature on the concept of competency, Runciman (1990) explores the range of definitional problems associated with the concept. In view of the fact that the term 'competence' is used so widely within nurse education to denote a nurse's ability not only to perform certain activities, but also to perform them to particular standards or performance criteria, it is clear that the concept of competence embraces notions of judgement. It is important to emphasise, then, that the authors' intention was to direct their investigation towards an exploration of skills and not of competency, which might include a judgement about how well the skills had been developed.

In considering the skill domains identified above in more detail, we note that each domain can itself contain many elements. For example, Burnard (1989, p. 32) has argued that 'the range of what constitutes interpersonal skills is vast'. He includes counselling, interviewing, social skills and the ability to work in groups. To this could be added teaching, information-giving, advising and relationship-building.

Observational skills involve the senses and will include noticing, watching, listening, smelling and feeling.

'Cognitive skills' is a generic term including a wide range of mental processes that form a necessary part of patient care. They include, for example, problem-solving skills, which, it has been argued, are 'central' to nursing practice and represent the divide between the professional nurse and the auxiliary nurse (Roberts *et al.*, 1993). Problem-solving and decision-making skills are likely to include, *inter alia*, appraisal, discrimination, prediction, risk assessment, evaluation and judgement (Bryans and McIntosh, 1996).

Finally, managerial skills, according to the competencies required of registered nurses, include actions involving leadership, liaison, care-planning, recording, ordering, teaching and supervision, team-working, delegating, motivating, prioritising and allocating resources.

In considering these four domains and noting the complexity of each one, it immediately becomes clear that the notion of a hierarchy of skills linked to a hierarchy of tasks may be difficult to sustain.

THE REALITY OF SKILLS IN USE

The notion of hierarchy in both tasks and skills is often exemplified in the arena of personal care of patients, which is regarded as requiring basic or simple skills, while the carrying out of more technical procedures is taken as being synonymous with a higher level of skill.

For a number of reasons, this is not helpful in elucidating district nursing care. First, each individual patient's care may require a number of nursing interventions of differing complexity because the patient may have several concurrent needs. The complexity of such need is frequently masked because, like earlier research studies in this field, systems of recording visits usually require the nurse to select the main purpose of the visit as a record of the care undertaken. It is acknowledged, however, that palm-top computers now permit the selection of a limited number of nursing interventions from a list.

Second, the nursing task to be performed does not necessarily provide an adequate indication of the patient's needs, which, for example, may be psychological in nature. Addressing psychological needs requires a range of interpersonal, observational and cognitive skills, and is an aspect of care that is, for the most part, unrecorded. Thus it has to be concluded that, in many situations, the nursing tasks undertaken cannot be used as proxy indicators of the skills required to give holistic care.

Thus the central challenge of a research study designed to investigate the nature and range of district nursing skills was to explore the four skill domains outlined above in an attempt to illuminate processes that were essentially invisible. However, before moving on to describe how this challenge was addressed, it is important to ask one further question. The four skill domains include interpersonal, observational and cognitive processes, which the majority of people use successfully, albeit with different levels of expertise and related to areas other than patient care. It is probable then that all grades of nurse will use skills from all four skill domains, with the possible exception of managerial skills. Their ability to use such skills stems from socialisation, individual cognitive capacity, professional and other forms of education or training and experiential learning.

While it is possible to identify the skills that are conferred by education or training, it is much more difficult, if not impossible, to identify skills learned experientially. The critical question that needs to be addressed is this: while experiential learning and skill acquisition by nurses of lower grades inevitably occurs, does it follow that they will acquire problem-solving and decision-making skills? If it does, attempts to differentiate between the skills used by different grades of nurse will be confounded, and it will not be possible to provide evidence to question the current dilution of district nursing skills. It is important therefore to examine the role of experiential learning in skills acquisition in order to identify whether there are additional factors that need to be taken into account in a research study.

ROLE OF EXPERIENTIAL LEARNING IN SKILLS ACQUISITION

Learning from experience and learning from a role model may mean that specialist practitioners will develop knowledge and skills that transcend the boundaries of their formal specialist education, and nurses working at lower grades may similarly become capable of using skills more often associated with nurses working at a higher grade. Experiential learning is not well understood, although Schön's work suggests that it is a gradual iterative process during which the practitioner encounters certain problematic situations and tests out ways of responding (Schön, 1991). A potential problem with experiential learning that has not been fully acknowledged by Schön is that learning pertaining to a particular issue or problem situation may, in the field of nursing care, stem from a relatively small number of patients. It could therefore lack breadth. In addition, the learning may not be shared widely beyond immediate colleagues and may not be assimilated in a coherent manner, as is more formally acquired theory. This inevitably means a lack of recognition of such learning, and, as such, its development and critical appraisal is inhibited. Experientially learned skills are therefore a very difficult territory to explore. Fortunately, however, it is possible to draw on the work of social psychologists who have begun to tease out the relationship between formally acquired knowledge, experientially acquired knowledge and skills. Kanfer and Ackerman (1989) proposed a model of skill acquisition that integrates a growing body of work on the development and use of skills, and is based on a sequence of research studies. They argue that individuals:

- possess a certain level of cognitive resources
- have varying levels of motivation
- are presented with tasks that vary in the extent to which they demand cognitive resources.

These three features can be identified simply as ability, motivation and opportunity. The first is straightforward and relates to the basic intellectual abilities of the individual. The second, motivation, is more complex, and Kanfer and Ackerman have used the work of Kahneman (1973) to explicate the importance of motivation within skill acquisition and its relevance to experiential learning. Kahneman identified two aspects of motivation: distal and proximal. Distal motivation relates to choosing to do one thing rather than another, while proximal motivation processes involve the activities of self-monitoring and self-evaluation – or the appraisal of personal performance and the subsequent modification of performance. These processes are fundamental within experiential learning, as Schön (1991) has identified.

Kanfer and Ackerman (1989) argue that self-evaluation is most beneficial after the acquisition of a critical mass of knowledge, in other words that the activity of self-evaluation or reflection, a key element in experiential learning, will not yield useful results unless the knowledge base is sufficient to provide a basis for full appraisal. This important point is also echoed in the work of nursing authors such as Marks-Maran and Rose (1997), who have developed a model for reflective practice and argue that the practitioner interprets events in the light of current knowledge and associated theories. It seems therefore that the level of an individual's initial professional education, together with the extent to which he or she is motivated to self-evaluate, will set certain limits on the extent to which experiential learning will take place. In short, there is an important symbiotic relationship between formal education and the capacity to engage in and develop professionally from experiential learning. This body of work would therefore suggest that experiential learning among the less well-qualified nurses within the district nursing team cannot confer all the skills featured in the four domains.

The Kanfer and Ackerman model has its critics, one of the identified drawbacks being that there is an insufficient acknowledgement of the ways in which individuals interact with their environment and develop skills over time (Russell and Kuhnert, 1992). The precise interaction between formal and experiential learning also needs more detailed exploration. Moreover, the role played by a number of other mediating factors, such as attitudes, values and context, needs to be explicated. However, what is clear is that a key element in the proposed research study must be to try to capture the differences in the use of skills between different grades of nurse and relate these to theories of skill acquisition.

CHALLENGES OF RESEARCHING THE SKILL DOMAINS

Before describing the aims and methods of the study, it is important to identify the challenges inherent in studying the use of skills from the four domains outlined above.

First, all members of the district nursing team are very likely to use practical, interpersonal and possibly even observational skills. It may be the case then that the study would not identify neat divisions of skill between grades. Could this run the risk of providing managers with a justification for increasing rather than halting skill dilution? An associated challenge, in relation to the research questions, was to seek explanations of why skills transcend grade boundaries and what the significance of this is.

Second, as the authors have already suggested, it is difficult to conceive of a single skill being used on its own. In order to give a simple uncomplicated injection, a nurse needs a minimum of practical skills and interpersonal skills. In giving care to seriously ill people, he or she may use practical, interpersonal, cognitive and observation skills in an integrated way, possibly simultaneously. How could the proposed study overcome the problems of earlier work and capture the complexity of care?

Related to this is the third point, that certain interpersonal skills are highly complex and could be described as skills within skills. For example, negotiating skills may involve listening, information-giving and seeking, advising, explaining and persuading. Thus the research methods require an accommodation of the use of multiple skills, possibly used within a single interaction.

Fourth, there may be problems of interpretation and overlap within the domains. For example, touching a patient is an action that may move rapidly from nursing care in the practical skills domain to reassurance, which would be classified as the interpersonal skills domain. Similarly, the domains may be interdependent; for example, the use of particular interpersonal skills within a patient assessment may be necessary to identify information about the patient, which then triggers certain cognitive processes such as discrimination and risk assessment. How then can such relationships between the domains be captured, if at all?

Finally, there is the all-important invisibility factor. As already stated, district nurses' skills include unseen processes of cognition, which may hold one of the keys to differentiating between different groups of nurses. Another aspect of invisibility relates to those processes in which there is an intent to achieve some goal over the course of time. For example, some relatives are reluctant to accept an increase in nursing support within the home because this is seen as a manifestation of reduced independence or diminished capacity for coping. District nurses adopt certain strategies to overcome such reluctance, but they take time to accomplish such a mission. These strategies may be virtually indistinguishable from normal everyday expressions of concern or advice, and they may therefore be invisible to a researcher.

DEVELOPING THE STUDY

Given the issues outlined above, the research questions for guiding the study were developed as follows:

- What range of nursing skills can be identified in the nursing care of ill people at home?
- What differences in skill level can be identified between the different grades of nurse?
- What factors are taken into account when delegating care to practitioners of differing levels of skills?
- How are patients' needs taken into account when deciding which grade of nurse should visit?

What then would be the best solution to the study of skills used by the district nursing team? We have seen how there is a problem with the use of multiple skills, that skills may overlap and interweave, and that they include invisible processes.

The possibility of in-depth interviews with members of several district nursing teams was considered. An attempt could be made to invite team members to describe and explain their use of skills in different circumstances. Unfortunately, it is unlikely that nurses will be able to identify cognitive skills in detail as it has been shown that self-reporting on cognitive activity is problematic, a finding that is well exemplified in the work of Luker and Kenrick (1992) on decision-making.

The next method considered was the use of non-participant observation of nurses at work. While this would appear to be a viable option, there are certain concerns about the method that need to be addressed. First, nurses might try to present their practice in the best possible light. Second, the presence of an observer could so change the interaction that there would be, as a consequence, reduced opportunities for the nurses to use certain interpersonal skills. However, the work of a number of researchers who have used non-participant observation of nurses at work shows that this is not the case (Armstrong-Esther *et al.*, 1989; Brocklehurst and Butterworth, 1996; Twinn and Lee, 1997).

There is a third issue relating to observation that is important and that was considered by the research team. If a practitioner is observed on a limited number of occasions, the patient's needs and her or his environment will present the nurses with quite specific opportunities for demonstrating skill. Thus an observation study might merely reflect the opportunities for practitioners to use skill rather than the full range of their skills *per se*. Another key challenge therefore is to try to avoid such a limitation.

Despite the challenges inherent in an attempt to undertake non-participant observation of skills, this did in fact form the main plank within the overall research design. However, two problems emanated from this decision. First of all, it was important to include an acceptable sample from within each grade of nurse and also to observe nurses working in two different health board environments in order to identify whether there were important organisational factors influencing the use of skills. Thus 76 members of 21 district nursing teams were included from 2 different health board areas in Scotland, encompassing nurses from all grades. This was a substantial amount of observation even for a team of three research fellows, particularly as it was the intention to take intensive notes of actions and interactions, so the second problem was one of containment and data management. It was decided therefore that while each of the participants would be accompanied for a whole morning, only one patient who had complex needs would be the focus for data-gathering. This was called the focus visit, and a total of 76 focus visits constituted the main basis for the observation study.

It was intended that non-participant observation would open up the nature of nursing visits to scrutiny and provide data on practical skills and interpersonal skills. However, it was hoped that it would also offer the opportunity to provide the research team with important cues relating to cognitive processes that could be pursued with each nurse. In order to capitalise on the extent to which the focus visit could yield insights into cognitive and observation skills, the link between the patient's needs and the skills required to care for him or her, and the reason why a particular grade of nurse was visiting that day, it was decided to undertake a pre-observation interview with each nurse. This was complemented with a post-observation interview in which events or interactions occurring during the visit could be discussed and explained from the nurse's perspective.

The pre-observation visit might reveal a nurse's concern that a carer was not fully coping with the relative's care. The researcher would then attend carefully to any exchanges relating to this problem, observing nurse–patient and carer interaction to identify strategies that the nurse used and the carer's response to these. It was important therefore that the interviews and observation sessions occurred as close together as possible. Accordingly, the pre-observation interview was undertaken during the late afternoon prior to the observation session the following day, and the post-observation interview took place immediately after the morning's visits. This interview was also followed, where possible, by researcher observation of the team meeting and administration time in order to provide some opportunity for gathering data on managerial skills.

One of the problems referred to earlier was the question of particular patients' needs offering a limited range of opportunity for any nurse to demonstrate skills. One of the problems for this study was the possibility that auxiliary and maybe enrolled nurses would be accompanied on visits to patients who would not often be visited by registered nurses owing to the fact that their needs were more readily met by nurses working at lower grades. This would not be helpful in unravelling some of the more complex issues relating to skills or to matching patient need with the skills of the practitioner. Thus a deliberate attempt was made within the data-gathering to select some focus visits that were common to more than one grade of nurse.

It was also felt that patients themselves might have important perspectives on the different grades of nurse who visited them and the care given. A total of 20 interviews were therefore undertaken with patients to provide a consumer view of the use of skills.

Despite the opportunities to observe and discuss the use of different skills, which appear to have been provided by the combination of observation and interview, the possibility was considered that nurses might still have difficulty in identifying the skills that they expected to use, or felt they had used, on a visit. In order to avoid a situation in which participants simply could not identify skills, the nurses were offered skill diagrams drawn from Coomber *et al.*'s (1992) study in

Newcastle upon Tyne on skill mix. These provide a visual representation of the skills that might be associated with particular tasks. There is a risk of course that the participants might use skill diagrams as an *aide-mémoire* and proceed to select all the skills that they believe they should have employed. However, the important check on this is that, of course, the researcher was observing the visit, so questions would be asked if the nurse's selection of skills from the diagram represented an over-generous assessment of what actually occurred.

Finally, this was such a politically sensitive study that the research team decided to expose the proposed research methods not only to piloting, but also to an expert group of practitioners from all grades within the district nursing team. This group met once and received a presentation on the study methods, with the express invitation to them to challenge the team on the sensitivity of the research design with regard to the full range of skills that are used. The authors were delighted that the expert group had no reservations about the overall aims and design for the study.

EARLY FINDINGS FROM THE STUDY

The study has produced a vast amount of data, which, at the time of writing, is still being analysed. Analysis has been undertaken using the software package QSR NUD.IST, and, while some of the key themes have been explored, there still remains a considerable amount of analytical work to do. It is therefore not possible to present material that addresses all the points raised in this chapter. Instead, the authors have selected three themes of relevance:

1. the difference in the nature and range of skills used by practitioners who have different levels of professional preparation
2. the identification of how the skill level of the practitioner is taken into account when district nursing care is delegated by one practitioner to another
3. the district nursing care of carers, because it links with Nolan's work described in Chapter 9.

It must be emphasised that findings represent some 'early interpretations' of the data.

Skill differences in practitioners with different levels of professional preparation

There were considerable differences in the use of skills by the different grades, but the differences tended to become less at the more senior grades. Assessment was regarded as the exclusive territory of G and H grade nurses, although some staff nurses were allowed to undertake first assessment visits where the G or H grade nurse was intending to return the following day.

All nurses were seen to use observation and associated evaluation skills. Nurses noted a wide range of different aspects of the patient's physical condition, for example skin, breathing, urinary output, pain, circulation and pressure areas. The widest range of observations were made by the G and H grade district nurses, who included the general household environment, safety issues, household 'atmosphere' and signs of coping and not coping among the observations they made. These types of observation were not noted among auxiliary nurses and were noted to a much lesser extent among enrolled nurses.

The ability to identify potential risk was seen as a key skill of the registered nurses as opposed to the auxiliary nurses. The following quote from a district nursing sister illustrates this:

> I said... I'm putting the nurses in on Saturday and Sunday which she was grateful for because things got worse, which I had foreseen – whereas if the auxiliary went in she'd have looked at the picture differently. She would maybe have said – 'oh well she's having a bad day today'. (DN2.4)

The use of skills was influenced not only by the level of knowledge or experience, but also by what certain grades of nurse were permitted to do. In addition, while a recognition of the needs of carers was shared by all qualified staff, including the enrolled nurses, direct carer support and the ramifications of carer support were most frequently observed to be the domain of the G grade district nursing sister. Additional data illustrating the skill differences between practitioners with different levels of professional preparation will be included in the next section.

How skill level of the practitioner is taken into account in delegation decisions

G grade nurses were asked specifically about how they took account of patient need in making decisions about who should visit. It was noteworthy that where there was any element of risk or unpredictability in the patient's situation, they would undertake the visit themselves. The data showed that, to some extent, the recognised role of particular grades was the key to decisions about how patients' needs could best be met by the different grades of practitioner. For example, in trying to make a distinction between the staff nurse (E and F grades) and more senior nurses at G and H grade, some nurses emphasised the importance of decision-making and the level of responsibility:

> My whole job is making decisions ...my staff nurses do make decisions but I have got to take responsibility. I've got to help them make decisions as well, to make sure that they know what they are doing and that they are making the right decisions. (DN1.1)

However, it was noted in one of the study locations that it was the nursing roles within a particular team, rather than the grade of staff, that influenced delegation decisions. As this G grade district nurse comments:

> We are having to look at roles quite clearly but not as a list of tasks. It's job specifications in relation to the team that you are working in, that have to be looked at more clearly. Traditionally, the roles of the various grades have been very clear because the first visit was always done by the G grade. The way we got round this is that we say any trained nurse can do the first visit but the first visit must be delegated by a G grade. Also the G grade has to visit the patient within a time limit to do the full assessment visit. (DN8.6)

Many of the staff nurses had considerable technical expertise and could be more up to date in certain aspects of patient care than their G grade counterparts. This led some G grade district nurses to take the view that staff nurses should be allowed to undertake first assessment visits, while others affirmed the importance of community nursing experience in the conduct of assessments and supported the notion of assessment as an exclusively G grade activity. A district nursing sister comments as follows:

> Basically we oversee them [staff nurses], depending on how much experience they've got and what the first visits are going to be ...Obviously a

> lot of these girls haven't got much district experience. They haven't done the course. (DN8.4)

Some patients also had clear views about the appropriateness of the grade of nurse relative to their own needs, as this auxiliary states:

> Some of the houses you go into sometimes, if there is an acute nursing need, they are disappointed and they say, 'Oh we were hoping it would have been a real nurse.' And it's fair enough. I could understand that if I had someone who was needing nursing and it was untrained staff – maybe I would feel the same way. (AUX2.1)

Patients and relatives most often perceived the differences between grades in terms of the range of tasks that were undertaken. About half of the patients observed that registered nurses carried out more skilled procedures; others observed that they were more aware of equipment that could be ordered and which agencies to liaise with. The knowledge and skills of the qualified staff were highly valued by many patients and carers, as these carers state:

> I do feel better if it is a nurse rather than an auxiliary if X has an infection. It is easier if it is someone who can deal with any problem that crops up. (CR3.1)

> She's a proper nurse – an RGN. She discovered the bed sore 2 weeks ago. The auxiliaries come when there's nothing wrong. The auxiliaries do certain things but these are routine things. When I ask A questions I always get answers. (CR3.4)

However, although grade was to a large extent a determining factor, there was some variation across the teams in which grades of nurse were encouraged to undertake particular visits. It was clear that an individual appraisal of the staff member also took place and that individuals working on the same grade could have clearly differentiated levels of skill. Thus the skill level of the practitioner of any particular grade was integral to the delegation decision. An H grade nurse states:

> we go out with them. We work with them. If I don't like something they are doing then once we get outside, I'll say to them – 'don't do it that way. Try it this way and see how you get on. If you feel that that's not comfortable come back and discuss it and we'll decide which way is best'. (DN6.1)

As this process develops over time, the G grade nurses become very familiar with the skills and capabilities of their more junior staff. Another H grade nurse discusses an enrolled nurse as follows:

> Y [enrolled nurse] has been here 10 years now and is excellent. ...Y has basically done everything that there is to do in district nursing other than controlled drugs and the technical stuff – I know how much she'll take on herself and I know where she'll draw the line. (DN7.5)

However, there was not a universal assumption of this careful staff appraisal as the following G grade nurse explains:

> When I'm there I'm in control. I can control the patients I decide to give her [EN]. When I'm not there I tend to find when I come back that she has gone out and done first visits. The other sister allows her. I mean she has been treated virtually from an E grade to a G grade when it suits everybody around her. I don't treat her like that. I don't give her anything which would compromise her grade because I feel that my grade is important too ...my enrolled nurse doesn't do things the way I want them done. She doesn't see anything as a problem. She doesn't seem to have any insight into a lot of things for all her x years of experience. (DN6.2)

This quotation demonstrates how the level of responsibility given to enrolled nurses can vary considerably, a point first made by Hockey (1972). The study evidence overall confirmed this to be the case, partly because of expediency and partly because of a careful appraisal of their skill level. Expediency related to pressures of workload and also to other factors such as the management of double visits, who last saw the patient, the overall balance of work within the team and the importance of keeping individual nurses within the team motivated. These more pragmatic concerns reflected issues of overall management of the caseload and maintenance of staff morale rather than a constant concern to match precisely patient need with grade of nurse or skill level of practitioner. The exception was where there had been reported problems with patients or carers that required assessment by a G or H grade nurse.

Care of the carers

The majority of the interpersonal skills identified were regarded by nurses as being fundamental in the interactions between themselves and patients' carers. In examining the data relating to carers, the strongest theme to emerge was that of supportive strategies enabling the carers to cope. There were a number of distinct categories within this general 'facilitation of coping' theme. First, there was a recognition of the symbiotic relationship between patients' needs and relatives' needs, and that meeting the needs of the patient as fully as possible also significantly assisted carers. One district nursing sister stated:

> I feel if I relieve his anxiety [patient] then I relieve hers [wife] ... there's been times when she's been quite tearful and I've sat down and had a few words with her... but I do think that she feels better if his symptoms are relieved. (DN5.4)

One key area of support related to helping the carer get sufficient sleep, and nurses were vigilant, in this respect, with those who were undertaking heavy 'round-the-clock' nursing care. Understanding how carers might respond to suggestions of night-time assistance was important to its successful introduction. A number of carers resist night-time assistance, for example because they feel it is their duty or that the patient would not like having someone strange in the house at night.

The importance of continuing assessment of the carer and the patient was also acknowledged in relation to the provision of 24-hour care. A district nursing sister comments:

> Because things are so volatile, we're reassessing every visit, every day and care of the carers 'cos they're managing to cope 23 and a half hours so that he can stay at home. But if things start to change in any way then we'll have to see about getting other services or looking to other forms of care. (DN2.1)

A nurse's appraisal that a greater degree of nursing assistance was necessary in order to support a carer was regularly made in the knowledge that a carer might not welcome it. A common strategy in this situation was to introduce more help by degrees so that support was given as unobtrusively as possible in order not to undermine the carer's role:

> What we've got to do is really go slowly on it [giving more care] so that we get in gradually and make it not – 'it's not that you're not coping but we're here and we may as well do this while we're here'... and we'll maybe get around so that were giving more help. (DN5.2)

Support for carers also involves teaching about nursing care procedures. This kind of teaching was observed frequently, and nurses recognised that it helped carers to maintain a sense of control and competence, allowing them, in some cases, to lead an approximately normal life. Support also involves emotional support; there were many comments from all grades about the importance of this and a recognition of the emotional vulnerability of many patients and their carers:

> Her husband needs a lot of support. I had a long discussion with him and he is beginning to come to terms with what is happening to his wife. But he is very emotional and cries. I spend a lot of time there. (DN4.3)

While nurses can identify vulnerability among carers, they also recognise that carers may not want to reveal their true feelings to patients for fear of upsetting them. Thus judgements about the optimum method of giving support can involve deliberately seeking a private discussion with the carer, away from the patient or, as the following nurse explains:

> I'm going to go back to see her to allow her to talk when he is away at the day centre. I know that there is something blowing and boiling and she should be getting respite. (DN4.3)

Emotional support may not be confined to the main carer but instead encompass the whole family. An enrolled nurse comments as follows:

> It's the whole family you're treating there as well because... sometimes the son is there and he's asking different things and they're trying to bounce off one another ...it's just total reassurance they need, somebody to listen and talk to them and hopefully help with some situation. (EN5.1)

While recognition of the needs of carers was shared by all qualified staff, including the enrolled nurses, direct carer support was most frequently observed to be a G grade responsibility, as the following quote from an enrolled nurses shows:

> I have no doubt that she [carer] does have needs. It's a sad situation. But I've not heard her saying ...Her emotional needs I don't know, but I've no doubt she has them. (EN2.1)

With respect to paid carers who visit the home, the role of the district nurses in relation to the offering of support and guidance seems to remain constant. However, it was notable that, with paid carers, the nurses assumed a much more managerial approach despite the fact that they had no line managerial responsibility for them:

> There are two carers and the carer we met today didn't have any training at all before she came to the job ...she needs a lot of support and a lot of confidence building and that was an extra element that I didn't anticipate. (DN4.2)

CONCLUSION

In this chapter, the authors have attempted to identify the key issues that need to be addressed when considering the nature and use of district nursing skills. Hopefully, the points raised will have relevance to all community nurses. The nature and use of skills will remain high on the professional agenda for some time to come as community nurses wrestle with new patterns of working in integrated teams and self-managed teams, with the increasing trend towards outreach and the expanding use of social care.

The authors have argued that the nature and range of skills in use in district nursing have been seriously underestimated. As a consequence, changes in grade mix have been made on a set of assumptions rather than evidence. However, gathering sound evidence on the correct balance of grades within a district nursing team poses a considerable challenge given the contextual influences of differing neighbourhoods and the complex nature of skills acquisition, skills development and experiential learning. Managers undoubtedly have moved towards incremental grade dilution as a result of these difficulties and because there is no acceptable methodology for doing otherwise. However, it is time to question the assumption that grade mix can ever be satisfactorily accomplished at senior management level. While this chapter has reported only the early findings of our study, it is clear even at this stage that the knowledge, skill and evidence required to decide the appropriate grade mix lies at the level of the nursing team. The team leader alone can make a careful assessment of patient need, together with the all-important appraisal of the knowledge and skills of the different members of the nursing team. It could be argued then that a satisfactory solution would be the devolvement of budgets to a more appropriate level. Time will tell whether the recent White Paper (DoH, 1997) and the changes that it spells out will create the environment for such a change to occur.

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CHAPTER FIVE

Community nursing research in mental health

Sawsan Reda

This chapter discusses the process of undertaking research in mental health from a personal perspective. It will describe the setting up of the research and the challenges that were encountered as the research study progressed. The key outcomes for knowledge and practice, and the recommendation for future research in mental health nursing, will be addressed.

BACKGROUND TO THE RESEARCH STUDY

After the completion of a degree and specialisation in mental health, I decided to pursue research into mental health. My PhD supervisor was heading a team for evaluating the closure of psychiatric hospitals. The team consisted of researchers from various professions in mental health other than nursing, including social work, and I was invited to make a contribution as the nurse researcher. This opportunity provided excellent experience in research and in particular helped the development of skills in research methods and design. A research team creates a culture of exchange between colleagues of different disciplines, through the medium of a sharing of ideas and results, and it was this ethos which encouraged me to formulate a research study in the field of mental health nursing.

My study originated within the framework of the team's main project, the specific area of interest being the development of an understanding of the nurse's role and public attitudes during the transition of care from hospital to the community.

The main project was initiated in 1985, when the North East Thames Regional Health Authority (NETRHA) took the decision to close Friern and Claybury hospitals. In order to study the effects of hospital closure on patients' transition from hospital to the community, an independent research team was set up in an attempt to evaluate and monitor the process. This major research project had four elements:

1. a clinical study of outcome for long-stay patients (the elderly and those requiring dementia care)
2. the effect of the move of acute services into the local district
3. the cost-effectiveness of community services run by various agencies
4. the administrative process for provision of community care.

A number of studies were conducted to cover these four elements. A comparative design was used in which all patients meeting the inclusion criteria of the research study received assessment while still in hospital. Long-stay patients who were to be discharged to community facilities (leavers) were matched with those likely to remain in hospital for at least another year (matches). Both groups (leavers and matches) were assessed again (follow-up interview) 1 year after the leavers had been discharged. The leavers and their matches were divided into annual cohort groups, representing years since the transition to community care began. The aim of this main research design was to identify changes in patient characteristics between those receiving hospital care and those who had lived in the community for 5 years. Characteristics studied during the assessment were attitudes towards living in the community, and mental, social and physical states. For detailed information about the decision-making process relating to the closure of these two asylums (the Friern and Claybury hospitals) and evaluative studies carried out over 10 years, see Leff (1997).

In order to complement the four elements of the main study outlined above, it was decided to investigate crucial factors in patient readjustment within the community; these were staff attitudes and public reactions, first to the closure decision and second to moving people with mental health problems into their area. The following discussion will refer both to the main study and the personal study, and these terms will be used to distinguish between the two.

As little research had been done in this area, it was necessary to develop new research methods and then to design and pilot them. In addition, it was possible to use various research tools that had already been developed by the team and for which the reliability and validity had already been established (Thornicroft *et al.*, 1993). As the tools included measures of patients' psychological, social, mental and physical health, it would have been difficult, if not impossible, to design such tools personally within a short period of time.

There were clear benefits that stemmed from the association of the personal study with the main study. For example, it was possible to compare the data I collected with those collected by a colleague on the same group of patients (O'Driscol and Leff, 1993). In addition, being a member of a multidisciplinary research team highlighted the importance of researching mental health problems from a number of different perspectives in order to study the role of nurses in the community. Such perspectives included patient needs, various community services that nurses provided, public acceptance of community psychiatric services and the changes required in the nurses' roles to secure public support for their role in the community.

SOURCE OF FUNDING

The main study was funded for 10 years by the local health authority NETRHA, the Social Services Department and the King's Fund as part of a national plan to evaluate the decision of hospital closure. I was working as a staff nurse while conducting the personal PhD study; however, expenses for the project were covered by the main funding.

DEVELOPMENT OF THE ORIGINAL RESEARCH IDEA

It was expected that the results of the main study would have important implications for future developments in the policy for the care of mentally ill people and consequently for the nurse's role in the community. The design of the personal study was based on the hypothesis that patients' readjustment within the community and their clinical outcome, as described in the main study, would depend on their preparation before discharge and on staff and public attitudes towards community care. The personal study design rested on the assumption that most problems for patients, staff and local residents are likely to occur in the first 6 months after opening a mental health facility in the community. In addition, staff roles in the community were expected to depend on their attitudes to the changes taking place and on their preparation for work outside psychiatric hospitals. The investigation for the personal study will be considered under three subheadings: patient study, staff study and public study.

THE PATIENT STUDY

Design

The objective of this study was to identify any significant differences in the condition of patients while in the hospital and after 6 months and 1 year in the community. The research tools used were those used in the main study. A total of 20 patients (11 residents and 9 day patients) were interviewed before leaving the hospital and at 6 months and 12 months after their move to the community. In addition, non-participant observation was used before patients' discharge to describe patients' preparation programmes. The structured interviews included questions designed to elicit patients' attitudes toward living in the community.

The facility to which the patients moved was a Queen Anne detached house. The building had 12 bedrooms and was converted to house 20 patients. Daily activities were organised for resident patients.

Key findings informing knowledge and practice

The results showed a significant increase in the patients' social networks, this being a result of the number of professional contacts rather than of contacts with relatives or the general public. Patients preferred community living to hospital living and showed an improvement in their social behaviour over time. Significant differences with respect to severity of psychiatric symptoms, such as delusion, hallucinations and anxiety, as identified by the Present State of Examination Schedule, were found during the course of community as opposed to hospital living for all 20 patients (Reda, 1994). Patients were more likely to express delusion and hallucinations in the community than during their stay in hospital.

Since there is no control group, it is unclear whether these changes were due to patients' moving to a new facility or to the progression through time of their illness. However, it could be argued that the move to a new facility is more likely to have an effect on patients' behaviour than is the passage of a short period of time, given that the patients had been ill for many years. This argument was supported by the findings of the main team project that a similar group of patients did improve in the new facility after 1 year, and that the control group who remained in the hospital showed no change in clinical or social state over time (the project team's other patients acted as the controls for the personal study) (Reda, 1994).

Obstacles encountered during the study

A number of obstacles were encountered during the course of the study, as follows:

- There was difficulty in obtaining a large sample as any one community facility holds only about 20 patients. In addition, it is difficult to obtain a random sample as most patients were chosen by the staff, and this might have biased the sample.
- A major shortcoming in achieving internal validity is the lack of an adequate description of what comprises the nature of care received.
- There was an inability to complete the observation study because of staff anxiety and the lack of objectivity of the researcher in assessing outcomes.
- There was an inability to generalise or compare the findings with other local initiatives because of the absence of similar community facilities.

THE STAFF STUDY

The aim of this part of the personal study was to identify differences in opinions of the staff after they had been working in the community for 6 months, having regard to their experience, their perception of their roles, their preparation for work in the community and patients' needs.

Design

Tape-recorded interviews took place with 16 staff members when they were first employed to look after the above group of patients and again 6 months after commencing their work in the community. A semi-structured interview schedule was developed by the researcher for this purpose. For a detailed discussion of the methodology and the results, see Reda (1995a).

Key findings informing knowledge and practice

The staff highlighted certain areas of difficulty in their care for patients in the community, including patients' slow progress, the need to identify and explain inappropriate behaviour to patients, a lack of patient motivation, institutional behaviour on the part of patients, patients absconding, monitoring patients' medication and the need to resolve financial matters with the DSS.

Behaviour that affected patients' readjustment in the community and that was disturbing to their immediate neighbourhood included begging, poor hygiene, picking up cigarette ends and inappropriate sexual behaviour. Staff made a number of suggestions to improve patient adjustment, including education of the public, improving patients' appearance, 'weaning' patients off medication, afternoon and weekend structured activities for patients, a high ratio of trained staff to untrained staff within the community facilities, an intensive patient rehabilitation programme and proper assessment tools.

Overall, the staff expressed satisfaction in working in the community and believed that patients' quality of life had improved. They described their role in the community as unstructured, domestically orientated, encouraging independence, providing individualised care and encouraging self-worth.

The staff expressed a degree of confusion about the roles of qualified and unqualified colleagues. They considered that a professional qualification was not needed to work in the community. This created a conflict between qualified and unqualified staff members. The unqualified staff reported that they found that their qualified colleagues were not supportive. The unqualified staff suggested that a basic training programme should include practical solutions to deal with patients' and relatives' problems. They also reported a need to learn about psychiatric conditions and medication. They pointed out that qualified staff are required to deal with patients' more difficult problems. They also indicated that courses are more available to qualified than unqualified staff.

Obstacles encountered during the study

Again, a number of problems were encountered during this phase of the personal study:

- It was found that the use of a control group in this study was impossible because different types of facility employed different types of staff. Thus the staff members acted as their own controls.
- The size of the sample was small because community facilities tend to have a limited number of staff and a high staff turnover. Consequently, there was insufficient statistical power to detect change in attitude.

- The staff were generally apprehensive about being interviewed.

THE PUBLIC STUDY

The objective of this study was to identify local residents' perceptions of mental illness, their reactions towards former patients who moved to live in their neighbourhood and their needs for preparation before patients were moved into their neighbourhood.

Two hypotheses were tested. The null hypothesis was that no difference would be found at the beginning of the study between the study and control groups in their attitudes towards psychiatric patients. The directional hypothesis was that contact with psychiatric patients would result in greater positive attitudinal change among residents in the study group compared with the control group.

Design

A quasi-experimental design was used in which a study group and a control group of residents identified from the electoral roll were interviewed on two occasions: before and after patients were moved to the residential facility in the study group neighbourhood. The control group consisted of 100 residents of similar social strata who lived in a similar area and who had no contact with either this facility or any similar facility.

A semi-structured interview schedule was applied before the patients moved into the community and again 6 months later. A repertory grid technique, which is a quantitative attitude measure, was used on the same two occasions (Reda, 1996a). The questionnaire that was used as a basis for the interview schedule was designed to elicit public perceptions of mentally ill people in their own words as a qualitative measure of attitudes. The repertory grid technique, on the other hand, is a highly structured procedure used to complement the semi-structured questionnaire and provide a quantitative measure of public attitudes. Residents were interviewed in their homes, each interview lasting about an hour.

Negotiations for access to local residents began before the first interviews. A letter was sent 1 week before the actual interviews to the local residents living within a hundred yards of the community facility who were identified from the electoral register. At the end of each interview, the interviewees were asked whether they would be interested in a follow-up interview. Local residents showed interest in participating in the study.

Key findings informing knowledge and practice

It was found that public attitudes toward patients with a mental illness remained negative even after the patients had lived in the neighbourhood for 6 months. Casual contact between local residents and patients appeared to have little effect on residents' fear of mental illness. Interestingly, the presence of the mental health facility in the area did not of itself disturb the local residents. Their attitudes towards mentally ill people had developed from previous experience or from coverage of mental illness in the media. As a result of these attitudes, staff members shielded patients from coming into contact with local residents. It is worth noting that, even though local residents were against closing psychiatric hospitals, they indicated that they would not like to be admitted to a psychiatric hospital if they became mentally ill.

Finally, while local residents objected to having patients moving into their neighbourhood, a significant number indicated the need to open new mental health facilities. Paradoxically, they also expressed willingness to offer help and participate in activities with former patients suffering from a mental illness.

ISSUES ASSOCIATED WITH GAINING ETHICAL APPROVAL FOR THE PUBLIC STUDY

The work for the personal study with patients and staff was given ethical approval as part of the main study, and my attachment to the team was helpful in gaining credibility when approaching the psychiatric services for interviewing personnel. However, the process of seeking ethical approval was not entirely straightforward.

At the beginning of the public study, attempts were made to obtain consent from the appropriate ethical committee, as well as planning team approval for the study. Despite consent being given by each ethical committee approached, considerable resistance was met particularly from administrators (non-qualified in the mental health field) and the planning team in two out of the three districts involved in the study. Resistance to the study appeared to be based on the following factors:

- Negative attitudes toward consulting local residents about moving people suffering from a mental illness into their neighbourhood are based on the notion of 'normalisation'. According to this ideology, mentally ill patients are entitled to move into a house without local residents being informed.
- The planning team regarded the study as a potential vehicle for encouraging local residents' objections to, and concerns about, local mental health facilities, including opposition to the closure plan for the hospital on the basis that it would mean living close to people with mental health problems.

Fortunately, full approval was gained from the third district.

PROBLEMS ENCOUNTERED IN RECRUITMENT TO THE PUBLIC STUDY

A number of issues relating to the process of recruitment to the public study are worth noting.

First, it was found that the electoral register was inaccurate because people's names were either not recorded fully or were not up to date. In addition, the presence of a high proportion of squatters in the area meant that some sections of the population were not recorded at all.

Second, it was difficult to trace members of the public who had been interviewed at the beginning of the study for the purpose of conducting their later interviews. This difficulty may be due to the fact that this inner city area contains a large number of people from ethnic minority groups who are not in stable jobs and who thus move around in search of employment. A detailed description of the results and implications of the study can be found in Reda (1995b, 1996a–d).

IMPLICATIONS OF THE RESULTS FOR PRACTICE AND EDUCATION

The results could help to develop an understanding of the factors that foster a greater acceptance of mentally ill people in the community. For example, it is clearly important for staff members and former patients to examine messages that the public receive from various sources in order to understand the nature and basis of prejudice. In addition, greater efforts to encourage and facilitate communication between local residents and former patients could improve patients' social skills and support their rehabilitation programme.

The study highlighted the need for staff to engage in a planned programme of communication with local residents to help them to understand the behavioural problems of patients that stem from institutionalisation. Some members of the public showed an interest in conducting voluntary work at the mental health facility, and such willingness needs to be exploited as far as possible.

The results of the study provided basic data that could help in the further development of structured questionnaires that could be used to explore related issues in different community settings with distinct population characteristics. Further studies would help to validate the current study and add to our knowledge of this complex issue.

There is a need for evidence-based care in the community, an important first step being to establish objectives for community services. These objectives should contain sufficient detail to allow staff and patients to promote and monitor progress in developing these services.

Staff need objective methods to assess a suitable programme of daily activities. Planning a programme of activities (such as sightseeing, art or domestic work) should be based on patient needs rather than staff capability.

Due attention needs to be given to continuing professional development, and funds for training courses and conferences should be allocated for each staff member rather than by facility. This would ensure that training opportunities are provided for all staff members.

While some local residents maintained stereotyped attitudes towards people who had formerly been resident in a psychiatric hospital, the majority welcomed prior preparation and information about mental illness. It has to be remembered that public perceptions are not entirely unfounded as patients showed a deterioration in mental and social state. Thus local residents need to be approached sensitively, and staff should make efforts to involve local residents by maintaining meaningful interaction with them. Finally, it is important to point out that research into public attitudes does not create opposition to opening mental health facilities.

OBSTACLES TO RESEARCH IN MENTAL HEALTH NURSING

On completion of the attachment to the research team, the author moved to higher education as a university lecturer. Reflecting on the research experience, it can be clearly seen that conducting research studies in the area of mental health is complex. There are relatively few studies of a similar nature that can be used as a background for work in this field or to provide baseline work for the development of new research. It has also proved difficult to extend the work into related areas, such as the evaluation of community services, decision-making in mental health patient care and a more in-depth investigation of public attitudes towards psychiatric patients moving into their neighbourhood.

It could be argued that the difficulty in developing research in mental health is the result of a range of factors. For example, the lack of research in mental health leads researchers to develop projects that are of a basic descriptive nature, and such projects are less likely to attract funds. Second, the lack of reliable baseline assessments or measurements, and the absence of control groups, makes it impossible to separate changes due to the passage of time from intervening variables of interest such as the effects of moving patients from a hospital to a community setting or staff attitudes. Third, there is limited expertise in theoretical and methodological studies in mental health, such as the analysis of factors conducive to an improvement in patients' readjustment within the community. In addition, the organisational culture within many mental health units is not research orientated, and this makes it difficult to encourage practitioners to collaborate in research. An associated problem is that co-operation with researchers of proven track record in research is rarely obtainable. For psychiatric nurses to establish a track record in research, it is necessary to make contact with people from outside the work context and persuade them to collaborate in proposal-writing for a grant application. In order to establish such a network, one has to construct potentially important and interesting research ideas in mental health that are likely to attract the support of colleagues, referees and fundholders. This poses considerable challenges for those who are already involved in full-time and sometimes stressful work.

RECOMMENDATIONS FOR THE DEVELOPMENT OF RESEARCH IN MENTAL HEALTH

On the basis of the author's experience with one specific aspect of mental health research, a number of recommendations for further research in this field can be made.

First, replication of the above 'staff' study on a wider scale and over a longer period would be a very useful addition to our knowledge in this field. Such a study could help to evaluate psychiatric nurses' role in the community and further develop our knowledge of factors that might influence patients' readjustment in the community.

Second, there is an urgent need to evaluate the variety of professional development and other courses on offer in order to identify the relevant and successful areas of training and education. Such an enquiry could also help to identify which groups would benefit most from such courses.

Third, there is a dearth of research on nurses' attitudes towards hospital closure, the roles that they are required to adopt following hospital closure and their transition to such new roles.

In relation to the investigation of patients' preparation before moving to the community, more work would be of value, as would an evaluation of their rehabilitation programme. In tandem with such investigations, it would be useful to identify factors that promote positive public attitudes towards people who have been resident in psychiatric hospitals.

Greater encouragement should be given to mental health nurses to engage in research activity in both their basic training and their subsequent careers, with the provision of sufficient support to undertake this research. Consideration should be given to the possibility of ring-fencing funds, however small, for clinical nursing research. This would better support the move to evidence-based practice.

It is important to build a nucleus of colleagues to exchange knowledge and experience about their research activities. This might add credibility in grant applications and also facilitate data collection. Among the efforts to alter the culture in this way, one important strategy could be to involve graduate students in a multidisciplinary research team so that they could take part in the study and at the same time learn research skills. In support of this, senior research workers could assume some of the responsibility for supporting more junior researchers, working alongside junior colleagues for their mutual benefit.

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CHAPTER SIX

Community mental health nursing: an interpretation of history as a context for contemporary research

Edward White

EARLY HISTORY

The first community psychiatric nursing service in the UK is reputed to have been initiated at Warlingham Park Hospital, Surrey in 1954, when the Physician Superintendent recognised that pressure on beds had followed an increase in the number of hospital admissions that arose from the traumas of World War II (Nolan, 1993). He used the opportunities provided by the Mental Treatment Act of 1930 to implement a scheme that was essentially a pragmatic method of relieving pressure on hospital beds 'with a consequent better service to patients within the hospital' (May and Moore, 1963). At first, two nurses were assigned to the social work department of the hospital and functioned as 'social work aides' (Greene, 1990); only later did a 'distinct nursing function become obvious'. At a later stage, two more nursing staff were seconded to 'the project'.

Each nurse had a caseload of between 20 and 30 patients, which constituted their 'ward' (May, 1965). A regular weekly 'ward-round' was held under the leadership of the responsible consultant psychiatrist, who exercised indirect supervision. Over three-quarters of the cases had had one or more admissions to a mental hospital, and, over the course of a year, approximately a third relapsed and required readmission. Evidence to show the 'chronic nature of patients' illness' was apparent in the broad analysis of caseloads of the time; 50 per cent of referrals were suffering from schizophrenia, 25 per cent from endogenous (psychotic) depression and the remainder from senile psychosis or long-standing neurotic illness (May, 1965). After 7 years' experience, the job content of the four 'outpatient nurses', as they were called, was summarised as the supervision of patients who did not require hospitalisation, the follow-up and support of discharged patients, the supervision of outpatient clinics, the organisation and running of outpatient clubs, and finding jobs and accommodation for patients (Moore, 1961).

The significance of this development was slow to be acknowledged in the UK but, in 1957, a second service was developed at Moorhaven Hospital, near Plymouth, Devon. Moore (1961) reported similarities between the two developments, including the growth of demand for the service. In 1957, 44 patients were seen on 740 visits; in 1960, 116 patients on 1589 visits; in 1964, 165 on 2878 visits; and in 1966, 182 patients were visited on 3142 occasions (Greene, 1968). In a more detailed analysis of 145 patients in the latter year, Greene (1978) showed that patients on the nurses' caseload 'had a history of multiple admissions to hospital in the past'. Moreover, 40 per cent of patients had a primary diagnosis of schizophrenia, and 30 per cent one of depression, a similar picture to the early findings at Warlingham Park Hospital. Clearly, from the outset, there was an interest in investigating the nature and extent of the service, and this has formed an important part of subsequent research into community mental health nursing.

Both new services were subject to a number of 'early resentments'. For example, in Devon, the service met with 'some difficulties, misunderstandings and some opposition'; Greene (1990) reported that he had to justify the use of a scarce nursing resource for work outside the hospital without an increase in establishment. Some general practitioners welcomed the assistance of the psychiatric nurses, while others would have nothing to do with them. Even the consultant psychiatrists were divided. Indeed, at the time, Greene (1968) recognised that 'a weakness of the scheme' was that nurses who worked in the after-care service did not have special educational preparation for that work, a matter, he hoped, that would be 'remedied in the future'.

MODERN HISTORY: 1970–80

More than 30 years ago, Kirkpatrick (1967) predicted that the role of the 'community psychiatric nurse' (believed to be the first occasion on which this title was used in the published literature) would be contingent upon the social context in which it was to be performed. Therefore, because these contexts could be infinitely variable, the purpose of much of the literature published from 1970 onwards was to describe many of these; for example, Nickerson (1972) described service developments in Edinburgh, Wallace *et al.* (1972) those in Darlington, and Rodger (1973) those in Devon. Other early publications, whose accounts also rested at the level of description, focused on a particular client group, for example physically handicapped children (Deloughery, 1973), older people (Whitehead, 1974), adolescents (Haldine *et al.*, 1971) and alcoholics (Strong, 1975). Descriptive accounts thus formed the early forerunners of investigations into the role of community psychiatric nurses (CPNs). Accounts began to be published not only in the professional press in Britain, but increasingly in America (Duran, 1970), Australia (Eindor, 1973), New Zealand (Robinson, 1972), India (Matthew, 1972), Canada (Goldstein, 1973), South Africa (Coetzee, 1975) and Holland (Ramak, 1975).

FORMAL INVESTIGATIONS OF ROLE

It was not until the late 1970s, however, that the first more formal investigations into the role of CPNs began to be undertaken. Juliet Corn, then Research Assistant to Joan Parnell, a district nurse with the Queen's Nursing Institute, was undertaking fieldwork for a descriptive study of community psychiatric nurses. Her published work (Parnell, 1978) was the first to provide a broader national picture of community psychiatric nursing and, in effect, provided the watershed between the early and the modern history of CPN practice and education. Based on accounts provided by 453 CPNs of the 717 known to be involved with 143 schemes, Parnell's (1978) DHSS-funded study was the first to confirm the 'rather fragmentary way' in which local CPN services had tended to develop. Some of the services described to her were an extension of those provided by a psychiatric hospital, with ward or day hospital staff spending part of their time visiting their former patients. Other services were provided by staff, based either within hospitals or in the community, who had a full-time commitment to that type of work. Almost three-quarters of CPN staff were based within a psychiatric hospital, either in separate premises in the grounds (40 per cent) or at ward offices (28 per cent). CPNs worked between 5 and 9 hours 15 minutes each day; the maximum recorded was 14 hours 45 minutes. On the whole, however, the services from CPNs were not available at the weekends, only 10 per cent working on Saturday and 5 per cent on Sunday (Parnell, 1978).

Parnell reported that the most frequent source of referral to CPNs came from consultant psychiatrists: 93 per cent of all the referrals that CPNs received. Few CPNs had a formal limit on the size of their caseloads, but 'where this did exist', it was between 40 and 59 patients. Just over a quarter of Parnell's respondents specialised in a particular type of work, and, of those who did so, resettlement work in group homes predominated. Similarly, nearly 6 out of 10 CPNs specialised in the care of a particular group of patients; where that was reported, almost half of such specialisation occurred with patients suffering with schizophrenia. More generally, Parnell (1978) found that 89 per cent of all CPNs reported visits to patients with schizophrenia, on average 11 per week, during a specified week when they kept a research diary of work activity. Furthermore, 87 per cent of CPNs visited patients with depression, on average six times per week. In addition to these patients with a serious mental illness, patients with 'other neuroses' were visited by 63 per cent of CPNs, about three times per week, that is, nearly four times less frequently than those with serious mental illness.

Thus from the findings from Parnell's (1978) national research and from the earlier review of Hunter (1974), the description of community psychiatric nursing service provision in the mid-1970s was of a workforce predominately based in psychiatric hospitals, whose balance of orientation was toward the interests of patients with serious mental illness in response to referrals from psychiatrists. By way of further historical illustration, the CPNs at Warlingham Park Hospital remained 'consultant orientated' for the first 22 years of the service. It was not until September 1976 that one CPN accepted referrals from general practitioners and not until October 1980 that a 'second CPN was made available to general practitioners' (Sharpe, 1982).

Parnell's findings concurred with those of Sladden (1979), whose observation of five CPNs in Edinburgh during 1972 and 1973 was of an exploratory and descriptive character. Sladden's (1979) Scottish Home and Health Department-funded work concluded:

- In a high proportion of cases, the clients of this service had long-term or recurrent psychiatric problems of all types and had been in contact with psychiatric hospitals over a number of years, including a short inpatient stay over the previous year.
- Practically all clients were selected and referred to the (CPN) service by (psychiatric) hospital staff.
- The (CPN) service made extensive use of the parent hospital's premises and facilities. More than half of the group's working hours were spent on the premises, and nearly half of all encounters took place there. The chief recourse of the (CPN) service's staff for help or consultation was to psychiatrists at the hospital, and contact was more frequently made with hospital than community staff.

Sladden (1979) reported, at the time, that general practitioners were ill-informed about the existence of and functions of the CPN service. Most of them felt a need for a psychiatric nursing service in the community, but few felt that the existing service was available to help them. There was a tendency for them to regard the CPN service with a 'certain latent antagonism as a potential source of interference, or competition'.

The present writer (White, 1983) later offered one possible explanation for this. He noted that friction between competing groups of doctors had characterised the historical development of the general practitioner and that the latter part of the nineteenth and twentieth centuries had been occupied by the careful construction of divisions between those doctors who worked in hospitals and did specialist work, and those who did not work in hospitals and remained generalists. Indeed, Bowling (1981, p. 47) had earlier asserted that general practitioners became part of the unified medical profession at the expense of their remaining at the bottom of the medical hierarchy, 'their status currently as uncertain as their role'. The problem with general practice 'still seemed to be the lack of role definition based upon an independent body of knowledge; a prerequisite of full professional status'. Titmuss (1968, p. 41) thought that, although professional people declared their faith in the 'generic, the whole, the comprehensive and the multidisciplinary', they still wanted to specialise and to define more clearly their own professional, administrative and volunteer roles; 'to acquire and cultivate one small allotment of skill and knowledge was a great comfort'. White (1983) was cognisant of Cartwright and Anderson's (1981) finding that one possible 'small allotment' to cultivate (mental health work) had become increasingly irksome to general practitioners. It was therefore attractive for general practitioners to be provided with the opportunity to refer such clientele to CPNs. However, as White (1983) also recognised, a confusion arose between general practitioners and CPNs because of a possible mismatch of understanding about the purpose of a 'referral'.

REFERRAL AND ASSESSMENT

To some general practitioners, referral meant delegated task; that is, the encounter was in lieu of contact with the doctor, and, had sufficient time been available, the general practitioner would have dealt with the matter alone. A CPN understanding of the notion of referral, on the other hand, assumed that the referrer did not have the personal resource to deal with matters alone and recognised that somebody else might have; that is, even given infinite time, matters could not be satisfactorily dealt with without recourse to another. Thus, a 'referral' to a CPN that contained a prescriptive component, or a request to devote time, may have been considered by some general practitioners as a request to undertake a delegated task. This would often have run counter to the CPN's assessment brief, which could revise, or resist, the preconditions of the request, a clear contradiction of delegation. Indeed, in such circumstances, the result may have differed from the affirmation expected by the 'delegating' general practitioner. Conversely, at times when the challenge of an alternative view was expected from the 'referral', a mere CPN endorsement of the existing view of the general practitioner may have served only to disappoint. White (1983) regarded these circumstances as a struggle of expectations in which the general practitioner held, and could therefore exercise, the means of influencing the potential for CPN development. CPNs were tied paradoxically by the expectations of both becoming no more efficacious than general practitioners themselves (for that would further threaten the vulnerability of general practitioner status) and becoming therapeutically special and different (in order to simulate discriminating referrals). Different outcomes were expected from different referrers, indeed, different outcomes with the same referrers with different clients and/or on different occasions.

This tension, to be the same as (or at least no better than), but also different from general practitioners, was further illustrated by another early paradox. CPNs were expected not only to hold an 'all-comers brief' (White, 1983), much in the same manner as general practitioners held themselves (the notion of sameness), but also satisfactorily to delineate their role (the notion of differentness). Since the delineation of their role involved CPNs in identifying areas that they considered to be outside their sphere of work, it was impossible so to do without narrowing the focus down from the all-comers brief, which general practitioners found attractive.

CHANGING ATTITUDES

The requirement that arose from this complex interplay was for CPNs to present their credentials to general practitioners and other medical referrers, both at the level of individuals and at the level of the service. For, if not, as Sladden (1979) observed, 'Serious conflict between doctors and nurses is unlikely so long as existing status distinctions remain unchallenged, and values and perspectives derived from their common clinical background are shared. Difficulties may arise, however, if doctors disagree among themselves about what is expected of a community psychiatric nurse.'

The capacity for CPNs to influence and change the attitudes of professionals and the public was reported by Pollock (1986, 1990) from her review of the salient literature (MacDonald, 1972; Stobie and Hopkins, 1972; Sharpe, 1980). Pollock, a protégée of Sladden at the University of Edinburgh, focused her work on the process and outcome (rather than structure) of community psychiatric nursing. This was one of the first studies so to do, save the earlier exception of Paykel and Griffith (1983), whose field work began in January 1977. Pollock listed 11 other 'diverse motivations' for the continued development of community psychiatric nursing beyond the early experiments (Pollock, 1987, p. 115):

1. That institutional care led to an undesirable secondary handicap and therefore hospital admissions should be avoided in favour of home-based nursing care (Roberts, 1976);
2. That there was a need to reduce the number of in-patients and their length of stay, in line with government policy and, therefore, psychiatric nurses were well placed to provide the necessary supervision of early discharged patients (Marais, 1976);
3. That patients, when cared for by nurses outside psychiatric hospitals, could maintain their social connections and avoid the stigma of an institution (Harker *et al.*, 1976);
4. That psychotropic medication administered effectively by CPNs could help avoid patient relapse (Warren, 1971);
5. That a CPN assessment of a patient's condition at home, allowed an examination of the social context in which the disorder occurred (Hunter, 1978);
6. That home assessment arrangements allow nurses to support family members and carers (Roberts, 1976);
7. That CPNs were able to respond quickly to implement treatment (Leopoldt, 1979a, b);
8. That CPNs could relieve medical staff outpatient clinics and/or compensate for a shortage of psychiatric social workers (Sharpe, 1975);
9. That because the work of community psychiatric nursing was rewarding, staff wastage would reduce (MacDonald, 1972);
10. That exposure to community psychiatric nursing could benefit student nurses, whose educational programme was considered too institutionally orientated (Sharpe, 1975);

11. That CPNs usefully disseminated information to hospital-based colleagues about the condition of their clientele (Maisey, 1975).

While the list contained items that were not mutually exclusive, Pollock (1987) nevertheless captured the impression that early forms of community psychiatric nursing could be defended on several counts beyond the expediency that gave rise to its inception, described earlier in this chapter, and listed by Pollock herself as item 8 above.

However, it was not until 1985 that community psychiatric nursing was first unequivocally endorsed in public. In evidence to the Social Services Committee on Community Care, which 'warmly welcomed and encouraged the development of CPN services', the Director of the NHS Health Advisory Service (HAS) reported that 'the CPN is probably the most important single professional in the process of moving care of mental illness into the community' (Horrocks, 1985, p. 697). However, Horrocks also made some key observations about the service:

> Despite this, the usual finding on HAS visits is of understaffed CPN services. The CPNs carry excessive caseloads and lack adequate transport, telephone and secretarial/clerical support. Opportunities for training nurses to be CPNs are often lacking and insufficient CPNs have been enabled to specialise, for instance in the needs of the elderly mentally ill. Finally in some Districts, medical policies inhibit referral by General Practitioners direct to CPNs. (1985, p. 697).

Horrocks' overview therefore described not only the apparent success of community psychiatric nursing over more than 30 years since it had begun, but also the reality of its (then) circumstance: understaffed, underresourced, undertrained and, increasingly, under critical scrutiny. Skidmore and Friend (1984, p. 109), for example, described the success of community psychiatric nursing as the 'skilful practice of muddling through'. In particular, the findings from a study carried out from 1979 to 1983 put the developing notion of specialisation within community psychiatric nursing into doubt; 'our (1000) observations revealed that clients received no material benefit by being treated by specialists as opposed to non-specialists' (p. 179). Moreover, they suggested that specialism, rather than advancing the role of the CPN, 'dilutes the service'. They noticed that the 'seeds for such growth had already been sown' and were concerned that the CPN service would fragment into specialism on the American scale: 'the left-handed male agoraphobic specialist'. Although Skidmore and Friend (1984) did not describe the method by which they judged their notion of 'effectiveness', their series of articles was a potent influence both for

CPNs to begin to account for their practice, beyond mere description, and for others to call yet louder for it.

RECENT HISTORY: 1980 TO THE PRESENT

Much of the subsequent debate on the work of CPNs can be traced back to a discussion document published by the Social and Community Psychiatry Section of the Royal College of Psychiatrists (RCP), which first met in 1978. This claimed that 'there was agreement on most aspects of the work of the community psychiatric nurse' but that there were 'some differences of opinion among the professional groups who were consulted, concerning roles and responsibilities' (RCP, 1980, p. 114). The RCP Working Group noted that, in this, there was great variation between one service and another, but it considered that liaison and direct services to patients were important features. These included visiting former inpatients and their families, and offering long-term support; identifying specific problems and the referral to appropriate resources; assessing former patients for evidence of change, particularly for deterioration that might require further attention, together with assessing newly referred patients; administering long-acting antipsychotic drugs and then assessing their effects; the application, by some CPNs, of behavioural psychotherapy; and the management of physical care, especially of elderly patients. CPNs were reported to act as advisors to other colleagues in the primary health-care team, such as district nurses and health visitors, as well as those who worked in the accident and emergency departments of general hospitals. Contact with social services departments was also considered to be important. Other activities included visiting 'at-risk' groups, including those who had previously taken overdoses of drugs, the parents of non-accidentally injured children, battered wives, alcoholics, gamblers or others with psychiatric problems who came to the CPNs' attention not necessarily through the medical services but through social services and the police.

Those who wanted to see CPNs more closely associated with primary health-care teams, the document continued, suggested a ratio of one CPN to every 12 000–15 000 population. This meant one CPN for every 5–6 general practitioners and every three district nurses. In written evidence to the Working Group (CPNA, 1978), the Community Psychiatric Nurses Association suggested that 'a better ratio' would 'eventually' be 1:7500.

WORKFORCE PLANNING: A CRITIQUE OF THE EVIDENCE

In a later examination of these early CPN workforce planning targets, White (1989) traced the mathematics back to their origins. In July 1984, Dr P.J. Carr (President), Yvonne Baxter (Chairwoman) and Heather Rankin (Secretary) of the Community Psychiatric Nurses Association were examined as witnesses before the House of Commons Social Services Committee on Community Care. Carr (1985, pp. 411–12) confirmed an alteration of the CPNA suggestion to the RCP of 6 years earlier:

> At Manchester Polytechnic, where I work, we have the only national research centre for mental nursing (CRIPN, Centre for Research into Psychiatric Nursing) and we have done quite a lot of research there on community psychiatric nursing and we have decided that the notion that we are heading towards is the one community psychiatric nurse per 10,000 population.

The final report of the Joint Organisations Working Group, Target 88 (Joint Committee of Mental Health Nursing Organisations, 1987), also noted that most regional health authorities' CPN manpower needs were related to one CPN to 10000 people in the population. Moreover, the Target 88 report claimed that the basis of many workforce ratios came 'from some work in the North Western Region in the 1970s'. While not made explicit in the Target 88 report, White (1989) confirmed with the original authors that the reference was to an adaptation by Carr *et al.* (1980) of the seminal work of Shepherd *et al.* (1966) and of project work by Driver (1976).

Driver (1976) had undertaken a small project, as part of the CPN course at Manchester Polytechnic, to 'assess the demand for community psychiatric nursing services in the Chester Health District and to pinpoint possible growth areas' (p. 100). Her own conclusions acknowledged the methodologically weak design of her study, which she described as 'insignificant, invalid and unreliable' (p. 100). She nevertheless reported that 'on average, a general practitioner would like to be able to refer to a community psychiatric nurse 3.13 per cent of the total number of patients on their list'. She also reported that, on average, 30.5 per cent of their patients 'were suffering from mental illness of some form or other'. Her finding of 3.13 per cent was, 4 years later, both misread and misapplied by the pioneering work of Carr *et al.* (1980) as 13.13 per cent. Driver's figure of 30.5 per cent was not used in any of their calculations; instead, they used an annual prevalence rate (the number of patients consulting with psychiatric illness per 1000 at risk) at 140 per 1000, as described by Shepherd *et al.* (1966).

Thus, using an arbitrary figure of 15 000 population, Carr *et al.* (1980) calculated that 275.73 patients would be generated for CPN recruitment (15 000 x 14 per cent x 13.13 per cent = 275.73). This, the authors concluded, was a 'realistic' figure, and it 'appeared that one community psychiatric nurse per 15,000 population was a feasible figure to aim for in the short term. Moreover, a population ratio of 1:7500 in years to come would not be unreasonable.'

However, White (1989) showed that, if Driver's (1976) finding of 3.13 per cent, rather than 13.13 per cent, had been applied by Carr *et al.* (1980), a population of 62 924 would have been necessary to generate the 275.73 patients, which was originally regarded as a 'realistic' figure (62 924 x 14 per cent x 3.13 per cent = 275.73). Furthermore, Carr and others had applied the figure of 13.13 per cent to a subsample of general practitioner patients, whereas Driver's figure of 3.13 per cent related to the total patient population. The application of Driver's figure to an arbitrary population of 15 000 would have generated 469.5 patients for CPNs, far beyond the 275.73 regarded by Carr *et al.* (1980) as realistic.

White (1989) acknowledged the innovative nature of the work of Carr and his colleagues and argued that some CPN workforce planning targets had been developed since that were 'bottom up'. However, as in other areas of social science (see Rice, 1982, in relation to the persistence of the Hawthorne effect theory), the folklore of these 'top-down' target figures had persisted for others, quite innocently and independently of rigorous empirical evidence to support them.

Whatever ratio was used as the basis for local growth, a Working Group of the Royal College of Psychiatrists (1980) recommended that, before CPN services expanded further, the respective roles of health visitors and social workers should be considered.

CONTINUING THE EXPLORATION OF ROLE

Much of the recent community mental health literature has been concerned with the role ambiguity of CPNs not only in relation to health visitors (Maxwell, 1974; Clarke, 1980) and district nurses (Wilson, 1985), but also particularly in relation to social workers (Altschul, 1969; Cole, 1977; Martin and Kenny, 1979; Brewer, 1983).

The review of social work and community psychiatric nursing reported by Hunter (1980) was predicated on his interest in patients and their families and not on 'the continuation of particular forms of employment' for the professions involved. He concluded that CPNs and social workers were 'complementary'. More critically, Ramon (1988) described the reality as a 'hotpotch approach bedevilled by power struggles, by a pecking order resisting change [see also Lancet, 1985; Morrison, 1985; Sturt and Waters, 1985] and by an incompatibility of perspectives on mental distress and its amelioration'.

However, in a relative sense, Manning (1988, p. 16) found it 'encouraging' that the 'superior value of the then Mental Health social workers, and of social work management' (compared with community psychiatric nursing) had been demonstrated by the work of Wooff *et al.* (1988). Based on a random sample of 10 CPNs, drawn from a team of 17 in one CPN service, and 6 mental health social workers (MHSWs) in Salford, Greater Manchester, Kate Wooff developed an epidemiological methodology based on the previous work of Sladden (1979) and Paykel *et al.* (1982) to observe staff–client interactions, between June 1984 and August 1985. She found that CPNs primarily applied a biological model of care and allowed or encouraged the ventilation of problems, while MHSWs mainly applied a psychosocial model. Moreover, CPNs were observed to relate to doctors (both psychiatrists and general practitioners) more than to members of other professions. They mainly used their skills to administer and monitor medication and observe psychiatric/behavioural and physical symptoms; counselling was undertaken relatively infrequently. In contrast, the MHSWs in her study 'clearly applied their social science knowledge base to their day-to-day activities' (Wooff *et al.*, 1988, p. 791) and clients' problems were perceived in terms of their functioning within family and community structures.

Not only were differences reported between the two occupational groups, but also changes were noted within the clientele of CPNs over time. In earlier work, Wooff *et al.* (1986) found that the largest single diagnostic group of patients cared for by CPNs, those with schizophrenia, had consistently fallen between 1979 and 1982 as a proportion of all patients seen – down to 23 per cent. It seemed reasonable to her to argue that the differing needs of psychiatrists and general practitioners influenced the diagnostic composition of patients seen by CPNs. This assumption had also long concerned one of her co-authors. Three years earlier, Goldberg (1985, p. 60) had presented a paper to a joint DHSS/RCP conference on community care, to 'provide a commentary on recent developments ...in a way that allowed planners to see the effects of different kinds of mental health service':

> We know from our informal contacts with CPNs that there is great career satisfaction in such work (neuroses) and it undoubtedly eases the burden on the family doctor. However, as the CPNs drift away from the hospital-based service, there is the risk that the care of chronic psychotic patients will take second place to work with people with minor affective disorders. (p. 60)

Goldberg concluded, therefore, that the sort of policy statement asked for in his paper would 'insist' that CPNs were part of multidisciplinary care teams with access to supervision of their work from both psychiatrists and clinical psychologists. This would acknowledge the 'unique contribution that CPNs can make between primary and secondary care services, but would emphasise strongly the importance of community work with the chronic mentally ill' (Goldberg, 1985, p. 60). At the same time, however, the HAS (Baker, 1985) reported that some hospital consultant psychiatrists were unduly anxious about the development of community psychiatric nursing services and felt the need both to control and to restrict their development. Many feared that 'if a CPN was not directly responsible to a consultant psychiatrist, errors would be made, inappropriate patients would be treated and resources wasted' (Baker, 1985, p. 15). No evidence was given to support these claims, although the HAS found that such anxieties frequently surfaced among consultant psychiatrists.

DEBATES ABOUT SERVICE ORGANISATION

Whatever the motivation for such interest, there has been considerable discussion about the organisation of community psychiatric nursing services and their management since their inception in 1954 (Hunter, 1974; Beard, 1981; Dick and Mandy, 1989). In broad terms, Leopoldt (1975) argued (as the World Health Organisation had done so before him in 1967) that two basic lines of organisation could develop. First, the organisation of CPNs could remain firmly linked to its place of origin – the psychiatric hospital – and they could work in hospital-based teams and take referrals exclusively from psychiatrists. Second, CPNs could become attached to health centres and take referrals from general practitioners and other primary health-care workers. Although other possibilities were described outside this dichotomy (White and Mangan, 1981), Parnell's (1978) research found a movement toward the second of Leopoldt's (1975) options (Shaw, 1977; Sencicle, 1981). However, Brooker and Simmons (1985), on the basis of evidence gathered in Camden and Westminster in London, found that the community orientation for CPNs that arose from their attachment to primary health-care teams did not necessarily weaken the links with the psychiatric hospital and outpatient department. Another study (Skidmore, 1986) also attempted to identify CPN effectiveness in three community psychiatric nursing base locations. No significant differences were identified between the methods of CPN practice and the location of their base.

However, Skidmore (1986, p. 242) suggested that all community psychiatric nurses required more skills-based education if they were to practise effectively (an activity that was not defined in his publication) and that 'existing methods of training/education' fell short of the necessary preparation to meet the needs of clients in the community. These findings were in keeping with those of Wooff *et al.* (1988), and, although Woof *et al.*'s were based on a comparison of the work of only five CPNs who had completed the 1-year full-time ENB course, in one service in the northwest of England that 'may not be typical of others', she concluded that 'if nurses are to continue to expand their traditional roles, then those who received basic training geared to the old roles must receive additional skills-training to equip them to embark on their new roles effectively'.

CONCLUSION: *PLUS ÇA CHANGE, PLUS C'EST LA MÊME CHOSE*

As late as 1984, exactly 30 years after the first CPNs were employed in the UK, evidence of the paucity of even the most basic information about CPNs was confirmed by the then Principal Nursing Officer (Mental Health) at the DHSS. In a twist of fate, Stanley Moore (ironically, previously Chief Male Nurse at Warlingham Park Hospital during the development of CPN innovation) went on public record at the time to admit that the way in which the DHSS estimated the number of CPNs in the UK was to study the 'situations vacant' pages of the *Nursing Mirror*. In so doing, he observed that there were about 8–10 vacancies, per week. Over a year, therefore, there would be about 400–500 new CPN posts. Moore multiplied these figures by the number of years since the baseline figure was provided by the first CPN survey conducted in 1980 (Baxter, 1984). This method of calculation was recognised as 'crude' and 'more of an indication of the desperation for information than a serious attempt at measurement of numbers' (CPNA, 1985, p. 7).

Thus, through these early historical accounts of service development and their corollary in relation to the educational provision

(White, 1990), a set of substantive and methodological issues have been identified which, with others, have continued to feature throughout the 45-year history of community psychiatric nursing (now 'community mental health nursing', as contemporary nomenclature has it). In particular, it is worth identifying:

- the immediate material constraints upon service development
- the early identification of previously hospitalised psychotically ill patients as the focus of work activity
- the power and prestige relations with psychiatrists
- the close association with social workers
- the relationships with other primary health-care professionals
- the suitability of mental nurse training for community work
- the technologies for keeping relevant information live
- the myriad of competing funding tensions.

Evidence of the recurring nature of many of these issues has been provided in more recent studies and reported elsewhere in collected works (Brooking, 1986; Brooker, 1990; Brooker and White, 1993, 1995). They have also featured in the reports of national surveys of community mental health nursing that have been conducted in the UK at 5-yearly intervals since 1980 (CPNA, 1981, 1985; White, 1991). These data sets have been uniquely useful in plotting trends in the structure of community mental health nursing over time, and the research output from them is now probably the most cited in the community mental health nursing literature. The information derived from these studies has been of reported value to clinicians, educationalists, managers, purchasers, researchers and policy-makers alike (see for example, RCP, 1992; Huxley and Kerfoot, 1993; DoH, 1994; Gournay and Brooking, 1992). The report of the Fourth Quinquennial National Community Mental Health Nursing Census is about to be published (Brooker and White, 1997), and, by way of a further example of their utility, the RCP has already updated the 1980 RCP policy position on community psychiatric nursing (RCP, 1997) in relation to preliminary research findings from the census. Moreover, a technical paper has recently reviewed the usefulness of survey method in particular, and quantitative methodologies in general, in which the latest census was used as a case example (White and Brooker, 1997). Similarly, a bibliography of 500 selected CPN-related publications, organised by four broad categories (practice, education, organisation and other) has been published by the present writer (White, 1995) to assist prospective researchers to locate published material germane to community mental health nursing.

All such contributions to the knowledge base of community mental health nursing have burgeoned in comparatively recent times, however, and must be set within a relevant, but otherwise poorly informed, historical context. This chapter has offered an interpretation of history as one such context for future community mental health nursing research.

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CHAPTER SEVEN

Assessing vulnerability in families

Jane V. Appleton

The identification of children in need and the needs of their families is critically important in view of the requirements of the Children Act 1989 and the recommendations of the Department of Health (DoH) (1995) and the NHS Executive (NHSE) (1996). Furthermore, since the introduction of the NHS and Community Care Act 1990, the issue of health needs assessment has become increasingly important in negotiations between purchaser and provider agencies. Community nursing staff are expected to have well-developed assessment skills in order to be able competently to identify and articulate 'health needs', provide appropriate support services to clients and make referrals to statutory and voluntary agencies where necessary. Since community nurses, and in particular health visitors, play such a valuable role in case-finding and needs assessment, it seems highly relevant to examine how community practitioners assess vulnerability in families.

This chapter will explore how current research illuminates our understanding of the complex issue of vulnerability. The chapter will initially examine definitions of vulnerability and characteristics of this concept before moving on to explore its eclectic origins and its relationship to community nursing. The concept of vulnerability will be examined in relation to 'risk' as the two concepts are often intertwined. The central focus of the chapter will be an exploration of the concept of vulnerability in relation to health visiting practice, as much of the research evidence stems from this branch of community nursing. Through an examination of the research evidence, the chapter will highlight the importance of research findings in increasing understanding about how health visitors both define and assess family vulnerability. It will outline the key practice issues currently facing community nurses who attempt to apply such abstract concepts to the practice setting.

DEFINING THE CONCEPT OF VULNERABILITY

The *Chambers Dictionary* (1994) defines the term 'vulnerable' as 'capable of being physically or emotionally wounded or injured'. A review of the literature indicates that the term 'vulnerability' is frequently used in nursing and community nursing; however, as Rogers (1997, p. 65) notes, 'the concept is not well-defined' and there is a limited consensus of definition about the term. Several attempts at defining the term in the nursing literature have linked vulnerability with a susceptibility to or risk of ill-health (Stember *et al.*, 1987; Schwarzer, 1994) and/or stress (Kessler, 1979; MacMullen *et al.*, 1992; Phillips, 1992). The term has also been used to describe how people's personal characteristics and their relationship to environmental factors may influence health (Rose and Killien, 1983; Rose, 1984; Lessick *et al.*, 1992). Some definitions link vulnerability with issues of powerlessness and an inability to protect personal rights and needs (Wells, 1986; Vonthron Good and Rodrigues-Fisher, 1993), while Rich (1992) equates vulnerability with an individual being personally threatened. Other authors have associated the concept with problems and increased demands within the family unit (Taylor and James, 1987; Demi and Warren, 1995). Essentially, however, it appears that the use of the term 'vulnerability' implies an individual or family unit susceptible to health problems, injury, danger, loss or neglect (Phillips, 1992; Rogers, 1997).

The term 'vulnerability' has been used in a number of health-care contexts, and several authors have offered examples of vulnerable populations. Vulnerable groups include people subject to domestic violence (Copp, 1986; Cody, 1996; Humphries, 1997), other victims of violence and crime (Copp, 1986, Rogers, 1997), children at risk of abuse (Cody, 1996) and other victims of sexual and physical abuse (Copp, 1986). The term has been used to describe people living in poverty (Rogers, 1997), travelling families (Cowley, 1995) and the homeless (Sebastian, 1985; Copp, 1986; Cowley, 1995; Rogers, 1997), particularly pregnant women or adolescents with babies and young children (Lessick *et al.*, 1992; Rich, 1992; Rogers, 1997). A significant amount of work on vulnerability has focused on aspects of perinatal and neonatal nursing (Angelini and Lynch, 1992; Lessick *et al.*, 1992; Savage and Conrad, 1992), including mothers who are hospitalised during the antenatal period (MacMullen *et al.*, 1992) or who have a high-risk pregnancy (Schwartz and Schwartz, 1977; Syson-Nibbs, 1985). Vulnerability has been used to describe those experiencing family difficulties during the antenatal period (Phillips, 1992) and babies who are born prematurely or with low birthweights and/or handicap (Copp, 1986; Lessick *et al.*, 1992; Schlomann, 1992).

As well as sick neonates, the term 'vulnerable' has been used to describe other groups of people who are ill, including those with chronic diseases and permanent disability (Cody, 1996; Rogers, 1977), people with HIV and AIDS (Lessick *et al.*, 1992; Rogers, 1997), individuals suffering drug or alcohol addictions (Lessick *et al.*, 1992) and a range of mental health problems, such as depression and schizophrenia (Zubin and Spring, 1977; Copp, 1986; Rogers, 1997), as well as the dying and terminally ill (Copp, 1986). Hospital inpatients (Wells, 1986; Morrison, 1994) have often been recognised as a vulnerable group, in particular frail elderly patients who are hospitalised (Davidson, 1986; Wells, 1986; Tappen and Beckerman, 1993) or those 'abandoned' in nursing homes (Copp, 1986, p. 257). Other vulnerable groups highlighted in the nursing literature include 'those in the process of divorce or other disruption of family life; those who are held against their will, such as victims of kidnap; those involved in warfare; hostages' (Cody, 1996, p. 257), people in prison (Copp, 1986), immigrant families and refugees (Rogers, 1997, p. 66). Indeed, a number of authors (Zubin and Spring, 1977; Copp, 1986; Rogers, 1997) have suggested that every individual can expect to experience vulnerability at some stage in life. Rogers (1997, p. 66) states that 'the experience of vulnerability touches us all', although 'some individuals are more likely to develop health problems than others'.

It is interesting to find that nurse researchers have investigated the concept of vulnerability from a number of differing perspectives. Research into vulnerability has been conducted with many different groups across the lifespan, and a number of authors have offered conceptual models of vulnerability (Zubin and Spring, 1977; Davidson, 1986; Lessick *et al.*, 1992; Rogers, 1997). Beginning with infants, Culley *et al.* (1989, p. 237) describe the vulnerable child syndrome, which 'refers to physically healthy children who are perceived by their parents to be at high risk for medical or developmental problems'. These children all had a past history of severe illness 'from which they had not been expected to recover' (Culley *et al.*, 1989, p. 237). Culley *et al.*'s (1989, p. 237) research describes how mothers of premature babies 'reported a significantly greater sense of [personal] vulnerability' and difficulties in their relationships with their children than did mothers of babies born at full term. Levy (1980) also found that parents who perceived their children as vulnerable used health-care services at an increased level, while Belcher (1988) found that mothers living alone and who were supporting chronically mentally ill adult children experienced increased stress levels, which led to a greater vulnerability to poor health for these women.

In the UK, a number of researchers have focused on the identification of family vulnerability by health visitors (Appleton, 1993, 1995; Newland, 1997; Williams, 1997). Other researchers have examined the perceived vulnerability of school-age children to accidents or health problems (Gochman and Saucier, 1982; Stember *et al.*, 1987), while Boehm *et al.* (1993) explored this issue among 18–22-year-olds at two colleges in America. These researchers examined students' perceived susceptibility to health problems as well as their desire to receive information about particular health issues. In terms of research conducted with older age groups Tappen and Beckerman's (1993, p. 38) review of the research literature has highlighted the fact that frail elderly patients who are hospitalised are 'especially vulnerable to adverse outcomes'. Vonthron Good and Rodrigues-Fisher (1993, p. 780) have described 'the actual and/or potential vulnerability of the older adult' involved in research activity. The breadth of focus of the research work in relation to vulnerability increasingly draws attention to the fact that the term may indeed have different meanings for practitioners.

CHARACTERISTICS OF VULNERABILITY

Several authors and researchers regard vulnerability as a continuum (Rose and Killien, 1983; Rose, 1984; Copp, 1986; Lessick *et al.*, 1992; Appleton, 1994a; Rogers, 1997) that is dynamic and constantly changing. Individuals and families move in and out of vulnerability at various stages of the life cycle, and this appears to be largely dependent on internal and external factors, and coping ability (Appleton, 1994a). Rose and Killien (1983, p. 65) offer an explanation of the continuum of vulnerability. The continuum ranges from a situation in which an individual experiences no stress to a highly stressful situation or event, with a recognition that people may move along the continuum as part of normal development becoming 'more vulnerable [in] times of biological, social and psychological transitions', such as during adolescence, pregnancy and old age (Rose and Killien, 1983; Wells, 1986; Rich, 1992; Rogers, 1997). High levels of stress appear to lead to ill-health (Rose and Killien, 1983; Rogers, 1997) and/or mental illness (Zubin and Spring, 1977). This continuum has some links with the vulnerability continuum emerging through later research work in health visiting.

As Lessick *et al.* (1992, p. 6) note, 'the level of vulnerability defines the position of an individual along a health–illness continuum, having a threshold beyond which illness can occur and below which health is manifest'. This threshold of vulnerability is also described by psychologists Zubin and Spring (1977) and is clearly different for each individual. Rose (1984) further highlights the close relationship between coping and vulnerability, while Rose and Killien (1983, p. 62) note the importance of determining factors that may be either 'supportive' or 'hazardous' to health. There is a general recognition in the literature that some people are more susceptible to the negative effects of stress than others and are therefore more likely to suffer health problems (Kessler, 1979; Lessick *et al.*, 1992; Phillips, 1992; Rogers, 1997).

A number of authors have suggested that degree of vulnerability is influenced by people's perceptions (Phillips, 1992; Rogers, 1997), and this view is particularly supported by research findings that have examined children's perceptions of vulnerability to health problems, illness or accidents (Stember *et al.*, 1987; Gochman and Saucier, 1992). Schwarzer (1994, p. 162) suggests that 'realizing some degree of personal vulnerability is a prerequisite for people becoming motivated to counteract threats and to avoid risks'. This 'perceived vulnerability to disease' (Schwarzer, 1994, p. 162) is regarded as an important factor in taking preventive health action and appears to have its origins in Becker's health belief model (Sarafino, 1990; Schwarzer, 1994).

A further characteristic of vulnerability is the recognition that an individual or family constantly interacts with and is influenced by the environment (Rose and Killien, 1983; Rose, 1984; Davidson, 1986). Lessick *et al.* (1992, p. 2) describe a 'vulnerability model' that they argue offers a structure 'for understanding individual–environment relationships relative to health and illness'. This systems model regards the individual and family unit as a potentially vulnerable system with 'biopsychosocial-cognitive dimensions' (Lessick *et al.*, 1992, p. 3), which interact with the environment and influence levels of vulnerability. Indeed, Zubin and Spring (1977, p. 109) have stated that there are two important elements of vulnerability: 'inborn' and 'acquired'. The inborn element reflects the genetic make-up of the individual and neurophysiological components (Zubin and Spring, 1977). In later work, Rose and Killien (1983, p. 64) refer to these inborn elements as 'constitutional factors'. Zubin and Spring (1977, p. 109) describe the acquired element of vulnerability as being 'due to the influence of traumas, specific diseases, perinatal complications, family experiences, adolescent peer interactions and other life events that either enhance or inhibit the development of subsequent disorder'. Phillips (1992,

p. 27), however, argues that vulnerability is neither 'a characteristic of the individual or of the environment', but should be viewed as a system incorporating both elements.

THE CONCEPT OF 'VULNERABILITY' VERSUS THE CONCEPT OF 'RISK'

In the literature, the term 'vulnerability' is often described in terms of, or used interchangeably with, the concept of risk. Indeed, as early as 1983, Rose and Killien had highlighted the wealth of articles focusing on high-risk groups and 'the identification of risk factors' (Rose and Killien, 1983, p. 60). This lack of clarity about the concept of vulnerability, and the fact that the term may be interpreted in different ways by community nurses, illustrates one of the key problems in trying to apply such an abstract concept to practice. In fact, in some branches of community nursing, such as mental health nursing, the notion of 'risk' may be a more familiar concept to practitioners than that of vulnerability.

A focus on the concept of 'risk' is a trend that is particularly evident in the mental health nursing research literature and the child protection/social work research literature. Indeed, if we reflect on some of the definitions of vulnerability offered earlier in the chapter, vulnerability has often been equated with the risk of ill-health or the 'risk of contracting a condition' (Stember *et al.*, 1987, p. 264). Research into the area of community mental health nursing has focused on the concept of risk in terms of assessing clients for their threat of violence (Doyle, 1996) or risk of dangerousness (Robinson *et al.*, 1996; De la Cour and Dorey, 1997) in an attempt to identify potential risk factors for predicting violent behaviour. Additionally, De la Cour and Dorey (1997) have examined risk assessment in terms of suicide and self-neglect. In these examples, risk can be defined as an attempt to establish 'the likelihood of an event occurring' (Prins, 1996, p. 182). What is interesting to note, however, is that, rather like vulnerability, risk is also an ill-defined concept. This would indicate that making an assessment of the risk of violent behaviour is a complex and ambiguous issue in community mental health nursing. In fact, Doyle (1996, p. 20) states that, although 'assessing risk of violence from clients is an essential aspect of the work of community mental health nurses... very little information is available on how they do this'. Robinson *et al.* (1996, p. 146) also highlight the shortage of 'research-based instruments that record empirical components of dangerous behaviour'.

References to 'risk' and 'risk assessment' can be found in abundance in the social work/child protection research literature, in which risk assessment is defined 'as the systematic collection of information to determine the degree to which a child is likely to be abused or neglected in the future' (English and Pecora, 1994, p. 452).

In the same vein as the mental health risk assessment tools that attempt to estimate certain behaviours, risk assessment in child protection work attempts to predict the likelihood of child maltreatment (Browne and Saqi, 1988; English and Pecora, 1994). Risk assessment involves:

> examining the child and family situation in order to identify and analyze various risk factors, family strengths, family resources, and available agency services. This assessment information can then be used to determine whether a child is safe, and under what circumstances a child should be removed from or returned to his or her family. (English and Pecora, 1994, p. 453)

However, it is important to highlight that the predictive value and ethical implications of such child abuse risk assessment instruments have been seriously questioned (Gibbons, 1988; Barker, 1990; Doueck, 1995). Yet this approach to assessing families and children has influenced a great deal of the research work in health visiting, which will be described in more detail later in the chapter. Indeed, Parton (1998) has reiterated that currently in the UK, because of limited resources, social services personnel are finding it impossible to undertake preventive work with families experiencing difficulties. He argues that priorities lie in 'investigating, managing and sifting "high risk" cases from the rest' (Parton, 1998, p. 18). He highlights the ambiguity of the term when he states that 'risks are virtual, can't be directly sensed, nor subject to scientific evaluation' (Parton, 1998, p. 23) and goes on to state that 'where the key concern is risk, the focus becomes, not making the right decision, but making a defensible decision' (Parton, 1998, p. 21). Risk is therefore viewed as a 'relative' concept (McGrath, 1997).

It is interesting to find that Rose and Killien (1983, p. 61) have tried to differentiate between the concepts of vulnerability and risk, describing vulnerability as 'personal factors that interact with the environment to influence health' and risk as 'the presence of potentially stressful factors in a person's environment', which are hazardous to health. They argue that the phrase 'at risk' is often 'used to identify [people] who may develop problems' in the future (Rose and Killien, 1983, p. 61). Rose and Killien (1983, p. 67) have suggested that risk and vulnerability are interrelated, 'that one affects the other in a dynamic way' and that 'characteristics of both the individual and the environment contribute to health and illness'. This view is further supported by the work of Phillips (1992) and Rogers (1997). Indeed, Rogers has stated that nurses will need to consider both personal and environmental characteristics when assessing clients' health needs. Rogers illustrates a model of vulnerability to conceptualise these aspects. She states (1997, p. 68) that 'what is needed is a "fit" between the needs and resources of the person and the demands and resources of the environment'. Rose and Killien (1983, p. 63) have highlighted the importance of identifying 'protective factors' such as a family's social support, which can be important in reducing the effects of stress and can have a positive influence on health.

THE ORIGINS OF THE CONCEPT OF VULNERABILITY

It is interesting to explore ways in which other disciplines may have provided a basis for developing the concept of vulnerability. Apart from Boehm *et al.* (1993) and Zubin and Spring (1977), most researchers appear to be fairly vague about the origins of their research work. Boehm *et al.* (1993), who examined students' perceived vulnerability to health problems, have based their work on the principles of behavioural change and learning theory, which has its roots in experimental psychology, while Zubin and Spring (1977), who proposed a vulnerability model to provide an indicator of vulnerability to schizophrenic episodes, state that the model was developed using the work of Hans Selye (1973) and incorporates a biological element of adaptation to stress. These researchers suggest that stressful experiences beyond 'the threshold of vulnerability' will cause an individual to 'develop a psychopathological episode of some sort' (Zubin and Spring, 1977, p. 110). However, if an individual is able to manage the stressful event, he or she will remain well (Zubin and Spring, 1977).

In psychology, much research has centred on the links between vulnerability, stress and health, and this has clearly influenced a lot of the thinking in nursing research. However, Selye's general adaptation syndrome, with its focus on physiological elements, can be criticised for more or less ignoring psychological responses to stress. In view of the fact that the literature has suggested that degree of vulnerability is influenced by people's perceptions (Phillips, 1992; Rogers, 1997), this is a viewpoint that appears to emerge from the transactional model of stress. This framework acknowledges that an individual's perception of a situation plays a large part in determining whether or not that situation is stressful, and takes into account the fact that different people find different situations stressful at different points in their lives. According to this perspective, stress is not just a response or a stimulus but rather a process in which the person is an active agent who can influence the impact of stress through behavioural, cognitive and emotional strategies. Thus stress will arise when a person perceives and evaluates a situation as threatening. The major proponent of this approach to stress is Lazarus (1976), and, unlike other approaches, the transactional model of stress provides a framework allowing the individual to adopt coping strategies in the face of unavoidable threat or demand. A more detailed account of Lazarus' work can be found in Chapter 9. McGrath (1997) acknowledges the complex link between constitutional factors, life situations and protective factors in a study identifying children at high risk of developmental delay.

Psychologists have also described the 'vulnerability–stress model', which is an 'interactive model of physical or mental disorders that proposes that an individual will develop a disorder only when he or she has both some constitutional vulnerability (predisposition) and experiences stressful circumstances' (Atkinson *et al.*, 1996, p. 709). This is sometimes known as the 'diathesis–stress model' (Atkinson *et al.*, 1993, p. 595). The proponents of this model argue that 'vulnerability makes the individual susceptible to the disorder, but it is only when he or she encounters the stress that the disorder actually develops' (Atkinson *et al.*, 1993, p. 595). According to this viewpoint, being vulnerable does not necessarily lead to physical or psychological ill-health but will depend upon the types of stressor an individual faces and an individual's coping mechanisms (Atkinson *et al.*, 1996). For example, research evidence indicates that women suffering from postnatal depression often have a history of previous depressive illness and therefore a 'pre-existing vulnerability' (Atkinson *et al.*, 1993, p. 595).

Indeed, a similar viewpoint on vulnerability can be found in the sociological literature where Brown and Harris (1978) examine the relationship between major life events and social factors, and the likelihood of women suffering depressive illness. Their research found that four vulnerability factors were significant in determining the likelihood of women suffering depression following a distressing life event or major difficulty (Brown and Harris, 1978). The four vulnerability factors were the absence of 'a close, intimate and confiding relationship with a husband or boyfriend' (Brown and Harris, 1978, p. 174), the 'loss of mother before eleven, having three or more children under fourteen living at home [and] lack of employment outside the home'

(Brown and Harris, 1978, p. 179). Haralambos (1985, p. 609) states that 'these vulnerability factors predispose a woman to depression only when triggered by disruptive or distressing life events'. These vulnerability factors can result in 'low self-esteem and an inability to cope' (Scambler, 1997, p. 28) and ultimately lead to depression. Brown and Harris (1978) suggest that it is the influence of difficult circumstances rather than an individual's personality that leads to a woman's inability to cope. They found that working-class women were more likely to suffer from clinical depression because they were more likely to have experience of one or more of these vulnerability factors.

Sociologists have also linked the concept of vulnerability with ill-health in general and have debated the sick role experience and how ill people may be 'vulnerable to exploitation' (Haralambos, 1985, p. 634). Nettleton (1995) and Haralambos (1985) highlight inequalities in the sick role because of the unequal power relationships that can exist between patients and doctors. This is particularly the case when patients become dependent on doctors for advice, referrals and treatment or when medical techniques are 'physically invasive' (Haralambos, 1985, p. 634). These examples illustrate how in other disciplines the term 'vulnerability' has been consistently linked with stress and ill-health.

VULNERABILITY AND ITS RELATIONSHIP TO COMMUNITY NURSING

In community nursing, there is little evidence of the concept of vulnerability being explored in any great depth apart from in the field of health visiting. Although it is interesting to note that, despite the lack of research evidence, the term 'vulnerability' is used by other community nursing specialties. Table 7.1 highlights current use of the two concepts 'vulnerability and 'risk' by the different community nursing specialists. Quite strikingly, the two terms have a diverse range of meanings for community practitioners.

The concept of vulnerability in health visiting

Within health visiting, and to a lesser degree in community midwifery and community paediatric nursing, 'vulnerability' is used to describe those families with additional health and social needs who require some input from professionals. Vulnerable families are identified in

Table 7.1 Use of the concepts of vulnerability and risk in community nursing

AS USED IN:	VULNERABILITY	RISK
health visiting	To focus on stresses and problems in the family unit, which may or may not be linked with child protection concerns	The term 'at-risk' family is sometimes used interchangeably with the term 'vulnerable' family. Many guidelines are in existence in Community Trusts for identifying 'family vulnerability' and these incorporate 'risk' factors/'risk' indices
school nursing	To focus on stresses and problems facing a child and sometimes his/her family/siblings. These stresses and concerns may or may not be linked with child protection concerns	The term 'at-risk' child is sometimes used interchangeably with the term 'vulnerable' child. Many guidelines are in existence in Trusts employing school nurses for identifying 'child/family vulnerability' and these incorporate 'risk' factors/'risk' indices
community mental health nursing	Client risks addressed with the intention of preventing vulnerability (Prins, 1996)	Assessing clients for their risk of violence or dangerousness. The term is also used for risk assessment in terms of potential for suicide or self-neglect
community paediatric nursing	Vulnerability often associated with a child and family's social and psychological needs. Sometimes used to refer to stresses and problems in the family unit, which may or may not be linked with child protection concerns	The term 'high-risk' is used as a measure of medical/physiological concerns/needs
district nursing	To focus on the actual and potential health/social needs of the client/family being nursed at home. Sometimes used to describe frail and/or elderly clients	The term 'high-risk' is used as a measure of medical/physiological concerns/needs
practice nursing	To focus on the actual and potential health/social needs of the client/family being nursed in the surgery. Sometimes used to describe frail and/or elderly clients	The term 'high-risk' is used as a measure of medical/physiological concerns/needs
community midwifery	To focus on stresses and problems in the family unit either during pregnancy or in the immediate postnatal period, which may or may not be linked with child protection concerns	The term 'at-risk' family is sometimes used interchangeably with the term 'vulnerable' family. Some midwifery units have guidelines for identifying 'family vulnerability' and these incorporate 'risk' factors/'risk' indices
community learning disability nursing	To focus on the effect of the learning disability on the client and family dynamics/social situation	'Risk assessment' is about weighing up the potential dangers to the client, e.g. road safety, danger of cutting oneself when chopping with a sharp knife. 'Risk assessment' is also about weighing up the potential risks of disturbed/violent behaviours that may endanger others.

order that increased interventions/support services can be offered to these families, in the hope that identified health needs can be met and child protection issues prevented. The term 'vulnerability' is often used interchangeably with 'high dependency', 'cause for concern', 'high risk' or families/children 'in need'.

The DoH (1995) has highlighted the potential for health professionals, particularly health visitors, to accurately identify and support 'children in need' and their families, and to protect vulnerable children. The refocusing debate that stemmed from the publication of *Messages from Research* has emphasised the need to identify areas in which more interagency work can be undertaken preventively with 'children in need' rather than 'children in need of protection' (DoH, 1995). Health visitors in particular are recognised as being in a unique position to identify families experiencing stress and to undertake preventive work with families because of their current, albeit often limited, universal access to families (NSPCC, 1996). In view of this important case-finding role, and the fact that the term 'vulnerability' has not been clearly defined in community nursing practice, it seems extremely important to investigate this concept in more detail. The remainder of this chapter will describe how the concept of vulnerability has been explored in health visiting practice.

Research exploring how health visitors define vulnerability

Although the term 'vulnerability' has been used for many years in health visiting, there have been few attempts within the profession to define what the term really means. There is also a lack of empirically based research evidence explicating the basis of health visitors' clinical judgements in identifying 'vulnerable families'. The literature reveals only three research studies focusing purely on the concept of vulnerability in health visiting (Appleton, 1993, 1994a; Newland, 1997; Williams, 1997). However, as early as 1980, Bolton (1980) had found that the widely used terms 'vulnerable' and 'at risk' had vague meanings for health visitors and that there was no consensus of definition for the term 'problem family'. Taylor and James (1987, p. 329), however, proposed that vulnerable families can be described as those families 'where there are severe problems in the family giving cause for concern, but where there is not enough evidence of actual or potential harm to the child/children for social services to become directly involved'.

In 1993, in view of the dearth of research evidence surrounding vulnerability, the author attempted to address this issue by undertaking a study to explore health visitors' perceptions of the concept and its relevance to child protection work. It was anticipated that, by analysing and recording health visitors' perceptions and experiences of vulnerability, insight would be gained into this concept. It was envisaged that this exploratory study would provide the groundwork for future research into the area of vulnerability.

The 1993 study adopted a broadly qualitative approach. Qualitative research takes an emic viewpoint and can provide 'rich descriptions' (Morse, 1991) and detail of a 'phenomenon or event about which little is known' (Morse and Field, 1996, p. 8). It seemed an ideal approach to explore and begin to understand the rather nebulous concept of vulnerability. The study was undertaken in two Community Trusts, one inner city and one suburban. Initial pilot work was undertaken in a third area in order to validate the research instruments. Following chief nurse and/or ethical committee approval, letters were sent to all health visitors working in the Trusts describing the research project and inviting their participation in the study. In the first stage of the study, a postal survey of 102 health visitors was conducted and a response rate of 58 (57 per cent) obtained. In stage two, 12 in-depth interviews were completed with health visitors selected through purposive sampling. The interviews enabled the researcher to explore the concept of vulnerability in more depth using information gathered from the questionnaires. Data were critically analysed, and several descriptive themes emerged. The remainder of this chapter will describe the findings of this research study in more detail, also highlighting subsequent research in this area. It will first explore health visitors' perceptions of 'vulnerability' before moving on to examine the evidence about assessing vulnerability in families.

VULNERABILITY – THE AMBIGUOUS TERM

A striking feature of the study was the lack of consensus and clear definition of the commonly used term 'vulnerability'. The fact that vulnerability is very difficult to define supported the findings of the literature review and is a feature reported in subsequent research (Williams, 1997). Vulnerability as an ambiguous and poorly defined term was an area discussed by the majority of health visitors 10 (83 per cent) in the interviews. Many had difficulty articulating their thoughts, and several commented on how difficult it was putting what they meant by vulnerability into words. Schön (1987) has previously described the difficulties that practitioners can have in making certain everyday performances verbally explicit. Schön (1983, p. 49) states that 'every competent practitioner can recognise phenomena... for which he cannot give a reasonably accurate or complete description', and he describes this as 'knowing in action'. However, it is interesting to note that, in contrast, Newland (1997, p. 43) found that the health visitors in her study were able to articulate a definition of vulnerability 'with a high degree of clarity and precision'. Newland (1997) highlights the possible links between vulnerability and health inequalities.

Many of the health visitors in the 1993 study felt that the term 'vulnerability' was open to individual interpretation, and it is likely that personal and subjective value judgements come into this, as the following quotation shows:

> I used to define some families as vulnerable but now I feel that it is such a poorly defined concept that I no longer feel comfortable with it. To define a family as vulnerable is therefore not enough; it requires greater qualification, i.e. vulnerable to what? Poverty? Relationships? Hardships? The dominant culture? (HV. 38)

Indeed, the analysis suggested that ambiguity is a feature embedded in the meaning of vulnerability. The fact that health visitors appear to treat vulnerability as if it is something non-specific and ambiguous would appear to link with Cowley's (1991a; 1995) contention that the management of ambiguity is a central feature in health visiting practice. Despite this fact, many health visitors thought that there ought to be some sort of consensus of definition of vulnerability. Several practitioners felt that it was precisely because the concept had not been properly defined that it was easy for society to ignore vulnerable families and children.

VULNERABILITY – A COMPLEX MIXTURE OF FACTORS

The complexity of the concept of vulnerability was highlighted in the analysis and was a feature also noted by Williams (1997) in her research on vulnerable families. Both the questionnaire and the interview data indicated that central to the concept of vulnerability is the interaction of a number of key factors rather than a simple sum of factors. Health visitors described vulnerability as a 'combination of factors' (HV. 56) and a 'complex mixture' (HV. 58). Isolating what are the factors that make one family vulnerable and another not was not

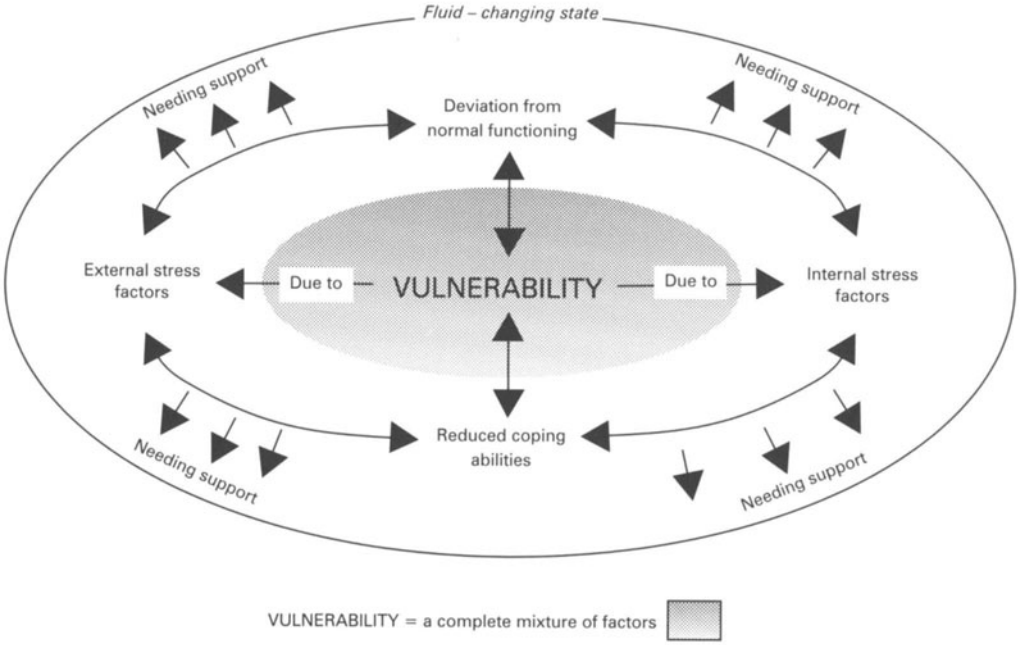

Figure 7.1 Health visitors' perceptions of vulnerability – a visual perspective (Appleton, 1994a. Reproduced with kind permission of Blackwell Science)

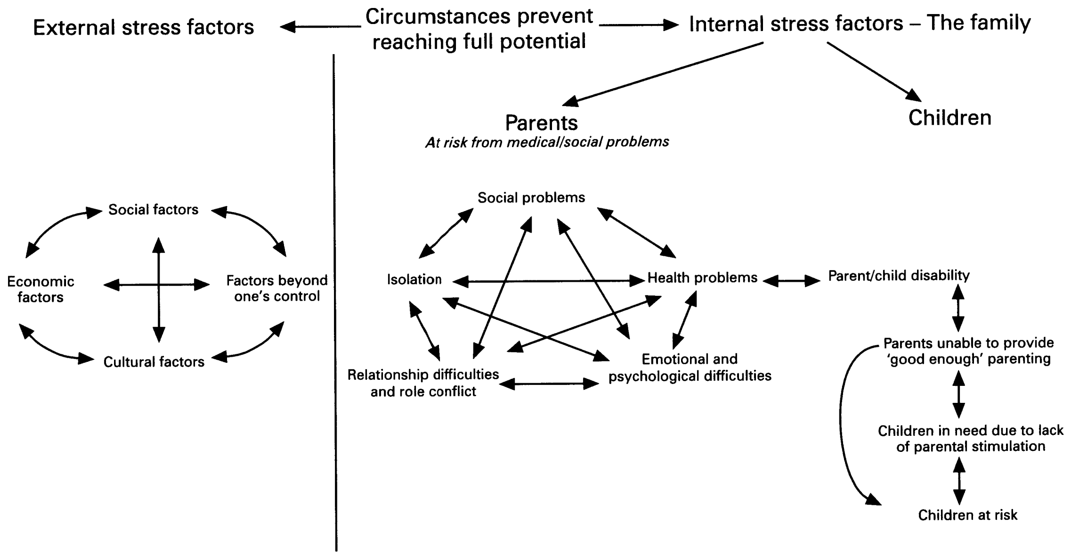

Figure 7.2 Vulnerability – an illustration of internal and external stress factors (Appleton, 1994a. Reproduced with kind permission of Blackwell Science)

an easy task for some health visitors and seems to relate to the ambiguity of the term.

It was evident that all respondents thought that vulnerability was a non-permanent state. Figures 7.1 and 7.2 display visual constructions of the health visitors' thoughts and feelings about vulnerability. Clearly, the concept of vulnerability incorporates a complexity of factors and may result from a combination of medical, psychological, social and cultural factors. Health visitors spoke about vulnerable families not being able to function normally and achieve their full potential, which appears to link to Seedhouse's (1986) view of health as potential.

Health visitors described vulnerability as a situation in which families were exposed to some form of stress, and it became evident that health visitors distinguished between internal and external stress factors. Cowley (1991a) previously highlighted the relevance of interrelating internal and external factors when health visitors complete needs assessments. Internal stress factors focus on those stresses within the family which have a direct effect on family members. The key stressor categories include:

- social problems
- isolation, particularly 'social isolation' (HV. 37)
- emotional and psychological difficulties, including mental health problems, bereavement or 'unhappy parents' (HV. 51)
- relationship difficulties and role conflict
- health problems, particularly disability
- parents being unable to provide 'good enough' parenting
- children in need because of lack of parental stimulation or care.

In an extreme case, this last category could result in a child being in need of protection. External stress factors included four main categories:

- social factors, including poverty and the threat of redundancy and/or repossession
- cultural factors
- economic factors
- factors beyond one's control.

The extent to which a family is affected by stressors is determined by two factors: first, how the family is able to cope with the stress, and second, the levels of support, both psychological and practical, to which a family has access. These are the two key factors that, when combined, appear to make a family vulnerable, and they have also been highlighted in recent research on family vulnerability (Newland, 1997; Williams, 1997). When describing vulnerability, several respondents spoke of families' 'coping abilities when under stress' (HV. 47) and 'difficulties coping with everyday stresses'. (HV. 49). The fact that vulnerable families lacked adequate support networks was a feature discussed by many of the health visitors. As previous research has also indicated, it is likely that families will differ in their coping abilities in similar stressful situations.

THE CONTINUUM OF VULNERABILITY

An important feature of the analysis was that the majority of respondents described vulnerability as a shifting focus, a non-permanent and changing state. The existence of a continuum of vulnerability that is a dynamic process was clearly evident (Figure 7.3). The analysis indicated that there are different levels or stages of vulnerability that appear to relate to heath visitors' levels of concern about children and families:

> There are different degrees of vulnerability and families are affected in different ways. (HV. 3)

It would seem that families move in and out of vulnerability at various stages of the life cycle, and this is largely dependent on internal and external stress factors, and coping ability. This has important implications for health visiting practice and the need for community nurses to reassess vulnerable populations regularly. Furthermore, Williams (1997, p. 21) describes vulnerability as 'a potential state' in which there is a risk that any family on a health visitor's caseload could be vulnerable at some point, a view recognised in earlier research (Zubin and Spring, 1977; Copp, 1986; Rogers, 1997). Shifting, variable concepts are undoubtedly problematic in an NHS that requires objective and substantiated facts to work from.

Surprisingly, the analysis of the questionnaire data showed no correlation between the length of time a health visitor had practised and the number of vulnerable families he or she had responsibility for, which contradicts the findings of Nettleton (1991), who in fact found the opposite.

The majority of interview respondents – 10 (83 per cent) – saw a distinction between vulnerable families and families with children on the Child Protection Register. This finding was supported by Newland's (1997) study in which the health visitors clearly distinguished

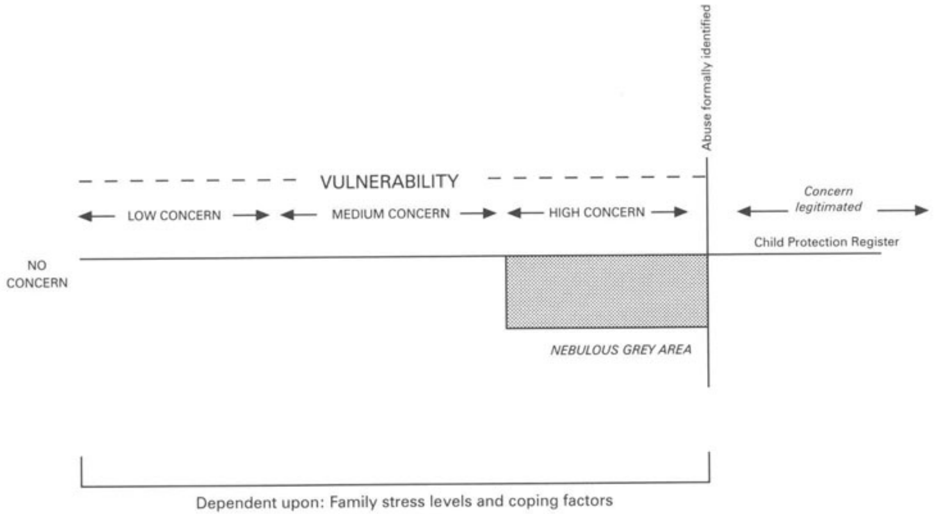

Figure 7.3 The vulnerability continuum
(Appleton, 1994a. Reproduced with kind permission of Blackwell Science)

between the concepts of vulnerability and child protection. However, Newland (1997, p. 4) is critical of the current study for implying 'that vulnerability is in fact the precursor to child protection' and for not isolating vulnerable families where child protection is not a concern. Obviously, in the majority of cases, vulnerability will never move over the edge from 'high concern' to actual child abuse. However, the continuum of vulnerability (see Figure 7.3 above) illustrates that there is a potential for this to occur:

> If you have a child protection issue I think in my book they are vulnerable and would come under the umbrella of vulnerability but it had got to a really chronic stage and was being dealt with as it was a child protection issue, but you could have a whole lot more that because of identification, input and actually containing it, don't actually get to be a child protection issue. (HV. 8)

Figure 7.3 (above) illustrates that at one end of the vulnerability continuum are the children who are on the Child Protection Register, where abuse has been formally identified and concerns legitimated (Cowley, 1991b). However, over half of the health visitors interviewed were clearly very concerned about those children who were not on the Child Protection Register and whom they identified as being vulnerable. These children often caused respondents greater concern than did those on the Child Protection Register. A continuing problem related to the lack of a universal definition of vulnerability. The analysis indicated that, to a certain extent, vulnerability can be ignored by society. Health visitors working in the inner city area also suggested that vulnerability may be perceived differently by professionals depending on the level of deprivation evident in the area in which they are working. They described cases in which children were removed from the Child Protection Register on transferring into the inner city area, presumably because of differing standards. This would support Wheeler's (1989) findings as she challenged the commonly accepted view that professionals have a common understanding concerning definitions of child abuse. It is further reflected in Williams' (1997, p. 23) study, in which vulnerability had 'different meanings' for health visitors depending on the particular 'socio-economic context' in which they worked.

ASSESSING VULNERABILITY IN FAMILIES

At this stage, it is important to move on to explore how vulnerable families may be identified within the health visiting service.

Research by non-health visitors – the checklist/screening approach

The identification of vulnerable families in the child protection/social work literature has been described by many authors as a form of screening (Gray *et al.*, 1977; Browne and Saqi, 1988; Browne, 1989) and is linked to the risk assessment work detailed earlier. Several research studies have been completed by non-health visitors that are 'based on the assessment of children and their families as high or low risk for child abuse and neglect' (Browne and Saqi, 1988, p. 58). A detailed review of the literature (Appleton, 1994b) found that the majority of research studies to date by non-health visitors have attempted to identify vulnerable families by using standardised checklists or other screening tools, all of which are extremely dubious in their validity (Gray *et al.*, 1977; Dean *et al.*, 1978; Waterhouse, 1981; Ounstead *et al.*, 1982; Monaghan and Gilmore, 1986; Browne, 1989). It is also interesting to note that these early studies assumed a link between family vulnerability and child protection concerns, which obviously raises important ethical issues about labelling children at high risk of abuse and parents as potential abusers (Barker, 1990; Doueck, 1995).

Perhaps one of the most widely cited studies is that described by Browne (1989), who developed a screening tool to enable health visitors to identify families with a high risk of committing child abuse in order to give increased support to these families. Browne's (1989) screening tool, a checklist, was to be completed by health visitors at around the time of a baby's birth and included the following risk factors:

- age of mother
- time period between pregnancies
- socio-economic problems
- history of violence
- record of psychiatric problems or socialisation difficulties
- family with separated parents or a single parent
- method of feeding

- post-delivery separation
- evidence of prematurity, low birthweight or handicap.

Browne (1989) describes using discriminant function analysis to establish the relative weighting for each risk factor and maximise optimum performance of the checklist as a screening instrument.

In Browne's (1989) study, health visitors carried out a retrospective evaluation of this checklist on 62 case conferred families with children under 5 years of age; the same checklist was completed on a further 124 non-abusing families, with two 'control' families matched to each abusing family on socio-demographic characteristics. The results showed that, despite the screening instrument being weighted, it was sensitive only to 82 per cent of the abusing 'non-accidental injury' families and identified 88 per cent of the control families as non-abusing. This means that the checklist was ineffective as a predictive screen as, alarmingly, 'it still misses 18 per cent of those families who will eventually abuse and incorrectly labels 12 per cent of the non-abusing families' (Barker, 1990, p. 16). Browne (1989) recognises the grave ethical implications of such a checklist, but Barker (1990), critiquing Browne's study, puts the position more starkly when he argues that using this checklist on a 'population of 10,000 families... would yield 1228 "high risk" families of whom only 33 would be abusers and 1195 false alarms... This means that 35 out of 36 families picked up by the checklist would in fact prove to be innocent' (Barker, 1990, p. 16).

Browne (1989, 1995) argues that this problem could be overcome by using a second screening, but, realistically. this proposal would carry similar kinds of danger, namely a high level of false positives and negatives, resulting in high levels of stress for families who have been identified wrongly as potential abusers. This study provides a very clear example of the potential for such standardised assessment tools to yield inaccurate results (Barker, 1996; Newland, 1997).

Many problems exist with the checklists and screening approaches for assessing family vulnerability. The validity of the checklists and scoring systems is often highly dubious, and insufficient causal evidence exists about the relationship between risk factors and family vulnerability (Browne, 1995; Crompton *et al.*, 1998). In fact, Gibbons (1988), in a DHSS-funded social work study to investigate whether child abuse can be predicted using screening measures, concluded that it was not feasible to prevent abuse by identifying risk factors in advance. Furthermore, some vulnerability assessment tools focus purely on social and environmental factors without considering the quality of the interaction between parents and child (Barker, 1996; Crompton *et al.*, 1998). There is often a lack of recognition that parents' experiences of vulnerability may vary depending on support networks and coping mechanisms (Barker, 1990; Appleton, 1994a; Newland, 1997). Overall research by non-health visitors has taken a somewhat mechanistic approach; by focusing on screening tools, the value of professional judgement in the assessment process often goes unrecognised and disregarded.

Research by health visitors

Following the traditions of other disciplines, the majority of studies completed by health visitors have also involved making assessments of vulnerable families using checklists and screening tools instead of focusing on the health visitor's own clinical assessment process. These studies are further limited in that most are pilot studies, which rather detracts from their usefulness (Hills *et al.*, 1980; Woods, 1981; Johnson, 1985; Fort, 1986). The studies are also heavily influenced by the screening approaches of non-health visitors.

One such study by Taylor evaluated the use of a checklist used by health visitors in one health authority between June 1987 and June 1990 to determine priorities within caseloads and increase interventions to high-risk families (Taylor, 1991). The evaluation took the form of a questionnaire, and of the 37 (53 per cent) health visitors who responded, 83 per cent recorded that they used the checklist. However, when health visitors were questioned about the degree to which the checklist assisted them in determining priorities within their caseload, 16 per cent found it very useful and 33 per cent useful, yet 41 per cent found it only of limited use (Taylor, 1991). Taylor concluded that more constructive methods of targeting within the health visiting service are possible but did not raise the question of clinical judgements as an alternative system for prioritising work with vulnerable families.

However, despite the inherent problems with this approach to assessing family vulnerability, these types of vulnerability checklist and screening tool continue to be used in health visiting practice. Indeed, Barker (1996, p. 407) has suggested that the lack of recognition of health visitors' clinical judgements and the continued use of these tools represents an attempt at 'deprofessionalisation'. Certainly, the continued adoption of this approach to identifying family vulnerability, despite the lack of a substantial research base to support its use, points to the fact that the idea of 'checklists' is firmly rooted in the management and practice of health visiting (Appleton, 1994b; Williams, 1997).

In view of the apparent reliance on standardised assessment tools in health visiting, a study was undertaken in 1996/97 to explore the extent to which these types of practice guideline are in existence in community Trusts in England to assist health visitors in identifying vulnerable families, and to assess their validity and reliability. This study found that 98 (63.2 per cent) Trusts issue guidelines to health visitors to assist in the identification of vulnerable families. Yet, when the guidelines were critically examined, a number of worrying features emerged. Many guidelines contained subjective criteria and provided little evidence of validity and reliability, and only 19 (19.39 per cent) respondents stated that the guidelines were based on published research (Appleton, 1997). A more sophisticated way of assessing family health needs is certainly required. A detailed exploration of health visitors' clinical judgements is suggested as an important focus for future research, which allows the recognition of professional skills and insights, and the importance of knowing the family, their social situation (Baird and Hall, 1985) and the local community.

Assessing vulnerability in families – the use of professional judgement

The literature reveals limited research evidence specifically exploring health visitors' clinical decision-making in assessing vulnerable families. Wheeler's (1989) phenomenological study, despite focusing on communication barriers in child protection work, has proved to be one of the exceptions, moving beyond the use of checklists and taking an important step forward in exploring how health visitors and social workers undertake family assessments. Although using a very small sample – five health visitors and five social workers – Wheeler's (1989) findings suggest that both professionals use a similar assessment process, combining both an assessment of interpersonal relationships between family members and a focus on physical aspects such as housing, environment and financial aspects (Wheeler, 1992).

During the course of the author's 1993 study, it was interesting to find that despite criteria being available in the study sites to assist health visitors in the identification of vulnerable families, a critical finding of the research was that a large proportion of health visitors were using their own professional judgements in the assessment of vulnerable families. This certainly contrasted with the previous literature and Browne's (1995, p. 59) assumption that 'health visitors commonly use checklists of risk factors both officially and unofficially'.

Despite describing the use of their own professional judgements in making assessments of vulnerable families, three interviewees talked about guidelines being used for anyone new coming into a caseload or for teaching newly qualified staff. However, the interview data clearly suggested that health visitors use professional judgements rather than guidelines in the assessment of vulnerable families but that some health visitors either make their own assessments with the official checklist at the back of their minds or subsequently refer to guidelines to confirm their assessment. It is worth pointing out, however, that this study has been criticised for failing to examine clinical judgements in the absence of checklists and screening tools (Newland, 1997); this issue is being addressed in an ongoing research study by the author.

Over half of the interviewees described problems with checklists and guidelines, pointing out their lack of validity in that they can result in families being identified as vulnerable when they are not perceived so by the health visitor and vice versa:

> I actually think it's quite dangerous if it's not used correctly because I don't think you can go through a checklist and just sort of tick off and say whether people fulfil criteria or not, and I think there's an awful lot that we say that can't be written down about these gut feelings and I think it's often that that's more important. And, like I said, it's not the problems that cause the family to be vulnerable; it's how that problem occurs, how it's faced up to, how it's dealt with and what the repercussions are that are far more important than the initial problem. (HV.3)

A significant finding of the study was that eight of the interviewees talked about 'other' vulnerable families, that is, those families which the health visitors identified as vulnerable but which did not fall into the Trust's criteria of what constitutes vulnerability. This obviously relates to the lack of any clear-cut definition of vulnerability. It also indicates that health visitors were using their own professional judgement, rather than official guidelines, in the assessment process.

ASSESSING FAMILY VULNERABILITY

An important feature of the analysis was the health visitors' perceptions of their role in co-ordinating information from a variety of sources to assess family vulnerability. As this theme developed, it became clear that, although most health visitors believed that there should be a universal assessment process, there would always be problems with this because health visitors are constantly making their own clinical judgements. When a health visitor makes a clinical judgement, it is likely to be influenced by his or her own personality, anxiety levels, knowledge and experience. This was clearly illustrated in the study:

> the concern is decided by each individual health visitor in their own way and that's going to be different from health visitor to health visitor, that's the problem with it, I suppose. It means each health visitor has their own way of assessing what their concern is and maybe that's more healthy... and maybe it isn't; I don't really know. (HV38)

This supports the findings of Wheeler (1989), who identified the professional's 'personal standards' and 'life experience' as important components in the health visitors' process of making family assessments. In the present study, all respondents discussed the assessment of vulnerability as an information-gathering process, and this again links with the findings of Wheeler's (1989) study. It became evident that the assessment process involved several key, interrelating factors, yet each health visitor would place his or her own individual and slightly different emphasis on these factors during an assessment. The health visitors in Newland's (1997, p. 39) study 'conducted a needs-based assessment', which aimed not only to identify general 'areas of need but also sought to identify the child in need'.

The health visiting assessment process is conceptualised in Figure 7.4 and illustrates a complex approach involving a range of health visiting skills. The findings suggest that the role of information coordinator, pulling together information from different professionals, is often left to the health visitor, and the time and effort involved in this process generally goes unrecognised. De La Cuesta (1992), in a study exploring basic social processes in health visiting, also describes the assessment as a complex process, saying that 'it involves a gestalt process where previous and present information are combined to form a picture that includes more than the sum of its parts' (De La Cuesta, 1992, p. 161).

The skills employed by health visitors during assessments include a range of interpersonal skills, such as listening, observing, building relationships and working openly with families. De la Cuesta's (1992) study described how health visitors use techniques such as 'selling their personality' and 'bargaining their way in' in order to build up relationships with child's main carer. Robinson (1982) and Chalmers and Luker (1991) have also described the importance of relationship-centred health visiting. Reassessment of situations is essential, and the

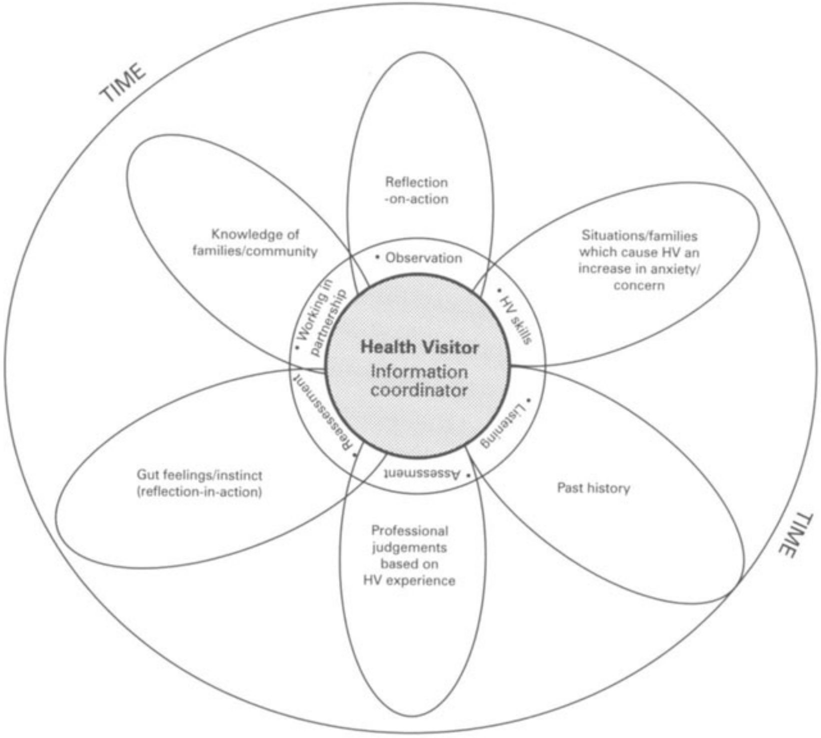

Figure 7.4 The health visiting assessment process
(Appleton, 1995. Reproduced with kind permission of T.G. Scott.)

analysis suggest that time appears to be an important component of the assessment process. Working openly and in partnership with families was reinforced by the health visitors.

Six key interrelating factors were identified in the study, reflecting the steps through which health visitors go when assessing vulnerability in families. These factors clearly are interwoven, and a different emphasis is placed on each by individual health visitors. These steps are outlined below:

1. Knowledge of families/the community

It was a commonly held view among the interviewees that health visitors needed to get to know the families and the community where they worked in order to make an accurate assessment. Only one health visitor was critical of this view, suggesting that health visitors derive a feeling of safety from their knowledge about families rather than being objective about what it is that is making them concerned.

2. Situations/families that cause anxiety or concern

The majority of interviewees spoke about vulnerable families in terms of the amount of concern or anxiety that they caused the health visitor. The analysis indicates that health visitors' anxiety levels are a measure of their perceptions of a family's vulnerability. This would support the findings of West and Savage (1988) and West *et al.* (1988), who found that dealing with difficult cases, 'especially where the circumstances seemed particularly complex or intractable', is one of the major causes of stress in health visitors' work.

Anxiety levels about situations clearly relate closely to individual health visitors' personalities. Two experienced practitioners gave examples of this when they described situations in which they and other experienced colleagues had assessed situations differently because of differing anxiety levels. This appeared to contradict some health visitors who suggested that anxiety levels decreased as they became more experienced.

3. Reflection-on-action

All interviewees emphasised the importance of reflecting on their experiences and discussing their clinical judgements or decisions with another health visitor colleague as part of the assessment process. This appears to echo Schön (1987), who uses the term 'reflection-on-action' to describe how practitioners discuss and think about an intervention or situation after the event. For many health visitors in this study, this appeared to be a way of seeking confirmation about a decision. Nettleton (1991) also highlighted the crucial nature of this type of support. Indeed, many health visitors talked about the fact that they would not be able to do the job if they did not have supportive colleagues, and this appears to be an important part of the health visiting culture.

4. Past history of the family

Although two interviewees felt strongly that a family should not be prejudged by its past history, this undoubtedly had an influence on the majority of the health visitors' assessments.

5. Professional judgements based on health visitors' own knowledge base and experiences

About half the interviewees chose to talk about making professional judgements based on their own previous experiences and knowledge base accumulated over years of practice. These health visitors appear to be displaying the characteristics of the 'expert nurse' as defined by Benner (1984, p. 3): 'the expert nurse perceives the situation as a whole, uses past concrete situations as paradigms, and moves to the accurate region of the problem without wasteful consideration of a large number of irrelevant options'. Interestingly, the health visitors and social workers in Wheeler's (1989) study also talked about 'life experience' as an important element in the assessment process.

6. Health visitors' gut feelings/instinct: reflection-in-action

Despite only nine (16 per cent) of the questionnaire respondents writing about the use of gut feeling or instinct, nine of those interviewed chose to talk about their instinct entering into the assessment process somehow, although many found it difficult to rationalise this:

> I know we're not supposed to believe in gut feelings; there's supposed to be no such thing as a gut feeling, but I mean you've got to listen to what your instincts tell you, haven't you, up to a point? And with years of experience, sometimes you see or absorb things almost subconsciously that tell you that you've got to keep a bit of an eye on here. (HV54)

This description of the use of intuition seems to link to Schön's (1983) use of the term 'reflection-in-action' to describe the combination of professional artistry, intuition and gut feeling. Professional artistry is 'the intuitive knowing in practice by which practitioners make sense of practice phenomena to inform professional judgements and determine strategies in practice' (Twinn, 1989) and is increasingly being recognised as an important element in professionals making sound clinical judgements (Fish and Coles, 1998). Schön describes 'reflection-in-action' as the thinking that a professional undertakes concurrently with action. This study suggests that there appear to be clear links between health visiting experience and instinct, as the following comment demonstrates:

> I think the longer I'm doing this job the more it becomes a logical process. I used to think you would go in and get a gut reaction; there would be an intuitive feeling, and a lot of health visitors I work with have described that. But I actually believe that those feelings are based on fact and what you observe, and if you sit down and think about what it is that's made you concerned you can usually identify factors that are raising concerns for you. So what I tend to do is that, if I feel that something's not quite right, I'll come back, write down why I'm concerned and try and pick out my own thoughts, whether there's any justification for the judgements I'm making... I just often think these subjective feelings that you have can have a foundation in fact. (HV39)

Wheeler's findings (1989) also indicate that intuition was an important element of health visitors' and social workers' assessments of families. The present study suggests that a number of health visitors, while admitting to using gut feeling, felt that they should not be using it because it could not be rationalised or verbalised, or 'would not stand up in a court of law'. If health visitor education taught practitioners to develop 'professional artistry', this might not be such a problem, and instinct would be more readily accepted as part of a legitimate tool in the health visitor assessment process. A recent review of the research has illustrated the profound influence of gut feelings in nursing assessments (King and Appleton, 1997).

STRESS FACTORS AND THE ASSESSMENT OF VULNERABLE FAMILIES

The research has illustrated that health visiting assessment of family vulnerability involves an information-gathering process and has presented the key factors described by the health visitors in this study. Several stress factors were also repeatedly mentioned by health visitors when describing how they assessed a family's vulnerability. These stress factors, and the family's ability to cope with them, appear to be crucial in determining whether or not families are identified as vulnerable. The stress factors include:

- relationship difficulties and role conflict within the family
- mother's health status
- lack of support
- any handicap or disability in a family member
- parenting difficulties
- housing problems
- financial difficulties
- non-use of the health and social services system.

How well families cope with such problems will vary widely between families, and the perceptions of both the health visitor and the family members are clearly paramount in the assessment process.

SUMMARISING THE RESEARCH

It is interesting to note how health visiting research into the concept of vulnerability has developed over the past two decades and moved from a broadly medical/psychosocial approach to predicting child abuse, to a developing knowledge base, dominated by practitioner research, one element emphasising the link between family vulnerability and child protection, the other that families may be vulnerable and in need of increased interventions for reasons other than child protection. This change in approach appears to reflect the developments generally in community nursing research, in which, over the past 20–30 years, research into nursing activity has moved away from a position where research was predominantly undertaken by non-nurses, adopting quantitative research techniques with a primary emphasis on measurement strategies. In contrast, much of the recent research into health visiting practice has been undertaken by community nurse researchers adopting broadly qualitative frameworks, attempting to make sense of practice phenomena to inform professional practice and education.

In today's NHS climate, with cutbacks in the health visiting service clearly in evidence and targeted client contacts the norm, it is essential that practitioners can articulate their knowledge surrounding vulnerability (HVA, 1994; CPHVA, 1998). The health and social needs of vulnerable families must be identified in order to ensure that services continue to be provided for these families. Smith (1998) has stressed the need to ensure that health visitors bid for resources to undertake preventive work effectively. After all, it is unlikely that health and social needs will be accurately identified if home visiting services are curtailed further. Effectively marketing the benefits of the service is of paramount importance in order to continue to support families in their own homes (Leach, 1997). The developing research base on family vulnerability must be used in the fight to demonstrate the effectiveness of community nursing services.

Furthermore, a question that needs to be raised is, why, when there is a significant amount of research outlining their potential weaknesses, do health visitors and their managers feel the need to continue to develop vulnerability scores and assessment tools? It is the author's belief, and a fact often ignored, that many of these so-called vulnerability tools and dependency criteria do not actually help practitioners to assess family vulnerability at all. Instead, what they really do is provide a classification system of families' needs, ranging from a state of high vulnerability to one of low vulnerability. Yet this sort of classification can only take place once a practitioner has made a professional clinical judgement that a family is vulnerable. They do not help to explicate the assessment process at all. If anything, they have the potential to undermine professional skills and judgements (Barker, 1996). A further dilemma surrounds the potential mismatch between a health visitor's professional judgement and a Trust's official guideline, which can result in conflicts for practitioners.

CONCLUSION

Risk assessment and the assessment of client and family vulnerability are becoming increasingly important to ensure that nursing and health services generally are targeted to the areas where they are really needed. This is illustrated by current government policy initiatives and the NHS research and development agenda, in which recent research tenders have called for work in the areas of health-care services for children in need, particularly those from materially disadvantaged families and minority ethnic groups (NHSE, 1997). Added to this, the English National Board for Nursing, Midwifery and Health Visiting is currently commissioning research into the effectiveness of midwifery education in preparing midwives to work with women from disadvantaged groups (ENB, 1998). With the recent NHS White Paper focusing on public health, and the intention that community nurses will work more closely with social services personnel, there will be an increasing need for practitioners clearly to articulate their knowledge of health and social needs of the local population they serve (DoH, 1997). However, apart from the field of health visiting, there is limited evidence on how community nurses are doing this.

To conclude, it is worth debating whether the ideas and themes generated through health visiting research can be transferred to other branches of community nursing. This chapter has highlighted the abstract nature of the concepts of vulnerability and risk. Yet, if we reflect again on these concepts and their links with community nursing, highlighted in Table 7.1 above, the two concepts are clearly in common usage in practice. Thus, in terms of future research that community nurses may wish to pursue, a starting point must be for each of these concepts to be explored in detail in each community nursing specialty. It seems an important step to clarify their meanings for practitioners and explore in more detail how nurses make assessments of vulnerable clients. Arguably, it could be unethical for community nurses to continue to use such abstract concepts in practice if no attempt is made to do this.

What also remains a problematic issue is the diverse meaning that the terms 'vulnerability' and 'risk' have for different community professionals. Clearly, all community nurses do not use the terms to mean the same thing; furthermore, even within disciplines, practitioners may not have a shared understanding of the concepts. When commissioners are contracting for nursing services and the phrases 'assessment of vulnerable families' and 'risk assessment' are used in contracts, they are likely to reflect different aspects of community nurses' work. In this respect, community nurses may not be putting forward a united front. It is unlikely that commissioners are aware of the breadth of meaning encompassed by the terms 'vulnerability' and 'risk'. It could be argued that community nurses as a group have an obligation to patients and clients to ensure that this work is clearly articulated and to confirm that potential purchasers are aware of the often unacknowledged skills and preventive work that community nurses undertake in identifying and working with vulnerable and 'high-risk' clients.

Finally, it is worth considering whether 'vulnerability' is really an acceptable term at all to be using when assessing families and children. Perhaps more thought should be given to the sort of terminology that community nurses and managers routinely use to 'label' certain clients. The author spent some time reflecting on this dilemma in relation to health visiting and wondered how she would feel if her family were labelled 'vulnerable' or 'high dependency': she did not think she would like it at all. The notion of 'interventions' may also be deemed too clinical by families. Despite a certain amount of professional reticence surrounding the word 'support', recognising that you are a family in need of extra support rather than a 'vulnerable' or high-risk' family may well be a more realistic and acceptable term for families as service consumers.

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CHAPTER EIGHT

Investigating the needs of and provisions for families caring for children with life-limiting incurable disorders

Alison While

Although death in childhood is rare, a small but significant number of families in the UK live with the day-to-day reality that their child will not reach adulthood. This has a profound effect upon these families, who require good professional support for their caring role (While, 1989). Many life-limiting incurable disorders make heavy demands upon families in all domains, including physical, emotional, social and financial areas. Thus family life may revolve around a constant daily routine of basic caring procedures punctuated by visits to secondary care centres.

The needs of this client group are clearly special, requiring a unique network of services. However, it has become apparent that large gaps exist in the provision of care for which these families feel a vital need (Baum *et al.*, 1990). The evidence indicates that there are considerable regional variations in both the type and quality of services available to families and, furthermore, that the disorder from which the child suffers may contribute to the level of involvement of professionals.

Against this background and in the context of demands from pressure groups, the Department of Health (DoH) initiated a programme of pilot projects for children with life-threatening disorders in 1992 as a means of developing local provision. The research described here was also commissioned by the DoH in 1992 in response to a research call for a national study: to provide evidence of the needs of families caring for a child with a life-limiting incurable disorder during the palliative and terminal phases of the illness; and to describe the extent and variety of support services available to these families.

DEFINING THE GROUP OF CHILDREN LIKELY TO DIE PREMATURELY

The disorders from which the majority of children die, for example accidents, prematurity and sudden infant death, were not the focus of this research. The study was concerned with the less common deaths of children from incurable illness, for whom plans can be made and appropriate care offered. A number of words and phrases have been used to describe children with a disease that will end in expected premature death. However, some incurable diseases, for example asthma, are treatable, and childhood cancer is increasingly curable (Birch *et al.*, 1988; Stiller, 1994), although the health deficits of survivors are not known. Furthermore, the palliative period may extend over many years for children suffering from degenerative or enzyme disorders, unlike the field of adult health, where it is more usually regarded as short-term. The study therefore adopted the term ‘life-limiting incurable disorders’ to define the research subject.

EXTENT OF THE PUBLISHED LITERATURE

The exact number of children living under the threat of premature death from life-limiting incurable disorders was not readily available. Published government statistics on death by cause are not detailed enough to yield a breakdown of the exact numbers, as can be seen from the Office of Population and Censuses and Surveys (OPCS) and Central Statistical Office (CSO) publications, and Thornes (1987) has acknowledged the scarcity of data. It is also unclear how Baum (1994) had calculated his figure of 20 000 children with life-threatening disorders in need of support.

The literature reviewed was conclusive in suggesting that the experience of caring for a child with a life-limiting incurable disorder takes a heavy toll on families and that much of the health care provided was not meeting their needs. Most of the literature reviewed pertained to the care of children with cancer, to the neglect of children with other disorders, although such children represent a significant proportion of children in need of palliative and terminal care. Despite an attempt to review all the relevant literature, no research was located comparing the benefits to the consumer of hospital, hospice and home care. Furthermore, the literature reviewed drew mainly upon small-scale studies, which did not permit a generalisation of their findings. Nonetheless, the literature indicated that the quality of care offered during the palliative and terminal phase of a child's life may have a profound effect upon the bereaved.

THE RESEARCH

The two broad research aims were articulated into four specific research objectives:

1. to estimate the incidence of life-limiting incurable disorders among children (aged 1–17 years) in England and Wales
2. to describe the needs of families caring for children with these disorders
3. to describe the services available in four contrasting regional health authorities (RHAs) to support children with life-limiting incurable disorders and their families
4. to describe the care management arrangements in selected district health authorities (DHAs).

The four RHAs included both rural and urban areas and one London area, and were selected in the knowledge that they would represent a contrasting variety and extent of support provisions for families caring for children with life-limiting incurable disorders, demographic variations and geographical spread for the study. Each research objective became an element of the research.

The number of children with life-limiting incurable disorders

Mortality and morbidity data were used as a basis for estimating the number of children with life-limiting incurable disorders in need of services. The data on the underlying causes of child death of 1–17-year-olds were provided by the OPCS. The data were considered in terms of the permanent place of residence subsumed into the 1987 DHA boundaries so that the mortality data reflected the number of actual past deaths of 1–17-year-old children relating to different DHA boundaries, non-UK-resident children having been extracted from the data set.

The analysis involved 5 years (1987–91) of child mortality data for England and Wales. A simple year's figures would have been unreliable since some of the disorders are very rare, and the number of deaths is therefore low. The longer timescale, however, brings its own problems, namely demographic changes and residential mobility trends (CSO, 1994) and treatment advances, and, furthermore, the 10th revision of the International Classification of Diseases (ICD codes) was about to be introduced. Therefore, 5 consecutive years of mortality data utilising the ICD codes (9th revision) to the level of three digits were manually scrutinised, the proposed list of diseases to the level of three digits having been approved by the research advisory group. The mortality data analysis was extended to include all deaths between the ages of 1 and 25 years, in recognition of the fact that advances in medical treatment have postponed the time of death for some disorders, for example muscular dystrophies and other myopathies, cystic fibrosis and chronic heart disorders. The data analysis permitted a mean number of deaths due to the selected disorders by age over a 5-year period to be calculated. Similarly, the mean number of life-limiting incurable disorder deaths per age group in each RHA throughout England and Wales was also calculated and set against OPCS population data over the same years to reveal an incidence rate of about 10:100 000 children aged 1–17 years. Calculation of confidence intervals indicated that the data were robust, with a very small range of error.

Consultant episode data and child disability register data from 1987 to 1991 were requested regarding the selected ICD codes of children of 1–17 years of age from all the DHAs (*N*=44) in the four selected RHAs. The NHS reforms, as a consequence of the NHS and Community Care Act 1990, disrupted the data collection process, with DHAs being possessive of their data sets. The RHAs were therefore approached to supply consultant episode data since they were the conduit for such data between the DHAs and the DoH. Again, the changing status of the RHAs posed difficulties, and further different practices regarding data-reporting pertained in the different RHAs. Only three out of the four RHAs were able to provide the data requested; two of these related to consultant episodes and one to consultant cases per annum. Additionally, the reliability with which the consultant contact data were recorded was thought to be suspect, especially with regard to disease category and the neglect of outpatient department work. The available child disability registers were too unreliable to warrant analysis. The available mortality data sets were therefore supplemented by data available on registers maintained by different organisations, for example the Cystic Fibrosis Research Trust, the Muscular Dystrophy Group of Great Britain, the Society of Mucopolysaccharide Diseases, Scope and the Childhood Cancer Research Group.

Comparison of the mortality and morbidity data in the same DHA did not reveal any relationship. However, the inadequacy of the DHA morbidity data source was a major deficit. The data available from the different organisations also presented difficulties; for example, the Childhood Cancer Research Group reported more than 5 500 survivors of children alive at the end of 1991 in England, Scotland and Wales, but had no data regarding the health status of these children and, furthermore, were only able to provide data regarding children of 5–14 years of age.

The research was therefore able to indicate the number of children requiring terminal care annually but was unable to develop a firm estimate of requirements for health and other supportive care provision among families caring for dependent children with long disease trajectories. The data indicated that neoplastic and cardiac disorders contribute significantly to death from life-limiting incurable disorders, while myopathies and cystic fibrosis caused a large number of deaths among older children.

Needs of parents caring for children with life-limiting incurable disorders

An interview survey was undertaken utilising a modified version of the OPCS childhood disability structured instruments (OPCS, Surveys of Children's Disability: Questionnaires). Random sampling was not feasible for two reasons: first, there were no known lists from which to generate a sampling frame, and second, the sensitive nature of the research and the ethical issues that it raised were important considerations. It was felt that parents should volunteer to participate in the research rather than receive a direct approach from the research team, thus ensuring that parents were not confronted by the life-limiting aspect of their child's disorder through contact with the research project. Recruitment to the study was therefore conducted through voluntary organisations and support groups via advertisements in their newsletters or distribution of project information letters inviting those interested to contact the research team. Advertisements were also placed in general magazines for the disabled, and press releases were sent to local BBC and independent radio stations in the four RHA areas. Ninety-nine families were recruited across the four RHA areas.

The potential bias through the underrepresentation of certain groups, for example ethnic minorities, has to be acknowledged. Sheard (1995) has asserted that self-help groups and voluntary groups are often disproportionately composed of white, middle-class families. However, little is really known about the composition of voluntary groups because of the dearth of research, although American evidence suggests that their membership is spreading (Borkman, 1990). Recruitment through health-care professionals also had potential bias not only through the purposeful selection of the 'good' respondent, but also through the exclusion of families whose child had a rare condition and was treated outside the geographical area.

The ethical issues raised by this type of research were a major concern (Lee, 1993). A letter was therefore written with the guidance from an ethicist and sent to local research ethics committees enquiring whether formal ethical approval should be sought since no patients (children) would be interviewed. It was noteworthy that OPCS, using the same instrument, had not sought formal ethical approval. Much time and many other resources were expended in gaining ethical approval, the idiosyncratic practices of the different committees (While, 1996) proving challenging at times.

The interviews took place at times and in places convenient to the families and were conducted by a highly skilled nurse interviewer. The interviews each took approximately 2.5 hours. Care was taken to support the interviewer with regular debriefing sessions, recognising the difficulties of collecting data in sensitive areas (Johnson and Plant, 1996).

The data yield from the interviews was enormous and was analysed using the SPSS statistical package on a VAX VMS 4000 series computer. A wide range of disorders were represented within the sample, although neoplastic and cardiac disorders were relatively underrepresented. The findings reiterated many of the findings of the previous empirical work, with unmet information needs and practical support needs being consistent themes across the data set. While valued by the sample parents, voluntary organisations were reported to provide mainly emotional support and disease information, leaving gaps in statutory provision unfilled. The findings indicated that a non-categorical approach may not always be appropriate because the different disorders gave rise to different severities of disability in different domains, reflecting the varied disease aetiologies and trajectories. The enormous care demands of some of the children was noteworthy, two-thirds of the sample children being in receipt of time-consuming treatment. Indeed, the heavy burden of care, and in consequence the 'day-to-day existence' of the families, gave rise to the question, would bereaved families view their experience and needs differently in retrospect? A proposal was put to the DoH to extend the original commission to enable the collection of retrospective data from bereaved families regarding what types of service and support were most and least helpful.

Provisions for families caring for children with life-limiting incurable disorders

Two postal surveys were designed to map statutory and voluntary service provision. Information about statutory provision was sought from three informants in each DHA area: the senior paediatric nurse, the community paediatrician and the Director of Social Services for each local authority. The questionnaires were similar in order to permit triangulation of the data. Disappointingly, there was a marked variation in response rates across both occupational groups and DHAs, which undermined the robustness of the data set. Nonetheless, the findings indicated a variation in service provision between RHAs and DHAs, although no conclusions could be drawn regarding the quality of that provision or its context. No relationship was found between child population and service provision, suggesting that the establishment of services arises as a result of a number of factors, of which a certain threshold of cases is but one.

Information about voluntary sector provision was derived from a national postal survey of all voluntary organisations likely to provide either direct or indirect (for example activity holidays) services to children with life-limiting incurable disorders and their families. The voluntary organisations were identified from six directories. such as those of Contact-a-Family (1991) and Disability Alliance (1992). The organisations were then contacted by telephone to confirm their relevance to the research.

Three hundred and thirty-one questionnaires were mailed and 266 returned (an 80 per cent response rate). The responding organisations were categorised into relevant (*N*=147, 55 per cent) or non-relevant (*N*=119, 45 per cent) on the basis of their declared provision of services.

This survey contributed to the limited empirical work exploring voluntary provision (Cornish *et al.*, 1996) and revealed much variation across the sector regarding all characteristics, including the provision of services. The diversity found was thought to be associated with a number of factors, including financial resources and the disorder of the client group served, as well as the motivation of the founder of the organisation. Health and social workers were identified as the main source of information regarding the voluntary sector.

Care management arrangements in different areas

An interview survey was conducted in 12 DHAs utilising a semi-structured approach to permit sufficient flexibility between the DHAs with different arrangements and available resources (Stein and Woolley, 1990) and between the interviewees from different occupational groups. The sample of 'key providers' was initially derived from the statutory and voluntary sector survey findings, and then all interviewees were asked to identify other 'key' providers who might be relevant to the study. Ninety-two interviews were conducted, with a mean of eight staff members in each DHA (range 2–11). The transcribed interview data were analysed for manifest and latent content, and themes were identified for quantitative analysis. The respondents ranged across the occupational groups and included nursing, medical and social work staff in addition to chaplains and counsellors.

There was a wide diversity in both the provision of services and the management of care for children with life-limiting incurable disorders. Many factors contributed to this diversity, the most prominent being the child's diagnosis. Diagnosis determined the way in which the child was referred into the health and social care system, the pattern of care provided, the services integrated into the care package and the membership of the team providing care. For example, children diagnosed with cancer or leukaemia experienced well-structured care by small specialist teams of oncology units, while children cared for within general services were part of a mixed caseload within which the services provided were prioritised according to immediate need. The arrangements for the management of care were also affected by the work methods of professionals, the resources available and the structure of service delivery.

Unfortunately the data indicated that some children and their families received a less than adequate service, the comparative excellence of the provision and management of services for children with neoplastic disorders emphasising their relative disadvantage.

Views of bereaved parents

This element of the research was commissioned after the data collection phase of the original project. An unstructured interview was used partly because it would enable interviewees to introduce data of prime importance to their individual experience (Bryman, 1992) and also because it was well suited to the exploration of views regarding sensitive and complex issues (Denzin, 1989). Recruitment to the study was again undertaken through voluntary organisations and support groups, the invitation being extended to parents who had been bereaved for at least 3 months and no more than 3 years, having cared for a child with a life-limiting incurable disorder. Families whose children had died of a neoplastic disorder were excluded from recruitment owing to the well-documented services and needs of this group.

The sensitive nature of the interview topic demanded special care to ensure that the interviews did not cause emotional damage to the parents. Highly skilled nurse researchers conducted the interviews and were careful to be sensitive to the needs of the families at all times (Flesch, 1975; Cowles, 1988). The use of the name of the child helped to focus the interview to the individual experience and establish a rapport between the interviewer and interviewee. Parents were invited to recount their story and to raise and develop issues of importance and concern to them, the interviews being free-flowing and conversational. A topic guide was developed to ensure, where possible, the collection of similar data during each interview. The length of the interviews varied considerably, with a range of 1–4 hours, although most took about 1.5 hours. They were conducted at a time and place convenient to the interviewee, often at an agreed time in the family home, and sometimes in the presence of others, for example a valued supporter. The transcribed interviews were coded thematically for both manifest and latent content (Miles and Huberman, 1994). Forty-four interviews were conducted, 15 with families whose child had died prior to his or her first birthday, and 29 with families whose children had been older. The interview data from the two sets of parents were analysed separately so that any differences in the experience of care provision, terminal care and bereavement support could be seen. Gorer (1969) has suggested that the bereavement experience of parents differs according to the age of the child at death, while Rando (1991) has disputed this distinction. A wealth of data emerged from the interviews, mutual support within the research team being a critical factor; collecting such sensitive data required a strategy to ensure the opportunity for sharing feelings, and regular meetings were scheduled during both data collection and analysis.

The loss of a child was a devastating experience for all the parents interviewed. The enormous improvement in life expectancies has rarefied the event making the loss of a child today perhaps more difficult to bear. Furthermore, the limited experience of childhood death reduces the opportunities for the development of caring expertise among primary health-care teams. The interview data indicated that not all study families experienced high-quality care during this difficult time, and it appeared that professional practice was not always informed by the available research.

An unexpected finding was the apparent lack of 'terminal' care provision for many of the dying children because of the failure to recognise that the terminal phase of life had been reached. This appeared to be due to a reluctance on behalf of both the professionals and the parents to accept that full palliative care should be instituted. Furthermore, despite Goldman *et al.*'s (1990) assertion that home is the preferred place of death, few children in this study had died at home, and, for those families who chose home as the place for their child's death, there appeared to have been very limited support from care professionals. Few parents had experienced supportive bereavement care, and, importantly, only *ad hoc* arrangements were described regarding surviving sibling support. Indeed, many parents expressed a need to talk about their dead child and found the interview a therapeutic experience enabling them to share their disappointments and hopes.

Looking back and looking forward

The study was both a research and an emotional challenge. Crucial to its success was careful planning, a helpful advisory group and a mutually supportive research team within a nurturing academic department. All members of the research team learnt from the experience, and it was pleasing to see the DoH (NHSE, 1994) and ACT and the Royal College of Paediatrics and Child Health (1997) develop recommendations for best practice drawing upon the research.

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CHAPTER NINE

Supporting family carers: a facilitative model for community nursing practice

Mike Nolan, Gordon Grant and John Keady

It is the purpose of this chapter to outline an assessment and intervention model that can be used to support and complement the family care provided to frail individuals living in the community. Although the approach is a generic one, intended for use by any formal service provider, particular attention is given to the role of community nurses in creating a more equitable and appropriate partnership with family carers. The chapter begins with a brief overview of the demographic and policy contexts that have shaped the emergence of community care, and describes the way in which family carers are usually perceived by service agencies. Alternative models are then presented, and it is argued that professionals in general, and nurses in particular, must have a fuller understanding of the dynamic nature of family care if more tailored support is to be provided to reinforce effective family care. The need to link assessment and subsequent intervention to the relevant stage of care-giving is highlighted, and a number of assessment instruments developed by the authors are considered, their theoretical bases being briefly outlined.

COMMUNITY CARE: THE UNIVERSAL PANACEA?

Countries throughout Europe are currently facing the challenges posed by their ageing populations, particularly the rapid rise in the absolute numbers and relative proportion of those aged 85 and over (BMA, 1995; Davies, 1995; Evers, 1995). In the UK, for example, it is estimated that the number of people aged 85 and over will increase from 897000 in 1991 to 3105000 in 2051 (BMA, 1995). While the pace of such an increase varies in different countries, the overall upward growth is consistent, as is the policy response. Therefore, despite diverse welfare systems, Davies (1995) contends that three common trends can be identified in all developed countries. These are to:

- maintain older people in their own homes for as long as possible
- place an increased reliance on family care
- reduce the cost to public funds.

There is a growing realisation that if the first and third of these aims are to be achieved, far greater attention has to be given to maintaining the supply of family care. Indeed, even in those countries with the best-developed welfare systems, for example the Nordic countries, it is now appreciated that a largely public and professional solution to care needs cannot be sustained (Evers, 1995). In a wide-ranging analysis of the limitations and aspirations of current policies for family care across Europe, Evers (1995) contends that the emphasis must shift away from services that seek to replace or supersede family carers (Twigg and Atkin, 1994) towards a system of complementary and supplementary interventions. Developing such a system is all the more pressing as demographic and social changes are placing ever increasing pressure on the number and availability of family carers.

As Allen and Perkins (1995) point out, a great deal of government policy is 'based on the assumption that the family is available and willing to provide care for its members at different stages in their lives'. Such an assumption is often accepted uncritically, but changing patterns of marriage, divorce, cohabitation and child-bearing (Clarke, 1995), and working relationships (Joshi, 1995) are increasingly challenging the naïve belief that the family will, or can, always care.

There is also an emerging critique of the whole concept of community care, which, as Walker (1995) notes, is 'full of symbolic meaning and idealistic connotations but is only a partial reality at best'. Walker argues that the health and personal social services are junior partners in any caring arrangements, the bulk of support being provided by informal sources, including friends and neighbours but especially the family. Across Europe, he estimates that over two-thirds of all care is provided by the family. Walker (1995) goes on to suggest that policy-makers and practitioners in the UK not only take family care for granted, but also make value judgements about who should be providing care and who is deserving of support. He calls for a radical change in professional values and attitudes leading to the development of a 'more sophisticated understanding' of the dynamics of family care, with a move away from short-term causal interventions to a long-term strategy of prevention. In short, Walker is advocating a reconceptualisation of the nature and purpose of professional relationships with family carers.

Twigg and Atkin (1994) followed a similar logic when they suggested that the dominant view of family carers held by professionals was as a resource. Consequently, the main purpose of intervention is to maintain the carers in their role. This is an explicitly instrumental view of carers that accords them few, if any, rights of their own.

The recent introduction of the Carers (Recognition and Services) Act 1995 in the UK provides, on the face of it, an opportunity to redress this balance. However, if change is to be achieved, the limitations of this legislation must be recognised and efforts made to overcome them.

THE CARERS ACT: A STIMULUS FOR CHANGE?

It seems to us that there are two major limitations to the Carers Act that implicitly reflect the instrumental orientation noted by Twigg and Atkin (1994). The first of these relates to the failure to afford carers an independent assessment. Although there is provision within the Act for a separate assessment whereby carers can be seen without the cared-for person, such an assessment can only occur if the cared-for person's needs are being assessed concurrently. The absence of a right to an independent assessment reinforces the persistent failure to view carers as individuals with needs and expectations of their own. Compounding this limitation is the continued insistence on equating carers' needs with the physical demands of caring. The Act therefore explicitly targets the 'heavily involved carer' who is providing substantial care on a regular basis. What constitutes 'substantial and regular' is not specified but is left to local interpretation. However, the practice guidance accompanying the Carers Act (SSI, 1996, p. 2) outlines a series of questions suggested to be useful in interpreting 'substantial and regular', these being:

- what type of tasks does or will the carer undertake?
- how much time does or will the carer spend providing assistance for the user?
- how much supervision does the user require to manage his/her life?
- is this (or will it be) a continuing commitment for the carer?

These questions are based on an explicitly task-focused view of caring, this being largely inconsistent with much of the recent research evidence suggesting that the objective components of caring tell us relatively little about the degree of stress that a carer is likely to experience (Kane and Penrod, 1995). The inherent risk, and cynics might say the implicit intention, of such a task-based model is that it provides an obvious means of rationing services on the basis of what appear to be easily determined criteria.

Although recognition of the above limitations is important, the Carers Act also provides a genuine opportunity to redress several years of relative neglect with regard to carers' needs, but, if this potential is to be realised, it is essential that the assessment of need starts from a carers' perception of their situation. Achieving this will provide a considerable challenge for assessing practitioners, as early evaluations of community care suggest that professional perspectives dominate assessments. Moreover, the views held by assessors are often at odds with those of users and carers (Ellis, 1993; Caldock, 1994a, b; Nolan and Caldock, 1996). Such difficulties are particularly apparent for those working with carers as there is no real tradition of practice in this area, and practitioners are thus inclined to draw even more heavily on implicit and tacit forms of knowledge (Twigg and Atkin, 1994). What is needed therefore is a coherent framework within which to address carers' needs.

Walker (1995) strongly asserts that a more overt partnership between families and professionals must be created, a view reinforced by Allen and Perkins (1995, p. 233) when they stated:

> real partnership with families and carers is needed if care for older people is to be shared. All the signs are that this will become more and more essential if the present policy of community care is to succeed.

Such a notion of partnership is clearly far removed from the 'carers as resources' model described by Twigg and Atkin (1994), and achieving this shift will require, as Walker (1995) advocates, a 'cultural revolution'. Elsewhere (Nolan *et al.*, 1996a), we have outlined conditions that we feel need to be met if true partnerships are to be developed. These include:

- an individual assessment of care-giver need that extends beyond the physical components of care and gives greater attention to the dynamic and multidimensional nature of family relationships
- the empowerment of carers so that they feel a sense of entitlement with regard to services

- more flexible and creative service responses
- a shift away, in many cases, from a model of professionals as 'doers' or providers of client care towards a role of facilitator, whose main aim is to enhance the skills, competence and expertise of family carers
- a redefinition of a 'successful' outcome that does not rely on global measures such as a reduction in burden but focuses instead on an individual appraisal of care-giving circumstances and needs.

It is, of course, relatively easy to write of such ideals from the safety of an 'ivory tower'. What is needed is a model that can be applied in practice.

WORKING WITH FAMILY CARERS: REALISING A PARTNERSHIP APPROACH

Whyte (1997), in a recent important book, has drawn attention to the potential role of family nursing as a framework for nursing interventions, particularly in chronic illness. She argues that, although many nurses have the personal qualities and professional skills to enable them to provide comfort and support for patients and carers, what they often lack is a theoretical framework to guide practice. In advocating family nursing as a way forward, Whyte (1997) stresses its collaborative and empowering qualities but also recognises that such approaches are in their infancy in the UK. However, she suggests that there are three levels at which nurses can intervene:

1. at the level of the individual within a family context, where the well-being of the individual is the primary concern
2. at the interpersonal level, where the concern is with specific inter-relationships within the family
3. at the level of the family unit, where the entire family is the focus of intervention – the so-called 'family systems' model.

Much of this chapter is consistent with such an approach, although our focus here will be primarily on the first two levels, particularly support for the carer and the cared-for person. This is not to deny the importance of the family unit as the focus of care but instead reflects, in part, the growing awareness of the complexity of the issues involved and our own better understanding and experience of working within a mainly dyadic family structure. Moreover, it is vital not to neglect the caring dyad as recent statistical analyses of carers suggests that the majority are what Evandrou (1993) terms 'sole carers' who shoulder the primary responsibility themselves. She estimates that there are approximately 3.5 million sole carers in the UK.

A partnership between professional and family carers, or families, has been advocated by numerous authors, some going on to describe and develop models to help to translate theory into practice. For example, Smith *et al.* (1991) looked at the need for support among daughters and daughters-in-law providing care for ageing parents. They found that current interventions were too global and outcome measures too general, and argued that improvements would not occur until the focus for interventions was defined by carers themselves. They suggested a number of factors to be important, for example:

- developing improved coping skills, especially in time management
- dealing with family issues, particularly negotiating private time with spouses and considering the impact of caring on their own children
- being able to respond to the older person's needs
- the quality of the relationship with the older person
- how to elicit formal and informal support
- dealing with guilt and feelings of inadequacy
- long-term planning, particularly what to do if institutional care were needed.

On the basis of their study, Smith *et al.* (1991) concluded that service assessments must be flexible and personalised.

Similarly, Dunst *et al.* (1989) outlined a model for the delivery of services to parents of children with learning difficulties using the acronym SHaRE (Sources of Help Received and Exchanged). This model is based on enabling and empowering families to identify their own needs and strengths. Underpinning SHaRE is the idea of competence and the assumption that individuals can achieve competence providing that their social systems are supportive and they are able to use their competence to acquire a sense of control over their lives. The roles of staff within this model typically include those of empathetic listener, resource, consultant, mobiliser, enabler and mediator. Dunst *et al.* (1989) argue that the model provides a way of redefining the purpose and rationale for professional interventions with family carers.

The work of Archbold *et al.* in North America (1992, 1995) provides another elegant practice model developed for work with the family carers of older people. This is a nursing model and is geared towards the health-care system operating in the USA, but we believe that it could be successfully transposed, both professionally and geographically, to other contexts. The model is given the acronym PREP, standing for Preparedness, Enrichment and Predictability, and it has three principle aims:

1. to increase the preparedness and competence of family carers providing home care to disabled relatives
2. to enrich and enhance the care-giving experience in order to maximise the satisfactions of both the carer and the cared-for person
3. to make the unpredictable aspects of caring more predictable by improving carers' coping skills and their ability to anticipate future care needs.

Our own work, which has been developing over the past 10 years, is consistent with such approaches and has also been influenced by the writings of such researchers as Bowers (1987, 1988), Rolland (1988, 1994) and Wilson (1989a, b), among others. The main theoretical underpinning is, however, the work of Lazarus and colleagues, who developed the so-called 'transactional' model of stress. However, we have extended thinking about care-giving beyond a simple consideration of stress or burden and highlighted the need to include the sources of potential satisfaction that carers may gain and also the coping mechanisms they use. It is also our belief that the sort of help carers require will vary depending on the stage of care-giving and their own experience and expertise. This suggests the need to consider how care-giving changes over time, that is, a temporal perspective is required. This temporal perspective is also influenced by the nature of the illness and disability that affects the cared-for person.

UNDERSTANDING THE DIFFICULTIES, COPING STRATEGIES AND SATISFACTIONS OF CARERS

To get a better appreciation of the approach we are suggesting, it is necessary to have a basic understanding of the transactional model of stress. Although there are a number of theories about how stress develops, there is a general acceptance that the transactional model provides the best explanation. Proposed originally by Lazarus (1966), and later developed by others, this model sees stress as resulting from a transaction between an individual and his or her environment. The stress process is based on a number of appraisals made by the individual in which he or she compares the nature of the demands faced with his or her perceived ability to cope. The sequence is usually seen to run as follows.

A demand or event occurs and a primary appraisal is made. At this point, the individual asks, 'Is this something to which I need to respond?' If the demand or event does not pose a threat, harm or challenge, no action is necessary. If it does pose a threat of some kind, a secondary appraisal takes place. At this stage a different question arises: 'What resources have I got to help deal with this event?' The individual then selects a coping response or resource to deal with the event. If no appropriate response can be made, stress is likely to occur.

Once a response has been selected and implemented, a reappraisal occurs. This time, the key question becomes, 'Has it worked?', that is, has the degree of threat, harm or challenge been met? If the answer is 'yes', a successful transaction (coping) has occurred. If the answer is 'no', the individual may try a different strategy. If the original demand cannot be dealt with successfully, negative consequences are likely to arise. If this pattern repeats itself, it usually leads to reduced morale, a deterioration in physical health and a loss of control over events.

This model explains why individuals react differently to the same event: some cope successfully and others do not. It also recognises that:

- demands or events are not all equally stress-provoking
- the same demand may result in a different coping response at different times
- stress is based primarily on subjective perceptions of events rather than their objective characteristics.

Family carers may not be aware of acting in the above way, but there is now growing research evidence in support of the transactional model among families faced with challenging care-giving demands (Quine and Pahl, 1991; Nolan and Grant, 1992a). The main lesson from this is that the objective circumstances of care are not as important as the subjective interpretation of demands and events. The use of objective indicators such as activity of daily living scales will therefore provide a partial and incomplete account of a carer's needs. Other, more sensitive approaches, are required.

An assessment framework considering physical, emotional, social and financial factors, with an appreciation of the nature of disability, is most likely to capture the causes of stress. Emotional and relationship problems are particularly difficult to deal with. Our own studies (Nolan and Grant, 1992a) suggest that the factors contributing most to carer stress are:

- a feeling of being out of control, constantly on edge or guilty
- caring for someone who is unappreciative, unwilling to help themselves or manipulative
- having insufficient family support
- a perceived lack of financial resources.

As with stress itself, people cope with potentially difficult circumstances in different ways. There are many descriptions of family coping strategies, but far less is known about successful coping and why some people appear to cope better than others. There is also some dispute over whether different tactics are employed in different circumstances. However, it is generally accepted that certain coping methods are more effective in dealing with certain types of demand and that people who can choose from a range of coping options are generally less stressed.

Four main types of coping strategy are usually described:

1. preventive action to ensure that stressful events do not occur
2. direct action to deal with the stressful event itself
3. reframing the meaning of events
4. dealing with the consequences of an event.

Our own research (Nolan *et al.*, 1996a) suggests that carers often use (and see as helpful) a wide range of coping strategies. Some of the most common are presented in Tables 9.1, 9.2 and 9.3.

Table 9.1 Strategies involving direct action

Strategy	*Percentage of carers finding it helpful (N=260)*
Finding out as much information as possible	85
Getting as much professional help as possible	83
Talking over problems with someone you trust	82
Relying on your own experience and expertise	82
Planning ahead	79
Establishing and sticking to a regular routine	78

Table 9.2 Reframing and other cognitive coping strategies

Strategy	*Percentage of carers using the strategy*
Realising the cared-for person is not to blame	92
Taking life one day at a time	88
Realising that there is someone worse off than you	81
Realising that no-one is to blame for things	80
Seeing the funny side of things	76
Gritting your teeth and getting on with it	76

Table 9.3 Strategies for managing stress

Strategy	*Percentage of carers using the strategy*
Keeping a little free time to yourself	79
Taking your mind off things by reading, watching TV, etc.	71
Maintaining interests outside caring	70

The above are only a selection of the strategies carers use, but it will readily be appreciated that they have numerous implications for the assessment and delivery of supportive services and interventions. For example, sufficient high-quality information is clearly very important to carers, yet a lack of information is still one of the biggest criticisms that carers have of the formal services. Talking over problems with someone you trust is also very helpful, yet many carers lack a genuine confidant, especially if their usual confidant is now the person they are caring for. Carers also have a very strong sense of their own expertise, yet many research studies have indicated that this is often ignored or overlooked by service providers (see Nolan *et al.*, 1996a, for a review). Routines are very often a vital part of carers' coping, yet services such as day care frequently ride roughshod over carers' carefully laid plans.

In terms of reframing events, realising that the cared-for person is not to blame for his or her condition is seen as a very effective coping strategy, as is realising that someone else is worse off. Humour and stoicism are also seen as important. Helping carers to recognise and develop such characteristics can provide an effective meaning of dealing with events that cannot be changed.

The importance of keeping some free time and maintaining interests outside caring is reinforced as a key strategy in helping to reduce stress. Flexible respite and similar services are therefore potentially very helpful, but they have to be acceptable to carers, fit in with their own routines and provide a service of acceptable quality.

Although there is a great deal of research on the difficulties of care, the rewards of caring have not been considered so closely. However, recent studies have suggested that satisfactions can be numerous and often co-exist with a range of difficulties (Nolan *et al.*, 1996a; Grant *et al.*, 1998). The sources of such reward and satisfaction are very varied, and elsewhere we have devised a framework to try to categorise them (Nolan *et al.*, 1996a; Grant *et al.*, 1998). However, Table 9.4 gives an indication of some of the more frequent sources of satisfaction. Although there is some variation by type of caring relationship (for example, spouses identifying more rewards than do children caring for a parent), such satisfactions are relevant across differing caring circumstances.

Table 9.4 Satisfactions identified by carers

Source of satisfaction	*Carers identifying this as satisfying (N=200)*
Maintaining the dignity of the cared-for person	96
Seeing the cared-for person well turned out	91
Knowing I've done my best	90
Caring as an expression of love	89
Seeing the cared-for person happy	88
Giving pleasure to the cared-for person	87
Keeping the cared-for person out of a institution	80
Seeing that the cared-for person's needs are tended to	79
Giving the best possible care	78

Although we still have much to learn about the role that satisfaction plays in helping to reduce carer stress and bolster their coping, there is growing evidence that rewards and satisfactions are associated with:

- improved carer well-being
- an increased commitment to the caring relationship

- a reduced likelihood of institutionalisation for the cared-for person
- the perception of the cared-for person as a valued person
- evidence of a good prior relationship with the cared-for person
- a more positive attitude about the future
- successful coping.

We believe that including satisfactions within an assessment of a carer's circumstances is important in gaining a more complete understanding of the situation. In particular, we suggest three factors that should be borne in mind.

First, an absence of satisfaction is likely to be associated with a poorer and fragile caring relationship in which carer well-being may be reduced. It may also serve as an indicator suggesting the need to look closely at the situation to determine whether either party is at risk. Research in the USA suggests that an absence of satisfaction should be 'taken very seriously' (Archbold *et al.*, 1992).

Helping carers to identify sources of satisfaction can, on the other hand, result in an improved caring relationship. Work from America indicates that efforts to 'enrich' caring can be a very useful form of intervention (Cartwright *et al.*, 1994).

Finally, it is increasingly recognised that carers are only happy with services if they are convinced that the quality of care offered to the cared-for person is acceptable because, as Twigg and Atkin (1994) suggest, carers often act as the 'arbiters of standards'. We have found that carers need to be convinced that services will maintain the dignity of the cared-for person, give them pleasure and so on. If these criteria are not met, services are frequently rejected or accepted reluctantly, thereby increasing the guilt that carers may feel.

This brief consideration of the balance between stresses, satisfactions and coping strategies provides an indication of the complex nature of family care and highlights the limitations of an assessment approach focusing primarily on the physical components of caregiving. As Bowers (1987, 1988) suggests, it is not the tasks of care that are important but the purpose or motive behind them. In other words, the main consideration is not what carers do but why they do it. Although space does not allow a full discussion here, Bowers (1987, 1988) suggested that there are five distinct but overlapping types of care, which vary according to their purpose. These types of care are termed:

1. anticipatory care
2. preventive care

3. supervisory care
4. instrumental care
5. protective care.

Elsewhere we have elaborated upon this model (Nolan *et al.*, 1995, 1996a), suggesting that reconstructive care and reciprocal care are the most important elements. Reconstructive care is concerned with carers' efforts to help the cared-for person to construct or reconstruct a role and purpose, to find a new sense of self in the face of chronic illness. The search for such a sense of self is a theme that recurs throughout the literature and is important in a range of quite differing conditions, such as multiple sclerosis, arthritis, myocardial infarction, spinal injury and stroke (see Nolan *et al.*, 1997, for a full review). Reciprocal care highlights the importance of creating and sustaining a sense of give and take in care-giving relationships so that one party does not feel constantly indebted to the other. Our work on the satisfactions of caring clearly illustrates the complex and subtle nature of reciprocity in care-giving.

It is essential that professional care-givers seek to understand the type and purpose of care being given and do not focus their assessments primarily on the physical aspects. A failure to do so will often mean that carers reject advice or assistance that is inconsistent with their care-giving beliefs. It is now clear that family carers have a sense of their own expertise that is every bit as strong as the feeling of professional expertise held by formal service providers. For example, Harvath *et al.* (1994) argue that there are two main types of knowledge: local knowledge and cosmopolitan knowledge. Local knowledge is based on a detailed understanding of a unique situation, an in-depth knowledge of an individual case. It is this type of knowledge that family carers possess. Cosmopolitan knowledge, on the other hand, results from an understanding of principles; it is more global and generic. Therefore, while professional carers may have extensive (cosmopolitan) knowledge about, for example, stroke in general, family carers are likely to have intensive (local) knowledge of a particular stroke. Both types of knowledge are important, but it is the in-depth understanding resulting from local knowledge that takes precedence.

EXPLORING THE TEMPORAL DIMENSIONS OF CARING

Knowledge does not of course develop in a vacuum, but demands time and experience in addition to (sometimes) formal training. It is here that the temporal dimensions of care-giving become important. There has to be an appreciation of how illnesses and the demands they impose vary over time. This is essential in offering effective care to both the cared-for person and the carer. There are a number of models that attempt to account for the variations in illness over time, one of the most comprehensive being that of Rolland (1988, 1994).

Rolland's model is based on a typology of chronic illness and was devised to assist both practitioners and researchers to better understand the nature of chronic illness and its impact on the cared-for person and his or her family. He contends that his approach has several implications for practice, providing a framework for assessment and intervention. Rolland believes the model offers a way:

> to think longitudinally and to reach a fuller understanding of chronic illness as an ongoing process with landmarks, transition points and changing demands... taken together, the typology and the time phases provide a context to integrate other aspects of a comprehensive assessment. (Rolland, 1988, p. 36)

At first glance, it would be all too easy to see Rolland's approach as having a primarily medical emphasis, but it is important to note that this is not the case. Although he accounts for important transitions and considers disease/illness progression, this is firmly cast within a biopsychosocial model that fully acknowledges the importance of social, family and emotional components.

Rolland differentiates conditions along four main dimensions – onset, course, outcome and incapacity – all of which have implications for assessment and intervention. A brief outline of some of these is given below, incorporating a family perspective.

In terms of onset, a disease may manifest itself in either an acute or a gradual fashion. An acute-onset condition, such as a heart attack, is usually unexpected and unanticipated, sudden changes and adaptations being required. This necessitates the mobilisation of resources and rapid skill development by both carer and cared-for person. Families cope best if they are able to manage highly charged situations, move between roles in a flexible way, problem-solve and make maximum use of outside resources. For example, in a family where traditional gender roles still exist, a sudden illness in the husband may require his partner to manage the financial affairs. At such a time, people need to be able to make decisions and solve problems while, at the same time, adapting to and accepting the interventions of relative strangers in highly personal matters. Not all individuals and families have either the skills or the ability to cope with such circumstances.

Alternatively, a disease that develops gradually may provide more time for adjustment but also generates the potential for greater anticipatory anxiety, especially prior to diagnosis. This can create a more prolonged period of uncertainty and doubt. As Corbin and Strauss (1988) suggest, the 'diagnostic limbo' is a particularly stressful period for both the person awaiting the diagnosis and the family. At this time, 'information work' is seen to be particularly important in order to try to reduce uncertainty.

Diseases may also run differing courses, which Rolland describes as progressive, constant or relapsing/episodic. In progressive conditions, the carer and cared-for person have to deal with symptoms that may result in a stepwise or progressive deterioration. This provides minimal relief while also requiring constant adaptation and role change, a combination that may soon lead to exhaustion. Moreover, progression may be rapid or slow. In contrast, constant conditions usually have an initial crisis and period of adjustment, followed by a long period of stability with a greater or lesser degree of disability. Relapsing conditions, on the other hand, have stable periods of varying length but require frequent movement between being symptomatic and symptom-free, with the uncertainty that this can cause. Carers are particularly likely to feel 'on call' and to have to respond rapidly to demands with little warning. The marked contrast between periods of 'normal life' and a crisis phase can be particularly taxing for both carer and cared-for person.

The outcome of a disease, particularly the expectation of death, is, according to Rolland (1988, 1994), a crucial feature that has a profound impact. Certain conditions, for example, osteoarthritis, have a very low expectation of death, whereas others, such as AIDS, are more likely to be fatal. A large group fits into the intermediate category and is usually associated with a shortening of the lifespan and an increased possibility of sudden death; cardio-vascular disease and recurrent myocardial infarction fall into this category. This last group causes particular problems with the constant awareness that 'it might happen any time', which may result in overprotection of the cared-for person. He or she may be wrapped in 'cotton wool', any independence and potential contribution being reduced as a consequence. Alternatively, some cared-for people may find paternalism desirable and relinquish responsibilities that they are capable of fulfilling

Diseases in which there is a high element of uncertainty about the outcome can cause carers considerable tension. People can, on the one hand, feel the need for a period of increased intimacy while at the same time wanting to disengage so that emotional separation is less painful.

The final dimension on which diseases may be differentiated is that of incapacity. Rolland outlined five areas of incapacity: cognitive, sensory, mobility, energy and stigma. Each of these requires differing adjustments, which are, however, crucially influenced by the families' expectations of the cared-for person. Those who tend to foster autonomy generally limit incapacity, whereas those who take over from the cared-for increase incapacity. Situations are particularly fraught when the carer and cared-for person have differing expectations of autonomy and independence, that is, differing beliefs about roles and responsibilities in the caring situation. The extent of incapacity varies considerably according to the illness or disability in question, Rolland suggesting that this poses particular stresses for families. So, for example, acute-onset conditions such as stroke usually result in maximum incapacity at the start of caring, whereas, for progressive diseases, the prospect of ever-increasing but uncertain degrees of incapacity is faced on a regular basis. However, as Rolland pointed out, this does give more time for preparation and allows the cared-for person to make a greater contribution to planning his or her future.

The four dimensions of disease processes – onset, course, outcome and incapacity – are united by what Rolland termed the 'meta characteristic', that is, predictability. Thus a disease may be more or less predictable on any or all of the above dimensions, or alternatively it may be quite unpredictable. The literature on coping recognises that stresses or demands that are ambiguous (Boss *et al.*, 1988; Boss, 1993) or unpredictable (Archbold *et al.*, 1992, 1995) are particularly difficult to handle. Therefore conditions that have a relapsing course, for instance multiple sclerosis, present unpredictable demands. Others, such as Alzheimer's disease are ambiguous because the cared-for person is physically present but psychologically absent (Boss *et al.*, 1988).

As well as onset, course, outcome and incapacity, the time phase of the disease is an important consideration. Rolland contends that, in psychosocial terms, there are three major time phases to consider – crisis, chronic and terminal – each of which requires distinct tasks and resources. The crisis phase relates to the symptomatic but prediagnostic period, which brings a set of practical and existential tasks. Thus, at a practical level, there may be adjustments to pain, incapacity or other symptoms, together with adaptations to diagnostic and treatment procedures, while establishing relationships with health personnel for both carer and cared-for. At an existential level, there is a requirement to create meaning out of the situation while maintaining a sense of control over events. This may be coupled with the need to move towards an uncertain future. The chronic phase spans that period between the initial crisis and the terminal stage. The timescale may vary tremendously but is often called the 'long haul'.

If the timescale is short, Rolland likens it to 'living in limbo', while a lengthy chronic phase may lead to the feeling that there is 'no light at the end of the tunnel'. There are critical transition periods between all these phases, with various 'business' that needs to be transacted before progress can be made. For example, in a crisis phase, one has to acquire an understanding of the nature of the disease and accept a diagnosis before the task of entering and coping with the chronic phase can be properly begun. Rolland feels that moving from the crisis to the chronic phase is a new period of socialisation for both the carer and cared-for person.

The notion of business or work in chronic illness is mirrored in the writings of Corbin and Strauss (1988, 1992). They believe that, while illnesses are partly determined by characteristics such as those suggested by Rolland (1988, 1994), they can also be shaped. This is a psychological process whereby the course of the illness is perceived in different terms depending upon the understanding that the person has. Shaping is largely determined by the amount of information that is available. It is during the diagnostic work that professional carers (usually doctors and nursing staff) and those with chronic illness and their carers first come into contact. Corbin and Strauss (1988) suggest that the main difference in perception at this stage, and indeed throughout the trajectory of the illness, is the importance that professional and lay people attach to various components of the disease. Therefore, for the cared-for person and carer, the biographical impact is the most important, whereas the professional is more concerned with the biomedical.

CARERS AS EXPERTS

The notion of business or work relating to chronic illness is consistent with the idea of carers and disabled people developing new knowledge, skills and insights. With respect to family care-giving, we have suggested (Nolan *et al.*, 1996a) that a 'carers as experts' model provides an appropriate frame of reference to help shape professional interventions. Within this model, caring is seen as comprising a number of interrelated practical, cognitive, emotional and relational components in which it is necessary for carers to become skilled if they are to provide effective care. The level and type of skill required will vary according to the stage of both the care-giving history and the illness, and to the types of demand that the carer faces as a consequence.

As individual carers progress through their caring history, it is our belief that they gain varying degrees of expertise, much along the lines described by Benner (1984) and Eraut (1994). Most readers will no doubt already be familiar with this model, which describes the way in which professional practitioners progress from novice to expert, higher levels of skill being dependent on experience rather than theoretical knowledge.

Data we have collected from a number of studies spanning several years (Nolan and Grant, 1992a; Nolan *et al.*, 1996a; Grant *et al.*, 1998) strongly suggest that family carers go through an almost identical process, albeit starting from a different vantage point. Therefore professional 'expertise' usually begins with a period of formal training in which the rules (theoretical constructs) and basic competencies (practical skills) are introduced. However, it is not until these have been practised and refined in the 'real world' that genuine expertise can begin to develop. Family carers, on the other hand, do not usually have the luxury of any 'formal' training and are lucky to get even basic information or advice when they 'take on' their role (Nolan and Grant, 1992b). Consequently, they develop their skills largely by a process of trial and error (Stewart *et al.*, 1993; Harvath, 1994), potentially prolonging the novice and advanced beginner stages.

It is the primary goal of the 'carers as experts' model to work with carers and help them to recognise deficits in knowledge and skills so that these can be developed more effectively. As previously indicated, the level of support needed will depend to a significant degree on the stage of the care-giving history and the illness itself. With regard to new carers just about to 'take on' the caring role (Nolan *et al.*, 1994), it is important to ensure they are able to make an informed choice and are both willing and able to provide the care that is required.

A key concept here is that of 'preparedness' (Archbold *et al.*, 1992), which is the extent to which carers feel competent to take on their role. High levels of preparedness, in terms of having the necessary knowledge, skills and emotional support, are associated with lower levels of depression (Archbold *et al.*, 1992; Harvath *et al.* 1994). Conversely, in circumstances in which carers feel ill-prepared for their role and are faced with an unpredictable situation, levels of burden are higher (Braithwaite, 1990). Taraborrelli (1993) argues that most carers 'take it on' in a state of 'initial innocence' in which they have very little information and advice, and are generally ignorant of both the extent and the nature of the care they will be expected to deliver. This is by no means an uncommon finding (Allen *et al.*, 1983; Lewis and Meredith, 1988a, b; Bell and Gibbons, 1989; Pitkeathley, 1990; Nolan and Grant, 1992a). Moreover, there appears to be little professional input at this time, and the limited support that is offered is confined to the physical aspects of care (Stewart *et al.*, 1993).

Community nurses have a potentially vital role to play here. With the trend towards ever more rapid hospital discharge set to continue (Wistow, 1995), there is often very little time in hospital devoted to assisting new carers to develop their knowledge and skills. However, when the carer and cared-for person return home, community nurses have an ideal opportunity to assess carers and provide support, advice and assistance appropriate to their needs. For example, studies focusing on transitions to care suggest that 'new' carers who have previous experience either of caring or of having worked in a 'caring' profession are more likely to adapt quickly and successfully (Stewart *et al.*, 1993; Taraborrelli, 1993). On the other hand, carers with no previous background of caring will operate initially as novices and are in need of some broad principles and guidelines to follow. As Braithwaite (1990) suggests, there is probably more to be learned about becoming a carer than there is about becoming a parent, yet we do not have the equivalent of antenatal classes for carers.

On the other hand, when assessments are being conducted with carers who have been in their role for some time, it should be recognised that they are likely to have developed expertise of their own (Nolan and Grant, 1992a; Nolan *et al.*, 1996a). In this case, assessors have to adopt a differing strategy that recognises carers' unique knowledge and seeks to blend it creatively with their own professional expertise. It is here that the balance between local knowledge and cosmopolitan knowledge is important.

It is often community nurses who will have the sort of intimate knowledge of family circumstances needed to blend such knowledge most successfully. To achieve this, however, may mean a reorientation of the nurse's role to that of facilitator and enabler rather than doer or provider, giving greater recognition to the emotional demands faced by carers. As Brody (1995) notes, there is a marked tendency for services to focus on those elements of care that are tangible and easy to describe, and to neglect the emotional elements such as conflict, guilt, anxiety and depression because they are 'too slippery'. However, it is not until we try to grasp such 'slippery' elements that policy and practice will begin to respond adequately to the needs of many carers. This does not mean that practical help should be neglected but rather that carers require a range of interventions tailored to their own circumstances.

At the opposite end of care-giving to 'taking it on', there is also a need to assist some carers in giving up their role. Although carers are often poorly served in the early and middle phases of care-giving, existing limitations are brought into most stark relief during the final stages. Describing the results of a number of studies looking at the manner in which older people entered nursing and residential care, Nolan *et al.* (1996b) note the invidious position in which many carers are placed, particularly when admission follows a period of hospitalisation. Because the older person is often too frail or too sick to be an active participant in the admission process, the onus is placed on the carer to be the prime mover. Moreover, owing to the need for a speedy discharge in the eyes of many professionals, particularly doctors, carers feel additional pressure to make decisions hurriedly.

With few exceptions, Nolan *et al.* (1996b) suggest that carers receive minimal help during this difficult period and generally consider that they were left to 'sink or swim'. A range of emotional reactions, including guilt, anger, relief and helplessness, were experienced. The literature suggests that such emotions can be prolonged and that, following the admission of a relative to care, many carers are left with a legacy of guilt and continued stress (Allen *et al.*, 1992; Zarit and Whitlach, 1992; Ade-Ridder and Kaplan, 1993; Dellasega and Mastrian, 1995).

If this situation is to improve, action is required in a number of areas. In particular, there is a need for a thorough discussion of alternative care arrangements prior to a crisis situation emerging. It is here that community nurses can utilise their close knowledge of family situations to best effect (Nolan *et al.*, 1996b). At such a time, family carers become novices again as they have few criteria upon which to begin selecting potential nursing or residential care (Hunter *et al.*, 1993; Dellasega and Mastrian, 1995).

Having selected a home, carers then have to 'live with the consequences'. Lewis and Meredith (1989) described the grief, guilt and loss experienced by many family carers following admission to a residential or nursing home but noted that professional carers tended to treat them as if their problems were over. It is now more widely recognised that, contrary to popular opinion, entry to care does not necessarily mark the end of care-giving for the family member but is the beginning of a different but still potentially stressful involvement (Bowers, 1988; Zarit and Whitlach, 1992; Ade-Ridder and Kaplan, 1993; McCullough *et al.*, 1993; Dellasega and Mastrian, 1995). Once again, sensitive and appropriate support from community nurses can do much to ease this difficult transition.

CONCLUSION

In this chapter, we have outlined some of the principles that we believe should underpin support for family carers. These principles have been derived from a number of established theories and also from extensive empirical studies with carers that we have conducted over the past decade. The 'carers as experts' model requires further development, and we are currently engaged in a number of studies that are exploring the nature of care-giving expertise in greater detail, as well as seeking to extend our understanding of the dynamics of care throughout the family system. Despite the need for further development work, we believe that the principles we have described are capable of direct practical application. To assist in this, we have developed a series of indices – CADI (the Carers Assessment of Difficulties Index), CASI (the Carers Assessment of Satisfactions Index) and CAMI (the Carers Assessment of Managing Index) – together with a guide for practitioners, in order to indicate how theory can be applied in practice (Nolan *et al.*, 1998).

We would like to finish this chapter with an acronym taken from this guide, which we feel best summarises our position. The acronym is EMPOWER, so that practitioners can empower family carers by:

- **e**stablishing a suitable environment for the assessment in order to ensure privacy and time
- **m**aking a genuine effort to build trust and rapport
- **p**roviding interest in carers as individuals with needs of their own rather than as just a resource or a problem
- **o**ffering honest, realistic options with an indication of probable delays or limitations in service delivery
- **w**illingly listening to the carer's and user's beliefs and values in order to obtain a balanced picture
- **e**ngaging in an open dialogue in which the experience and expertise of carers is validated and incorporated into the assessment process
- **r**elinquishing professional perspectives, having an open mind and being prepared to learn.

The latest government White Paper on the future of the NHS (DoH, 1997) highlights the key role to be played by primary care groups and places nurses at the forefront of developments. It is time for community nursing practitioners to be proactive and seize the initiative. One vital area is in the support of family carers. Adoption of the above principles within a temporal model of care-giving will, we hope, allow for the emergence of a truly facilitative model of professional practice.

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