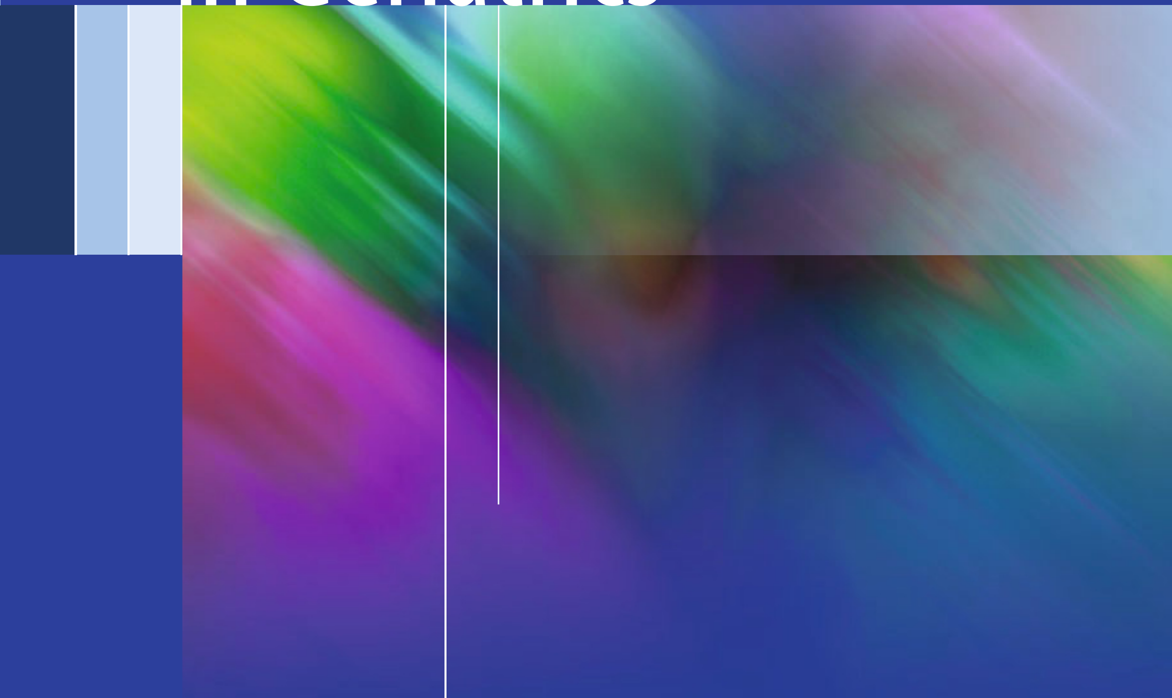
Ethical Considerations and Challenges in Geriatrics



Angela Georgia Catic
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Editor
Angela Georgia Catic
Department of Internal Medicine
Section of Geriatrics
Baylor College of Medicine and Michael E. DeBakey VA Medical Center
Houston TX
USA

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Contributors

Geri Adler, PhD, MSW South Central Mental Illness Research, Education & Clinical Center, Houston VA Health Services Research & Development Center for Innovations in Quality, Effectiveness and Safety, Baylor College of Medicine, Houston, TX, USA

Medha Airy, MD Internal Medicine, Nephrology Section, Baylor College of Medicine, Houston, TX, USA

Lisa Boss, PhD, RN, ACNS, CEN School of Nursing, The University of Texas Health Science Center at Houston, Houston, TX, USA

Sandy Branson, PhD, MSN, RN School of Nursing, The University of Texas Health Science Center at Houston, Houston, TX, USA

Ursula K. Braun, MD, MPH Baylor College of Medicine, Department of Medicine, Division of Geriatrics, Michael E. DeBakey VA Medical Center, Houston, TX, USA

Angela G. Catic, MD Department of Internal Medicine, Section of Geriatrics, Baylor College of Medicine and Michael E. DeBakey VA Medical Center, Houston, TX, USA

Totini Chatterjee, BS Internal Medicine, Texas Tech University Health Sciences Center, Amarillo, TX, USA

Family and Community Medicine, Texas Tech University Health Sciences Center, Lubbock, TX, USA

Bradley H. Crotty, MD, MPH Department of Medicine, Medical College of Wisconsin and Froedtert Hospital, Milwaukee, WI, USA

John W. Culberson, MD Family and Community Medicine, Texas Tech Health Sciences Center Lubbock, Lubbock, TX, USA

Carmel B. Dyer, MD, FACP, AGSF Department of Internal Medicine, Division of Geriatric and Palliative Medicine, University of Texas Health Science Center at Houston, Houston, TX, USA

Lauren J. Gleason, MD, MPH Department of Medicine, Section of Geriatrics and Palliative Medicine, The University of Chicago Medicine, Chicago, IL, USA

John M. Halphen, JD, MD Department of Internal Medicine, Division of Geriatrics and Palliative Medicine, McGovern Medical School, University of Texas Health Science Center at Houston, Houston, TX, USA

Gregory Holton, MD Internal Medicine, Baylor College of Medicine, Houston, TX, USA

Austin Hu, MD Internal Medicine, Baylor College of Medicine, Houston, TX, USA

Aanand D. Naik, MD Houston Center for Innovations in Quality, Effectiveness and Safety (IQuESt), Baylor College of Medicine and Michael E. Debakey VA Medical Center, Houston, TX, USA

Department of Internal Medicine, Baylor College of Medicine, Houston, TX, USA

Nicolin Neal, MD Post Acute Care, IPC Healthcare, Houston, TX, USA

Sabrina Pickens, PhD, MSN, GNP-BC, ANP-BC School of Nursing, The University of Texas Health Science Center at Houston, Houston, TX, USA

Fiona R. Prabhu, MD Department of Family and Community Medicine, TTUHSC School of Medicine, Lubbock, TX, USA

Susan J. Rottunda, BS Minneapolis VA Health Care System, Geriatric Research, Education and Clinical Center (GRECC), Minneapolis, MN, USA

Andrea Wershof Schwartz, MD, MPH Harvard Medical School, Geriatrics and Palliative Care, GRECC, VA Boston Health Care System, Boston, MA, USA

Lara M. Skarf, MD Section of Geriatrics and Palliative Care, Medical Service, VA Boston Healthcare System, West Roxbury, MA, USA

George E. Taffet, MD, FACP Chief Geriatrics, Geriatrics and Cardiovascular Sciences, Robert J. Luchi, M.D. Chair in Geriatric Medicine, Head of the Division of Geriatrics, Methodist Hospital, Baylor College of Medicine, Houston, TX, USA

Geriatric Epidemiology

1

Angela G. Catic

Introduction

Secondary to declining fertility and increasing life expectancy, the median age of the world's population is increasing leading to significant epidemiological changes including challenges within healthcare and social services. Throughout the twentieth century, fertility rates have declined in developed countries, and this decline has spread to developing countries over the last 30 years [1]. Increasing life expectancy has also contributed significantly to the aging of the population. During the twentieth century, life expectancy in developed countries increased by 71 % for females and 66 % for males. This was initially due to decreased childhood mortality, but, over the last several decades, gains are due to individuals living into advanced old age (>85 years).

Due to declining fertility rates and increased longevity, the geriatric population will increase significantly over the next several decades. While only 4 % of the US population was 65 years or older in 1900, the percentage of the population comprised of elders has increased significantly over the last century and is expected to continue to increase: 9.8 % in 1970, 13 % in 2010, and 20 % by 2050 [2]. In terms of actual numbers, the number of individuals age 65 years and older in the USA is anticipated to increase from 43.1 million in 2012 to 83.7 million by 2050 [2]. The aging of the population is not only occurring in the USA but throughout the world. There were 901 million individuals age 60 years or older worldwide in 2015 and this is projected to increase to 1.4 billion by 2030 and 2.1 billion by 2050 [3]. The aging trend is anticipated to be especially significant in lesser developed, generally younger countries such as Latin America and the Caribbean where there will be a 70 % increase in the number of elders over the next 15 years. During this same time

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A.G. Catic, MD
Department of Internal Medicine, Section of Geriatrics, Baylor College of Medicine and
Michael E. DeBakey VA Medical Center, Houston, TX, USA
e-mail: angela.catic@va.gov

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period, it is projected that the geriatric population of Africa and Asia will increase >60 %. In contrast, the population in Europe is already much older, so the elderly population is anticipated to increase by 23 % over the next 15 years [3].

Within the generalized aging trend, there continue to be disparities in longevity between men and women. Throughout the world, older women have a longer life expectancy than men and therefore comprise a larger percentage of the population. Between 2000 and 2030, women will account for 56–59 % of the elderly US population [4]. This gender gap is even more significant among the oldest-old (>85 years of age) where there are two to five times as many elderly women as men. This trend is expected to continue with females born in 2012 living 5 years longer than their male contemporaries [5].

The US geriatric population will become increasingly racially and ethnically diverse over the next several decades. This is secondary to the aging of individuals who immigrated to the country when they were younger as well as immigration among elderly individuals, especially from Latin America, Asia, and Africa. In 2013, 21.2 % of elderly Americans were members of racial or ethnic minorities and this is expected to increase to 28.5 % by 2030 [6].

Lesbian, gay, bisexual, and transgender (LGBT) individuals also represent a growing demographic within the elderly population. It is estimated that there are between 1.75 and 4 million LGBT elders ≥60 years of age and this is expected to double by 2030 [7, 8]. Elders who are LGBT have significant physical and mental health disparities compared to their heterosexual contemporaries including higher rates of feeling isolated and contemplating suicide. Unfortunately, many providers lack knowledge regarding the special health issues of this population.

The changing demographics of the geriatric populations have important medical, social, and ethical implications which will continue to develop over the next several decades. As the US government, medical systems, communities, and families adapt to the challenges of an aged population, an understanding of the unique medical and social needs of the geriatric population will help to ensure they receive ethical, individualized care.

Medical Implications of the Aging Population

Acute Versus Chronic Illness

In juxtaposition to past experience, there has been a shift in the leading causes of death from acute illness to chronic disease. Chronic conditions are defined as conditions lasting ≥1 year which require either ongoing medical attention or that limit activities of daily living [9]. In 2012, chronic diseases accounted for 68 % of all deaths with cardiovascular disease, cancer, chronic lung disease, and diabetes being most prevalent [10]. In the USA, the top ten causes of death among people aged 65 years and older are heart disease, malignancy, chronic respiratory disease, cerebrovascular disease, Alzheimer disease, diabetes, influenza and pneumonia, nephritis, unintentional injury, and septicemia [11].

The transition from acute to chronic illness as the leading cause of mortality represents a significant challenge for the healthcare system. Among individuals in the geriatric age group, chronic conditions are common, costly, and morbid. Three in four Americans age 65 years or older suffer from multiple chronic conditions [12]. Care for individuals with multiple chronic conditions accounts for 71 % of total healthcare spending in the USA, and, among elderly Medicare beneficiaries, this increases to 93 % of Medicare spending [13, 14]. With each chronic condition developed, the risk of impaired daily function, hospitalization, and premature death increases [12]. Over the next several decades, as continued growth in the number of elders with one or more chronic illnesses results in increasing strain on the healthcare system, providing high-quality, evidenced-based care will be critical to improving patient outcomes and minimizing financial burden.

Polypharmacy

As individuals are living longer and suffering from multiple chronic illnesses, many are taking numerous medications. This is reflected by the fact that elders comprise slightly more than 13 % of the population but consume 40 % of prescription medications and 35 % of over-the-counter drugs [15]. On average, individuals between 65 and 69 years of age take 14 prescriptions per year, and this increases to 18 per year among elders 80–84 years of age [15]. Unfortunately, increasing numbers of medications are associated with greater risk of adverse drug reactions and side effects. Among community dwelling elders, one in three taking ≥5 medications will have an adverse drug reaction within 1 year [16]. It is estimated that at least 350,000 adverse drug events occur annually in long-term care residents and more than half of these are preventable [17]. In addition, despite the implementation of Medicare Part D prescription drug benefits in 2006, drug costs continue to be a significant financial strain for many elders. This often leads to difficult decisions about how financial resources will be spent (i.e., food and rent versus medications) and medication noncompliance. When making medication decisions in the elderly, clinicians should incorporate the ethical principles of nonmaleficence (not inflicting intentional harm) and beneficence (having the best interest of the patient at heart). Careful consideration should be given to the patient's goals of medical care when considering the addition or discontinuation of any medication. In addition, the possible risks and benefits of all medications should be carefully reviewed so that patients can make an informed decision prior to starting any new therapy. Clinicians should have frank discussions with patients regarding the financial implications of their medication regimens and be open to considering lower-cost, alternative therapies or assisting patients in pursuing sources of reduced cost pharmaceuticals.

Dementia

Dementia, or major neurocognitive disorder, typically occurs in individuals over age 65 years and will have a significant impact on healthcare of the elderly over the next several decades. Dementia is a general umbrella term used to refer to disorders that cause significant decline in one or more areas of cognitive functioning (learning and memory, complex attention, executive function, language, perceptual-motor, and social cognition) and are severe enough to impact daily function. Worldwide, nearly 44 million individuals suffer from dementia. Alzheimer disease, the most common type of dementia, impacts 5.3 million Americans and this is projected to skyrocket to 16 million by 2050. The prevalence of Alzheimer disease doubles every 5 years after age 60 affecting 6–8 % of patients ≥65 years and 45 % or more of those ≥85 years. Vascular dementia is estimated to cause 15–20 % of cases of dementia. Other common etiologies of dementia include mixed dementia (Alzheimer and vascular), Lewy body dementia, and frontotemporal dementia.

Providing care for the large number of elders who have, and will develop, dementia in the near future presents significant financial and caregiving challenges. In 2010, the total estimated worldwide costs for dementia were $604 billion annually [18]. These costs included the direct costs of medical and social care; insurances including Medicare, Medicaid, and private insurance; and informal care costs which fall primarily on the families of individuals with dementia. In 2015, unpaid caregivers provided 18.1 billion hours of unpaid care to loved ones with dementia with an estimated value of $221.3 billion [19]. On average, family caregivers lose over $15,000 in annual income and spend > $5,000 for each elder with dementia [19]. Caregiving is not only associated with high financial costs but increased stress and medical issues. Among dementia caregivers, 60 % rate their stress as high or very high, 40 % suffer from depression, and 74 % are concerned about their own health in light of their role as a caregiver [19].

Surrogate Decision-Maker

Surrogate decision-makers, also referred to as a healthcare proxy or a durable power of attorney for healthcare, make medical decisions on behalf of an individual who has lost decision-making capacity. In a review of 3746 subjects 60 years of age and older at the end of their life, 42.5 % required decision-making regarding medical care during this time period [20]. Of these individuals, 70.3 % lacked decision-making capacity and 67.6 % had previously completed advance directive documents. Subjects who had appointed a surrogate decision-maker were less likely to die in the hospital or to receive all care possible (i.e., aggressive care) compared to those subjects who did not have a designated decision-maker. This study highlights the importance of encouraging patients to select a surrogate decision-maker as the loss of capacity is a frequent occurrence and having an appointed decision-maker can help to encourage patient autonomy.

Social Implications of the Aging Population

Health Literacy

Health literacy, which involves the ability to understand and use health information, is critical to optimally managing health issues. Defined as “the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions," it includes the ability to follow directors, do basic math calculations, complete forms, and interact with the healthcare system [21]. Health literacy can be influenced by basic literacy skills, educational level, socioeconomic status, ethnicity, communication skills of care providers, and specific health situations encountered. In the USA, >77 million adults have basic or below basic health literacy skills. A significant percentage of older adults have difficulty using printed health materials (71 %),forms or charts (80 %),and interpreting numbers and doing calculations (68 %) [22]. These challenges are particularly concerning for elders, who often suffer from multiple chronic conditions and are high uses of the healthcare system, as low health literacy has been associated with increased morbidity, mortality, and healthcare costs. Using a tool to assess health literacy can help providers to gauge potential challenges patients may face in navigating their health and to modify the plan of care accordingly. Developed in 2005, the Newest Vital Sign (NVS) is one available health literacy tool [23]. It is a quick, easy-to-use screen which assesses math, reading, comprehension skills, and abstract reasoning.

Living Arrangements

Elders in the USA have diverse living arrangements which can have important health implications. In 2015, 56 % of elderly noninstitutionalized individuals lived with their spouse (70 % of older men and 45 % of older women) [24]. The proportion of elders residing with their spouse decreased with advancing age. In contrast, 29 % of noninstitutionalized elders live alone and this proportion increases with aging [24]. While a relatively small number (1.5 million or 3.2 %) of individuals 65 years of age or older live in institutional settings, this increases with advancing age: 1 % in individuals 65–74 years, 3 % in those 75–84 years, and 10 % in those >85 years [24]. Providers should discuss living arrangements with their elderly patients to ensure that they are acceptable, safe, and provide the needed level of support based on their healthcare needs.

Finances

The financial situation of many elders has important implications for their health and social situation. In 2014, the median income of elders was $31,169 for males and $17,375 for females [24]. Ten percent were below the poverty level and another 5.3 % were "near poor," defined as income between the poverty level and 125 % of the poverty level [24]. Elderly African-Americans and Hispanics were more likely to meet criteria for poverty compared to Caucasians and Asians. In addition, the following were associated with higher levels of poverty: female gender, living alone as opposed to residing with family, and residing inside principal cities and/or in the South. Elderly individuals reported the following sources of income: Social Security (84 %), income from assets (51 %), earnings (28 %), private pensions (27 %), and government employee pensions (14 %) [24]. Of note, Social Security comprised ≥90 % of income for 35 % of beneficiaries.

Conclusion

Within the USA, the population of individuals ≥65 years of age is rapidly increasing in number and diversity with this trend expected to continue into the foreseeable future. This demographic shift will require the healthcare system to adapt in order to meet the medical, social, and ethical challenges of caring for this population. From caring for large numbers of elders with chronic conditions and dementia to relying more heavily on surrogate decision-makers to facing challenges of low health literacy and poverty, clinicians will need to develop and carry out individualized care plans to ensure the best possible health of each patient.

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2

Evaluating Capacity for Safe and Independent Living Among Vulnerable Older Adults

Aanand D. Naik

Case Presentation

Mr. Davis is an 84-year-old widower who lives alone in an apartment having retired from a long career as a corporate accountant. He ambulates with a rolling walker but has some difficulty rising from a chair and gets short of breath when walking across his home. He needs assistance with most instrumental activities of daily living, which he receives from his daughter and son-in-law who live 20 miles away. They help with driving but he remains insistent on managing his own medications and basic finances. He is independent in most basic activities of daily living but has some difficulty with bathing due to osteoarthritis of both shoulders. His past medical history is remarkable for ischemic cardiomyopathy with an ejection fraction of 30 %, atrial fibrillation, diabetes mellitus, chronic renal insufficiency, lower urinary tract symptoms with enlarged prostate, osteoarthritis of shoulders and knees, and gastroesophageal reflux disease. He takes more than a dozen medications (aspirin, metoprolol, carvedilol, atorvastatin, dabigatran, metformin, sitagliptin, furosemide, finestride, tamsulosin, acetaminophen, vitamin B12, and esomeprazole) and has four regular physicians. Four months ago he was admitted to the hospital due to heart failure exacerbation. At hospital discharge, he transitioned to a skilled nursing facility for 3 weeks due to functional impairment and multiple changes to his medications. After returning home, Mr. Davis' daughter suggested helping him prepare his medications using a pill tray, but he got angry and insisted that his memory was "just fine" and he would "manage his own damn pills." About that time, she also noted some late utility bills and his water was turned off for several days, which Mr. Davis blamed on the mail service not delivering his payment on time.

A.D. Naik, MD
Houston Center for Innovations in Quality, Effectiveness and Safety (IQuESt),
Michael E. Debakey VA Medical Center, Houston, TX, USA

Department of Internal Medicine, Baylor College of Medicine, Houston, TX, USA
e-mail: aanand.naik@va.gov; anaik@bcm.edu

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Despite getting his water service turned back on without his family's involvement, Mr. Davis' daughter had her father see a neurologist as she was worried that he was developing Alzheimer's dementia. The neurologist conducted a series of tests and noted that Mr. Davis has minimal changes on an MRI consistent with his vascular disease and a score in the normal range on a dementia screening test. His memory was appropriate for his age and education. On examination, he was pleasant with refined social graces and was able to express clear preferences. He reports feeling fine and states that he came to the neurologist only at his daughter's insistence. His neurological examination was otherwise unremarkable. The neurologist didn't find compelling evidence for Alzheimer's and recommends increasing his blood pressure medication to reduce his cardiovascular risk factors. Mr. Davis was doing well for the next month but then became acutely short of breath requiring another hospital admission for heart failure exacerbation. The admitting physician noted that Mr. Davis had gained 10–15 pounds since he was discharged from the hospital previously and his lungs had evidence of extravascular overload. Mr. Davis was able to describe his medications but also admitted he occasionally skips his furosemide dose because he gets frustrated with having to go to the toilet too frequently, especially at night. He was discharged home with skilled nursing care to help with medications and teaching for several weeks. His shortness of breath improved, but he complains that some days he feels lightheaded and he does seem to have more difficulty with getting dressed and bathing.

Mr. Davis has always been an independent person since he was 15 years old and took pride in being the one others turned to for help. He isn't worried about death but insists that his only wish is to live in his home until he dies. He is willing to accept some help from his daughter and son-in-law but doesn't want any strangers in his home. His daughter has become frustrated and tired as she now spends many more hours each week helping Mr. Davis with his activities of daily living and, when her father allows, supervising his medications and bills. She also worries about his safety when she is not at his home. At her wit's end, she comes to a local geriatric medicine clinic asking for guidance about how to manage her father, his safety, and if there are issues related to his competence.

Capacity for Safe and Independent Living

Mr. Davis has many of the characteristics of vulnerability [1]. Vulnerable older adults often present with recurrent morbidity (frequent readmissions and emergency department visits, adverse events related to medications, accidents and falls, etc.), despite availability and access to preventive therapies. They are also at high risk for harm including physical abuse, caregiver neglect, and financial exploitation. While cognitive impairment and depression are often associated with vulnerability and self-neglecting behaviors, this vulnerability does not typically result in complete incapacity to make decisions. Mr. Davis' neurological evaluation is consistent with this observation as his cognitive impairments were minimal and decision-making capacity remains mostly intact. However, as evidenced by the details of Mr. Davis' story, the capacity to identify, avoid, and remove oneself from harmful situations may be diminished. The clinical ethics consideration in these situations of vulnerability is determining whether or not a patient can both make and execute decisions regarding personal needs, health, and safety. In other words, *does the individual have the capacity to make and execute decisions for safe and independent living*? [2].

From a legal perspective, declarations of competence are often treated as a dichotomous phenomenon. One has capacity until a threshold is reached and then competence is lost. In situations of complete incompetence, access to treatment and legal rights can be taken away. Recent advances in the legal understanding of competence now include allowances for partial competence in which most rights and abilities are maintained except for narrow declarations of incompetence (e.g., medical decisions, voting, managing finances). However, in these declarations, the determination of competence is exclusively related to decision-making capacities [3]. In contrast, the capacity for safe and independent living is based on a two-dimension model of autonomy: decision-making and executive autonomy. These two dimensions are better characterized later in this chapter. Furthermore, the capacity for safe and independent living is best understood as a gradient rather than as a threshold phenomenon. This distinction is important to avoid unnecessary infringements of patients' rights. As a clinical phenomenon, the health-care team can identify a range of medical and psychosocial interventions to address some of the impairments contributing to declines in the capacity for safe and independent living. If the impairments are too severe, interventions fail to ameliorate them, or an older adult refuses to implement these interventions, then legal steps may be considered to more fully redress persistent deficits in capacity. With this approach, medical and social interventions are applied first and foremost before burdening the legal and governmental support systems.

Educational Pearl #1

- Vulnerability among older adults is best understood as impairments in the capacity to *make and execute decisions* regarding one's health, safety, and independence (this includes the abilities to recognize and to extricate oneself from harmful situations).
- Problems arise because, legally, capacity is often viewed as an all-or-nothing phenomenon.
  - Capacity should be viewed along a clinical gradient.
  - Treatments and interventions should focus on maintaining as much of the older adult's *autonomy* as possible without compromising health and safety.
  - Legal intervention, in the form of guardianship, is a last resort.
- When older adults lack this capacity, they are susceptible to medical morbidity and harms from self-neglect and elder mistreatment.

- In the USA, approximately 5 million older adults are exposed to these harms annually, including:
  - Physical violence
  - Emotional or psychological abuse (i.e., infantilizing the older adult)
  - Financial exploitation (includes material exploitation)
  - Neglect (intentional and unintentional)
  - Self-neglect

Two-Dimension Model of Autonomy and Capacity

Our clinical model of capacity for safe and independent living is grounded in the clinical ethics foundations of Faden and Beauchamp's Theory of Autonomous Action [4]. Their general theory of what makes action, not just decisions, autonomous was grounded on three principles: understanding, intentionality, and voluntariness. *Understanding* is defined by actions based on understanding of situation and choices. Understanding exists when an individual has the ability to (a) comprehend the circumstances and facts of a situation, (b) appreciate the personal consequences of each choice and/or action, and (c) demonstrate a rational process for choosing one versus another option. *Intentionality* is the state where actions are willed and performed according to one's plan. For intentionality to exist, individuals must have the ability to make and express preferences and choose a single option, develop strategies and tactics for executing a choice, and ensure the performance of strategies and adaptations to changing circumstances. *Voluntariness* is defined by an ability to act without controlling influences. This is manifested when actions are free of external coercion or manipulation and not compelled or inhibited by internal impairments. Adapting these three pillars of autonomous action to clinical care, it becomes clear that ethical standards based only on a capacity to make informed decisions is inadequate. Such standards do not consider most of the *intentionality* principle and part of the *voluntariness* principle. In response to this ethical gap and clinical need, we have previously proposed a two-dimension model of capacity, especially as it relates to the capacity for safe and independent living [5].

Our two-dimension model of capacity includes the dimensions of decision-making capacity and executive capacity. In this model, decision-making capacity is "the process of making decisions for oneself or extending that power to another individual when it is impaired" and executive capacity is the "process of carrying one's decision into effect either alone or by delegating those responsibilities to another individual." When applying this model to clinical care, especially the capacity for safe and independent living, both dimensions should be evaluated independent of one another.

Decision-making capacity is a well-studied area with conceptual and empirical foundations. Appelbaum and Grisso's empirically grounded model of decision-making capacity is defined by four criteria that parallel the Faden and Beauchamp's *understanding* principle described above. Applying these criteria to vulnerable older adults, an individual must *understand* the basic facts surrounding a decision; *appreciate* the personal impact of the decision, including one's capabilities and limitations; have a *reasoning process* for comparing the options and predicting the consequences of alternative choices; and be able to *make a choice* [6]. These criteria are the basis for most informed consent documents and similar legal declarations related to the capacity to consent for treatment (medications, diagnostic tests, surgery, and other therapeutic or diagnostic procedures).

In contrast to decision-making, *executive capacity* is the ability to execute one's decisions. Executive capacity is not the same construct as executional or performance capacity. Individuals with physical disabilities may not be able to perform their activities of daily living on their own. However, nearly all have the capacity to ensure that these activities are done appropriately and on time by other caregivers. In this sense, executive capacity is the ability to ensure that one's decisions have a predetermined plan, adapt that plan in response to changing or unexpected circumstances, and delegate these responsibilities to appropriate caregivers or surrogates when necessary or appropriate.

The interaction of decision-making and executive capacity in the context of the capacity for safe and independent living can be complex. Vulnerable older adults, such as Mr. Davis, retain some or all of their ability to make decisions about being admitted to the hospital or moving into long-term care but lack the ability to safely and effectively manage their medications or pay bills on time. From a clinical perspective, it may be difficult, and often impractical, to determine whether impairments are purely executive in nature or a mix of impairments in decision-making and executive capacity. A practical approach grounded in the functional domains of the activities of daily living are needed to better clarify how impairments in the capacity for safe and independent living impact health and safety in daily life.

Educational Pearl #2

The capacity for safe and independent living is based on two distinct dimensions:

Decision-making capacity—does the vulnerable older adult have the capacity to make decisions regarding safe and independent living?

Evaluated using four criteria:

- Understanding the basic facts surrounding a decision
- Appreciating the personal impact of the decision
- Reasoning through the options by comparing them and predicting the consequences of those options
- Choosing an option

Executive capacity—does the vulnerable older adult have the capacity to implement decisions (by themselves or with the assistance of others) regarding safe and independent living?

- Having a plan
- Adapting the plan when circumstances change
- Delegating responsibilities if one cannot physically enact the plan

The Functional Domains of Safe and Independent Living

For clinicians, it is important to move from theoretical concepts of capacity to practical domains that aid clinical assessment and intervention planning. Clinicians are often asked to assess vulnerable older adults, like Mr. Davis, who demonstrate declines in self-care behavior, live in unsafe settings, or have frequent exacerbations of treatable chronic conditions. The first step of this evaluation is to identify how impairments present within the context of five broad functional domains for safe and independent living: maintaining personal needs and hygiene, condition of the home environment, maintaining activities for independent living, health-care self-management, and managing financial affairs.

Personal needs and hygiene include the basic physiological needs for personal living and safety, for example, activities of daily living (ADLs) such as bathing, dressing, sleeping, toileting, and feeding. Transferring and ambulation within the home are other aspects of personal needs and hygiene. The condition of one's home environment includes routine maintenance, appropriate repairs, and the physical structure of the living environment. Respect for differences in lifestyle choices and cultural standards must be honored and respected. However, living situations and environments that threaten one's basic health or safety are not ethical and warrant a clinical evaluation. Dangerous environments include those with excessive exposure to toxins from pet and animal waste, accidents related to fire and electrical hazards, extremes in weather, and pathogens arising from garbage and sewage. Clinicians may examine whether patients understand their personal and environmental needs and the health and safety risks arising from the gap between their needs and current status. Patients should be able to participate in making a plan to accomplish tasks that address these gaps. Patients physically unable to perform the appropriate tasks may still retain capacity by identifying appropriate social and caregiver supports to fulfill these needs.

The other three functional domains include many functions classically thought of as instrumental activities of daily living (IADLs). Instrumental activities of independent living include shopping and meal preparation, laundry and cleaning, using the telephone, and transportation. Here again, executive capacity is a key consideration. Most vulnerable adults have begun to experience physical impairments and disabilities that limit the ability to personally perform these instrumental activities. However, most still retain executive capacity to participate in planning and ensure execution of these tasks by formal and informal caregivers. Management of health care and financial affairs is differentiated from the other activities for independent living because of their specific correlations to medical morbidity and elder mistreatment that often present to health-care and social services professionals, respectively. Health-care self-management includes all the routine activities associated with managing a medication regimen, monitoring of blood pressure or glucose, wound care, attending to medical appointments and tests, and communicating with professionals about changes in health status. For example, assessment of this domain includes evaluation of how an individual handles acute problems (e.g., infected cut on one's foot or severe chest pain) or practical obstacles (e.g., running out of medications). Managing financial affairs includes managing one's bank account or making everyday transactions, having an understanding of the importance and role of money, being aware of and paying routine bills, and a reasoning process for making financial decisions and reacting to new or unexpected circumstances (e.g., exploitation schemes). These latter two domains demonstrate the equal and robust roles that both decision-making and executive capacity have on maintaining key functional domains of safe and independent living.

Educational Pearl #3

The clinical assessment of a vulnerable adults' capacity for safe and independent living should include evaluation of *decision-making* **and** *executive* **capacity across each of five functional domains for safe and independent living**:

- Maintaining *personal needs and hygiene* (includes bathing, dressing, mobility and transferring, sleeping, and feeding)
- Condition of the *home environment* (includes maintenance and the physical structure of one's living environment)
- Performing *activities for independent living* (includes shopping, cooking, cleaning)
- *Health-care self-management* (includes medication management, wound care, self-monitoring glucose levels, attending routine medical appointment, awareness of acute symptoms)
- *Managing financial affairs* (includes managing daily transactions, awareness and payment of routine bills, and a reasoning process for making financial decisions)

Practical Approach to the Assessment of Capacity for Safe and Independent Living

Clinicians should assess capacity when a vulnerable older adult presents with signs or symptoms similar to those in Mr. Davis' presentation. These include:

- Frequent hospital or emergency department visits for treatable chronic conditions
- Frequent falls and injuries

- Change in physical appearance
- Unexplained weight loss
- Cognitive impairment or disordered thinking
- Depression or generalized anxiety
- Excessive polypharmacy, medication adverse events, and gaps in medication refills
- Missed appointments and poorly controlled blood pressure or glucose despite medications
- Limited support system and reports to social and/or adult protective services

When these warning signs present with greater frequency or number, clinicians should undertake a comprehensive assessment to identify specific impairments in the capacity for safe and independent living and identify specific interventions to address these gaps. Clinicians can target gaps in decision-making and/or executive capacity across the five functional domains of safe and independent living. Assessments should include the use of validated screening instruments and tests with population-based norms as well as more personalized clinical assessments including screening for judgment and capacity. Proxy reports and in-home assessments are also useful for gaining a clear understanding of executive capacity across the five domains. Many of these validated assessment instruments are common to the practice of geriatrics. We recommend that clinicians start with standardized assessment instruments as well as individualized clinical evaluations. Proxy reports and home evaluation should follow, especially if initial assessments fail to provide definitive understanding of executive capacity. All capacity evaluations should include individualized assessments of decision-making or judgment as well as strategies to ensure implementation of an agreed upon care plan.

We recommend beginning with *standardized assessment instruments* that have well-validated population norms and cut scores that can evaluate each of the following domains: cognitive function, mood (depression or depression and anxiety), activities of daily living (basic ADLs and instrumental IADLs or a combined tool such as Vulnerable Elders Scale-13), mobility screens (timed up and go or formal gait speed), and nutrition. The classic cognitive function screen is the mini-mental state examination (MMSE). However, other screening tests, like the St. Louis Mental State Examination (SLUMS) or Montreal Cognitive Assessment (MOCA), are now favored due to their greater ability to identify impairments in executive cognitive functions. Still other cognitive screens, such as the Executive interview (EXIT) and clock-drawing tasks, are more specific screening tools of executive cognitive functions and associated with declines in functional status and the capacity to consent to treatment. Another highly specialized screening tool is the Financial Capacity Instrument (FCI) which is used to evaluate decision-making and executive capacity for managing one's financial affairs and estate and conducting financial transactions. Additional standardized scales, often performed by occupational therapists, can evaluate a vulnerable older adult's executive and performance abilities with everyday, independent living skills. We have previously demonstrated the effectiveness of one such tool, the Kohlman Evaluation of Living Skills (KELS), in identifying adults with self-neglecting behaviors sufficient enough to be reported to Adult Protective Services [7].

Standardized assessment should always be followed with *individual assessments* of medical status (i.e., progress note with history and physical) and psychosocial status (commonly done by social work). Traditional medical examinations can identify geriatric syndromes that are common contributors to vulnerability, such as depression, delirium, and dementia, as well as diseases that impact everyday functions: memory, judgment, mobility, cardiopulmonary status, pain, etc. As part of the medical and psychosocial assessments, the clinical team should assess executive function within the context of the five domains of capacity for safe and independent living. The following are some examples of items that may be included:

- Personal needs and hygiene: physical examination of the hair, skin, and nails, gait evaluation, and screening for balance problems and recent falls.
- Condition of the home environment: proxy reports of the home environment or a home safety evaluation performed by an occupational therapist or home health service.
- Activities of daily living: ask patient to use the clinic's phone and call a friend or other service to ask for a ride (done through actual demonstration).
- Health-care self-management: ask patient to bring all medication bottles from home, even empty ones. Review medication fill and refill dates and pill counts or have a home health nurse do a home medication assessment.
- Managing financial affairs: proxy reports of bank statements, uncollected debts, or bills. Can formally assess performance with routine financial tasks, such as 1- or 3-item transactions, including making change or conducting a payment simulation using a check and register.

MED-SAIL Instrument

We have previously developed and validated a screening tool for Making and Executing Decisions for Safe and Independent Living or MED-SAIL [8]. The MED-SAIL tool was designed with the acknowledgment that remaining independent in one's own home is a primary goal for older adults, capacity for safe and independent living is threatened with vulnerability and aging, and health-care and social service providers in the community lack adequate screening tools. The tool draws from the conceptual and empirical literature in clinical ethics. Numerous focus groups enrolling community-based healthcare and social services professionals guided the design of the instrument and contents of the screening tool. Specifically, they helped identify scenarios that are intended to provide a sense of the respondent's executive capacity across each of the five domains for safe and independent living. These seven scenarios are as follows:

1. The door to your home is locked and you do not have a key.
2. You run out of a medication you take regularly.
3. You are home and suddenly there is a fire in your kitchen.

4. You notice that the cut on your foot is not healing and has become infected.
5. Someone calls saying you've won $100,000 and all they need from you is your social security number to verify your identity.
6. You are driving to the grocery store and you get a flat tire.
7. Your heating unit [air conditioner] breaks down and it is very cold [hot] outside.

The tool follows the structure of the decision-making capacity standards as developed by Appelbaum and Grisso and described in Table 2.1. These decision-making capacity standards are then applied conceptually to the specific real-world scenarios described above. When using the MED-SAIL tool, the clinician typically works through two to three of the real-world scenarios. Each scenario has prompts (see Table 2.1) that relate to the standards for decision-making capacity. Each of the standards are then scored and a total score is calculated. Population norms and precise cutoffs across a wide range of patient types have not been developed as of this writing. However, the tool is still of practical clinical use because clinicians can use MED-SAIL results in conjunction with the other parts (i.e., the standardized and individualized assessments) of their evaluation of the vulnerable older adult's capacity for safe and independent living. The clinical team may need to make additional referrals (e.g., occupational and physical therapists) when particular healthcare professionals are not part of the immediate team. Referrals for home-based assessments are particularly common and provide an important opportunity to evaluate the physical state of the older adult's home environment.

Table 2.1 Eliciting standards of decision-making capacity

Standards for decision-making capacity	Descriptions of each standard	Questions or prompts to eliciting each standard
Understanding	Repeat the simple scenario phrase in his/her own words	Please tell me in your own words what I just said
Appreciation	Assesses respondent's ability to appreciate impact of scenario on his/her own life	Would this be a problem for you? Why or why not?
Expressing a choice	Assesses respondent's ability to express choices/plans	What would you do in this scenario?
Problem-solving/consequential reasoning	Assesses whether respondent can perform abstract problem-solving in a new hypothetical situation	What would you do if [response to previous question] didn't work?
Comparative reasoning	Assesses respondent's ability to compare two options	Explain what is good or bad about these options
Generate consequences	Assesses respondent's ability to generate ideas on how to prevent the scenario from occurring or preparing in case it does	What could you do to prevent this from happening?

Interventions to Support Capacity for Safe and Independent Living

We recommend that clinicians create a final summary of all assessments to identify precise impairments across each of the five functional domains for safe and independent living and whether these deficits are in decision-making capacity, executive capacity, or both. By identifying precise functional impairments, the clinical team can then identify specific medical, healthcare, and social services interventions that can be prescribed/recommended to address these impairments. Interventions will either support the deficits of the vulnerable adult (e.g., treating symptoms of depression, providing a transfer bench for the bathroom) or reduce the effort needed to accomplish a task (e.g., engaging a home health nurse to assist with medication management, designating a proxy for financial affairs). This method of intervention is more aligned with traditional healthcare services and targets supporting of autonomy to live independently before restraining the vulnerable older adult's autonomy in the name of safety. However, the range of interventions can be quite varied from medical to social to legal. We categorize them broadly as:

1. Medical—medication management, disease management, psychiatric treatment referral, etc.
2. Environment—alternative living arrangement, home health, home safety evaluation, mobility aids, etc.
3. Social support—adult daycare, patient and family education, caregiver support, etc.
4. Community resources—link to community services, link to health insurance benefits, etc.
5. Legal services—advance directives, APS, power of attorney, representative payee, etc.

Appointment of a guardian or other legal surrogate decision-maker is a potential option to avoid subsequent placement in long-term care. Follow-up evaluations can then be used to determine the effectiveness of the prescribed interventions and the older adult's responsiveness to those interventions. The following table provides a set of treatment suggestions that link different intervention types that might be necessary based on the level of capacity impairment present (Table 2.2).

Conclusion

The local geriatrics clinic conducted a comprehensive geriatric assessment of Mr. Davis. The clinic confirmed many of the findings of his prior medical evaluations, all pointing to a state of vulnerability. The assessment found evidence for mild cognitive impairment not outside the range of normal for his age. Mr. Davis does not have major depression but does report some apathy and occasional feelings of sadness related to his current medical conditions. He requires assistance for most activities of daily living and has increasing difficulty with personal care and hygiene. The clinic placed a referral to a physical medicine physician for evaluation and possible joint injections to reduce pain and improve shoulder

Table 2.2 Suggested intervention for impaired capacity for safe and independent living

Intervention	Full capacity	Partial capacity	No or limited capacity
Medical	Disease management	Medication management Disease management Medication therapy	Psychiatric referral Assisted medication management
Environment	Home modifications Senior apartments Independent living Mobility aids	Independent living Assisted living Home health Mobility aids	Assisted living Nursing home 24-h personal care Mobility aids
Social support	Senior center Volunteering	Adult day care Senior center Caregiver support group	Adult day care Activities for stimulation Respite
Community resources	Housekeeping	Meals on wheels Geriatric care manager	Meals on wheels Geriatric care manager
Legal services	Power of attorney Living will	Representative payee Power of attorney Legal/financial oversight	Representative payee Power of attorney Guardianship Out-of-hospital DNR

Suggestions provided by Tziona Regev, MSW for the Capacity Assessment and Intervention clinic at Quentin Meese Community Hospital, Harris Health System, Houston, Texas

functioning with the goal of improving bathing and dressing. His home environment is stable but requires his daughter and son-in-law's involvement to remain at this level. He was found to have difficulties with executive capacity, especially with managing his medications and finances. While Mr. Davis was resistant to this finding at first, his difficulties during the evaluation itself seems to have been a tipping point. He was now willing to allow his family to prepare a pill tray for his medications, and his son-in-law became his formal power of attorney for financial decisions (Mr. Davis had a soft spot for a fellow accountant). The family also determined that adult day services once or twice a week might be of interest to Mr. Davis. An occupational therapy consult was also ordered to do a home safety evaluation and determine if any assistive devices were needed in the bathroom to further improve function and safety. Mr. Davis and his daughter agreed to return in 3 months to reassess his status and the success of these interventions. This capacity assessment and intervention plan will not reverse Mr. Davis' vulnerability, but may allow him to remain at home living as independently as possible for the immediate future.

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Surrogate Decision-Making and Advance Care Planning

3

Ursula K. Braun

Case Presentation

Mr. T is a 78-year-old veteran with metastatic bladder cancer to the bones and liver who has been hospitalized for >1 month with various complications from his nephrostomy tubes and infections. His wife of 10 years is at bedside continuously during the day and gets updated by the physicians regularly. The patient agrees to a DNR/DNI order during a palliative care consultation. He is fairly stable at the moment but bedbound and dependent in all ADLs needing total care. No family is able or willing to care for him at home, and he is transferred to a palliative care unit for comfort care; his wife is very appreciative of the care there given to him and the emotional support to her. After a week, two of his daughters visit. The patient has five adult children, three who live in the larger metropolitan area and two who live far away. The patient now completes an advance directive in which he names two of his daughters as MPOA. He does not complete a living will.

The next day, the patient's daughter (now MPOA) expresses anger that the patient is receiving hospice care and demands that he be transferred to the renowned cancer center in town "to be enrolled in clinical trials." Despite attempts to attend to her feelings and to explain the patient's medical condition, she asks the team to facilitate a "transfer," but the patient is not accepted at the cancer center because he is not a candidate for any clinical trials due to poor performance status. She is not happy with the care he is receiving in

U.K. Braun, MD, MPH
Center for Innovations in Quality, Effectiveness and Safety (IQuESt), Michael E.DeBakey VA Medical Center, Houston, TX, USA

Division of Geriatrics, Department of Medicine, Baylor College of Medicine,
Houston, TX, USA

Center for Medical Ethics and Health Policy, Baylor College of Medicine, Houston, TX, USA
e-mail: ursula.braun@va.gov; ubraun@bcm.edu

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the hospice unit but also not agreeable to transfer him to a nursing home closer to her or to take him home despite having asked for family leave papers. Neither she nor the alternate MPOA visits again, comes back for any meetings the team tries to arrange, or consistently returns phone calls in a timely fashion. The patient becomes weaker and intermittently confused. When he becomes unstable, the MPOA revokes his DNR order via telephone and requests his transfer back to acute care. Once in acute care and again temporarily stabilized, the patient again expresses on multiple occasions to different team members his desire to again be DNR/DNI. He does not wish to change his MPOAs. Since he has expressed the wish to be DNR/DNI in a consistent fashion, the team declines to change his orders when upon his renewed deterioration, the MPOA again demands that he be full code. The patient expires soon after.

Introduction

Surrogate decision-making is decision-making for others. A majority of patients will require decision-making at the end of life, and 70 % of such patients will lack decision-making capacity thereby requiring them to rely on others [1]. Advance care planning can ensure that patients receive the care they would want in the event that they become incapacitated. Advance care planning can be done in a number of ways: (1) informally, by discussing potential future care options with clinicians and persons most likely to be called upon as surrogate decision-makers, (2) formally, by completing certain documents and forms, and (3) ideally, through both informal discussions and completion of formal documents. A first step in formal advance care planning is naming a surrogate decision-maker, i.e., a *healthcare proxy* or *medical power of attorney* (MPOA), to whom authority for decision-making is transferred when certain conditions are met. If the patient does not name a proxy, each state has a legal hierarchy of accepted surrogate decision-makers that needs to be followed (see Table 3.1).

A second step in formal advance care planning can entail completing a *living will*, a document that stipulates which life-sustaining treatments would be acceptable or unacceptable in certain conditions. This document can be detailed or general, and surrogates can be instructed to either follow it strictly or they can have leeway in how to interpret instructions. However, formal advance care planning has been fraught with problems and criticized as not being effective for a variety of reasons: (1) not enough patients, particularly minorities, complete advanced care documents; (2) patients may not communicate their preferences clearly in the documents; and (3) perhaps most importantly, patients do not discuss with their proposed surrogate decision-makers sufficiently what underlies their choices leaving surrogates uncertain regarding their wishes. Despite many criticisms, living wills allow patients to decline certain interventions they do not wish and thus limit overly

Table 3.1 Legal hierarchy of surrogate decision-makers (in most states)

Legal hierarchy of surrogate decision-makers (in order of priority):
1. The appointed guardian of the patient, if any
2. The appointed durable power of attorney for health care, if any
3. The patient's spouse or state-registered domestic partner
4. Of-age children of the patient
5. Parents of the patient
6. Adult siblings of the patient (majority)

aggressive, unwanted care. Studies have shown that treatment preferences were followed for the vast majority of patients who have advance directives.

Advance Care Planning as a Process to Promote Patient Autonomy

The primary goal of advance care planning is to promote and respect the autonomy of a patient when choices regarding life-sustaining treatments are required [2]. It is a generally accepted standard that end-of-life (EOL) decision-making should be based upon patients' values, beliefs, and preferences [3]. A fundamental aspect of patient autonomy, which often has been overlooked, is respecting patients' preferred decision-making styles [4]. The literature on cultural competency shows that patients' preferred EOL decision-making styles can vary [5–8]. Race and ethnicity can affect patients' decision-making style, as well as their beliefs and preferences, thus influencing EOL decision-making [9–13].

Advance care planning has been recognized as a complex *process* and not a one-time conversation or simple completion of a form. Eliciting and understanding a patient's self-described decision-making style is crucial for clinicians who wish to assist patients in the difficult task of EOL decision-making. Figure 3.1 depicts a proposed typology of how patients approach decisions about EOL care and offers strategies to clinicians on how best to facilitate advance care planning with their patients [14]. It should be pointed out that the "avoiders" are the most heterogenous patient group with motives that could vary from "I don't know/don't care" to "I really don't want to think/talk about this" to "Why should I think about this when it is only in God's hands anyway."

Shared decision-making is a collaborative process that allows patients, surrogates, and clinicians to make healthcare decisions together by taking into account the best scientific evidence available as well as patients' values and preferences [15]. In this process, clinicians need to communicate complex medical information in lay language. This does not mean that physicians are purely sources of information only – fear of being perceived as paternalistic should not dissuade them from making a recommendation if appropriate. However, recommendations should be given upon invitation and in a sensitive way [16]. To improve these types of interactions, providers should seek out opportunities to learn or improve the communication skills needed to conduct difficult EOL care conversations [17].

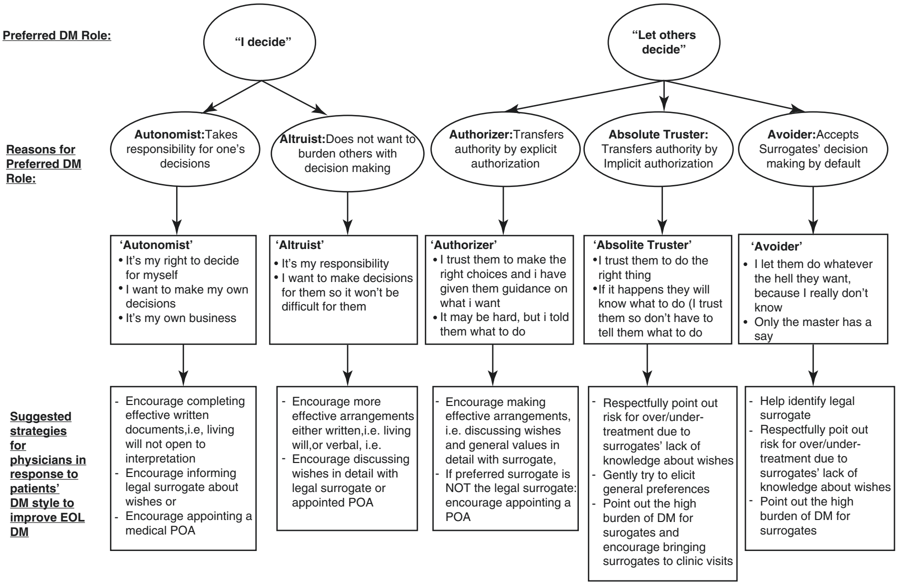

Fig. 3.1 A typology of how patients approach decisions about end-of-life (EOL) care. *DM* decision-making, *EOL* end of life, *POA* power of attorney

Many efforts have been made to improve advance care planning. For example, the PREPARE study aims to better prepare patients and their surrogates in communicating goals and to make better informed medical decisions through use of a website with embedded, culturally inclusive video scenarios [18]. It gives patients in varying stages of behavioral change (knowledge, contemplation, self-efficacy, readiness) a resource regarding how to identify a proxy and how to elicit goals and values for care and discusses options for patients to consider such as giving leeway/flexibility for surrogate decisions or not. While formal completion of a living will is an outcome measure in this trial, the process of multiple communication events between patient and surrogate(s), patient and clinician, and surrogate(s) and clinician is the more important focus of the PREPARE intervention.

Factors Influencing Surrogates' Decision-Making

If a patient is decisionally impaired, surrogates will have to make decisions for others. The classic way to invite *substituted judgment* is to ask: "What do you think the patient would choose if he/she could make this decision?" This question is not always an easy one to answer, even if a detailed living will is available. Additionally, studies have shown that even when surrogates think they know what a patient would have wanted, patients would actually have chosen differently [19–25].

When surrogates feel unable to make substituted judgments because they have not previously had conversations with the patient about his/her wishes, the *best* *interest standard* should be used to guide decisions. The underlying ethical value for this approach is the patient's welfare and beneficence. Acceptable clinical outcomes can be defined from the patient's perspective (based on the ethical principle of respect for autonomy) or a clinical perspective (based on the ethical principle of beneficence). An autonomy-based acceptable outcome assumes an expected functional status resulting in a quality of life the patient is willing to accept [26]. A beneficence-based acceptable outcome usually entails that the patient retains at least some interactive capacity without overwhelming disease-related or iatrogenic morbidity, disability, pain, or suffering [27]. Some have suggested using a "best judgment standard," combining both imputed substituted judgment and best interest, based on love for the patient [28].

Surrogates do not operate in a vacuum but struggle with cognitive, emotional, spiritual, and moral issues. They have different levels of health literacy, and often just understanding the complexity of medical details in a patient's care is extremely challenging. Frequent, clear communication from clinicians in lay language is important but difficult when multiple consultants focusing on specific organ systems, as opposed to considering the situation holistically, are involved in the patient's care. Surrogates do not wish to be held responsible for a loved one's death by other family members and need to balance preventing undue suffering with the desire to pursue any chance of recovery in addition to the need to preserve family well-being [29]. When surrogates have been informed of a poor prognosis, they do not always accept the information and can be overoptimistic. This does not necessarily stem from poor comprehension of medical facts but may be due to different beliefs, e.g., that the patient may have unique strengths, religious beliefs that the patient will recover, or the need to maintain hope to benefit the patient [30, 31].

Coping strategies that surrogates may use to assist in decision-making include recalling conversations with loved ones; sharing decision-making with other family members; cultural, spiritual, and religious practices; storytelling; and delaying or deferring decision-making which leads to life-sustaining treatment by default. Clinicians need to pay close attention to surrogates' emotional and spiritual needs and may need to facilitate when there is conflict in the family about medical decision-making. This requires excellent communication skills that are not traditionally taught during medical training. However, studies have shown that they can be taught to clinicians successfully and providers should seek out these opportunities within their institutions and medical organizations [17, 32].

Burden of Decision-Making for Others

Patients who have not made or communicated their decisions clearly are not always aware of the burden placed on surrogate decision-makers, even though this psychosocial and moral burden can be substantial and reach measurable levels of depression and posttraumatic stress [33–35]. When surrogates are uncertain about a patient's wishes, they can feel overwhelmed leading them to ask for "everything" to be done resulting in life-sustaining treatment by default even when such care might be futile [36]. If surrogates believe they are simply reporting a patient's decisions, because they are confident that the patient already made all important decisions regarding their medical wishes, they feel much less burdened in their role [37]. Similarly, the presence of an advance directive or a DNR order has been associated with decreased odds of significantly learned helplessness, defined as decreased motivation, difficulty in determining causality, and depression [38].

Advance care planning can reduce the burden of surrogate decision-making, and clinicians have a duty to point out to patients that they can lessen the burden on their proxies and empower them by facilitating conversations about EOL care [39]. Once general values and goals have been identified, discussions can move on to particular life-sustaining interventions and how pursuing or not pursuing these will fit in with the patient's goals. Clinicians should try to support the surrogates' role and their interpretation of patients' values as well as attempt to decrease their level of stress during the decision-making process [36].

Ethical conflicts about surrogates' interpretations of patients' wishes can occur [40]. Strategies to manage such conflicts can include suggesting a *time-limited trial*, i.e., an agreement to use certain medical treatments for a defined period of time to see if the patient improves or reaches a critical predefined clinical milestone [41]. This can also prepare the surrogate for a discussion of a possible shift to comfort care. Discussing *do-not-escalate treatment* orders is another strategy that can reduce distress and burden when withdrawing life-sustaining treatments is not acceptable to the surrogate [42]. Occasionally, involvement of an ethics consult will be required.

Racial/Ethnic Disparities in EOL Decision-Making

A multitude of studies have described racial/ethnic disparities in EOL care and EOL decision-making [43]. Clinicians should be aware of their nonverbal communication and try to consciously increase the amount of positive rapport-building nonverbal cues with African-American patients [44]. An advance care planning intervention in hemodialysis patients, SPIRIT (Sharing Patients' Illness Representations to Increase Trust),was shown to be particularly effective in African-Americans and helped surrogates to strengthen relationships with the patient, helped them to feel prepared, and gave them a sense of peace during and after EOL decision-making [45].

Surrogate Decision-Making for "Unbefriended" Patients

Unfortunately, there are patients, often among the elderly, who for various reasons do not have a default surrogate decision-maker to fall back on. In the absence of any family or friends, they have been called "adult orphans" or "unbefriended elders." In one study, 16 % of ICU patients and 3 % of nursing home residents had no available surrogate decision-maker [46]. Several strategies have been suggested to provide surrogate decision-making for these individuals including expanding the default surrogate list to include ethics committees, treating physicians, or professionally trained and certified health fiduciaries [47–51]. It is clear that seeking guardianship is unlikely to solve the problem when immediate treatment decisions have to be made. Additionally, guardians have no preexisting relationship to the patient, are financially compensated for their role, and often reluctant to limit life-sustaining treatment [48]. A patient preference predictor may be a possible tool to supplement the shared decision-making process – it predicts which treatment a patient would want based on which treatments similar patients would want in similar circumstances. Based on a survey of over 1100 patients, a clear majority (79 %) would like integrating the patient preference predictor into their care; thus, some have suggested its use for "unbefriended" patients [51]. The best approach for EOL decision-making in patients at risk for being "unbefriended" is prevention; clinicians should make special efforts in promoting advance care planning with such patients. A study of 262 homeless patients, a group at high risk for becoming "unbefriended," has shown that such efforts can be effective: 38 % of them completed advance directives in the intervention group (versus 13 % in the self-guided group) [52].

Physician Orders for Life-Sustaining Treatment (POLST)

Physician Orders for Life-Sustaining Treatment (POLST), also known as Medical Orders for Life-Sustaining Treatment (MOLST), started in Oregon in 1991 as "POLST Paradigm Initiative," a task force of healthcare professionals and ethicists from the Center for Ethics in Health Care at Oregon Health & Science University (OHSU). The "paradigm" is supposed to involve a process of EOL care planning that culminates in the completion of a POLST form, a standardized, highly visible, vividly colored, portable, single-page medical order set. The POLST form is an order set that synthesizes discussions between a patient and/or his/her surrogate decision-maker and a clinician (a physician or, in many states, also a physician assistant or a nurse practitioner). This order set is legally valid across the different possible care settings a patient may encounter within a single state. It can be used by a variety of providers in multiple settings including paramedics, fire departments, police, hospitals, and nursing homes to provide the care a patient desires. POLST advocates suggest using the "surprise question" – "Would I be surprised if this person died in the next year?" If the answer is "No," discussing a POLST form is advised. While POLST forms were developed for terminally ill or chronically debilitated frail elderly patients, in many states their use is not restricted to these groups. In 2004, OHSU's Center for Ethics in Health Care convened a task force of representatives from participating states to spread the POLST paradigm nationally. This National POLST Paradigm Task Force (NPPTF) created standards for endorsement of individual states' POLST programs; currently 19 states have NPPTF-endorsed state POLST Programs [53]. Three of these states are designated as having "mature" programs (Oregon, West Virginia, California) because POLST is used by 50 % or more of hospitals, nursing homes, and hospices in each region of the state. Figure 3.2 shows the status of POLST Paradigm Programs throughout the USA [53].

POLST differ from out-of-hospital DNR orders, which only apply when the patient is in cardiopulmonary arrest, as it can include orders not just about CPR but regarding hospitalization and feeding tube placement. POLST forms *can* be used by patients for

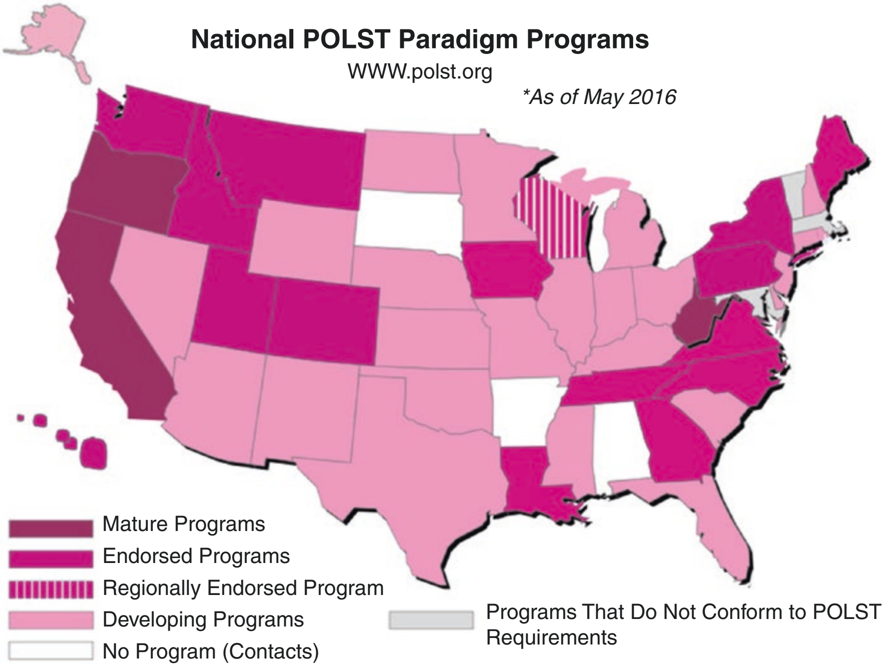

Fig. 3.2 National POLST paradigm programs

advance care planning; however, they are substantially different from advance directives: (1) Whereas advance directives can *only* be completed by patients who possess decision-making capacity, POLST forms can be completed with surrogates alone; (2) POLST forms are *legally binding orders*, and advance directives – unless they are very specific and indicate that instructions should be followed "strictly" – are expressions of preferences for desired and undesired treatments in the future that often need interpretation by surrogates together with the clinical team before they get "translated" into medical orders, e.g., "full code" or "DNR" orders; and (3) POLST forms are orders that follow patients into all care settings as opposed to DNR orders that are valid only for a limited amount of time during an acute hospitalization. The fact that POLST are binding orders and transferable into other care settings is both their appeal and a target for criticism, especially since the informed consent process leading to POLST completion can be unclear. Additionally, not all states require signatures by the patient or the designated surrogate.

Several studies have shown that POLST forms are generally leading to treatments that match the orders on the form, though less research has explored if POLST orders are truly congruent with patients' wishes [54–57]. The TRIAD (The Realistic Interpretation of Advance Directives) studies showed misunderstandings among prehospital providers' interpretation of POLST, raising patient safety concerns regarding around avoiding under- and overtreatment [58]. The Centers for Medicaid and Medicare Services' recent decision to compensate physician efforts to have end-of-life care discussions with their patients will likely spur future research into the content of such discussions and the quality of the informed consent process leading up to completion of advance directives, POLST, and other advance care planning tools [59].

Conclusion

At the end of life, many patients require important decisions to be made regarding their health care but, for a variety of reasons, lack the ability to make these choices. In these situations, designation of a surrogate decision-maker and presence of advanced directive documents (i.e., living will, POLST, MOLST) can help to guide care and support the principle of autonomy. Surrogate decision-making, the act of making medical decision on behalf of an individual who is unable to do so, is a difficult task requiring application of the substituted judgment principle or the best interest standard. Providers should encourage patients to discuss their wishes with the surrogate so that the decision-maker can feel confident that they are respecting the patient's wishes if they need to make important medical decisions. Living wills, POLST, and MOLST documents allow patients to specify what treatments would be acceptable to them in certain situations. POLST and MOLST are unique in that they serve as physician orders and are transferable between settings of care within a specific state.

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End-of-Life Care of Older Adults

4

Lara M. Skarf and Andrea Wershof Schwartz

Case Presentation: Part 1

Mr. K is an 82-year-old man with a history of hypertension, diet-controlled diabetes, low back pain, hyperlipidemia, and right carotid endarterectomy who was found to have an enlarging lung mass during an evaluation for syncope. He was diagnosed with stage IIIA squamous cell lung cancer and subsequently underwent chemotherapy and radiation under the guidance of his oncologist.

Mr. K is divorced and has a daughter who lives locally as well as two sons who live out of state. He previously worked as a house painter and doing odd jobs. He lives alone and is independent in his activities of daily living. He has housekeeping arranged through his local elder services. He attends religious services weekly. He does not drive but has a friend from his religious community who assists with transportation and shopping. His daughter is his health-care proxy.

Recently, he developed increasing symptoms of dyspnea with exertion, cough, and fatigue which have been attributed to his progressive malignancy. As his primary care physician, you wonder: Would it be useful to refer him to palliative care? What about hospice? What is the difference between the two?

L.M. Skarf, MD (✉)
Harvard Medical School and Section of Geriatrics and Palliative Care, Medical Service, VA
Boston Healthcare System, Boston, MA, USA
e-mail: lara.skarf@va.gov

A.W. Schwartz, MD MPH,
Harvard Medical School and Section of Geriatrics and Palliative Care and GRECC, VA
Boston Healthcare System, Boston, MA, USA

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Introduction

Older adults in the last decades of life often face serious or life-threatening illness. During this time, they may require not only routine medical care but also support from their physician and other members of the medical team around symptom management and end-of-life decisions. In this chapter, we will review the similarities and differences between hospice and palliative care, including when to consider referring a patient to one of these specialized teams. While hospice offers care to patients in the last 6 months of life, palliative care offers interdisciplinary support for patients at any stage of serious illness. We will also introduce tools for prognostication that can assist the clinician in offering guidance and clinical care appropriate to a patient's life expectancy and goals.

At the end of life, palliative care can provide symptom relief from distressing symptoms or suffering. In dealing with a patient's impending death, clinicians may be faced with the ethical dilemmas of when to withhold or withdraw life-prolonging medications or treatments. This chapter reviews examples of these dilemmas, including controversies regarding requests for hastening death and the ethical aspects of recent legislation around physician aid-in-dying (PAD), recommended approaches for addressing patient symptoms, and ethical aspects of assisting patients in defining their goals of care at the end of life.

What Is Palliative Care?

Palliative care provides specialized medical care for people with serious illness. It focuses on providing patients with relief from physical, emotional, and spiritual symptoms associated with a serious illness, whatever the diagnosis may be. Palliative care aims to improve quality of life for both the patient and family. Palliative care providers also focus on assisting the patient and caregiver in understanding illness, identifying personal goals and priorities, and using these goals and values to help direct and inform medical decisions. Palliative care is provided by a team of doctors, nurses and nurse practitioners, social workers, chaplains, and other specialists who work with the patient's primary medical team to provide an additional layer of support. Palliative care complements care provided by other medical providers and can be offered to patients independent of prognosis or treatment goals, including patients seeking life-prolonging or curative therapies. It is appropriate at any age and any stage of a serious illness. Early palliative care involvement for cancer patients has been shown to improve quality of life and mood and, in certain cancer patients, even increase survival compared with standard oncology care [1].

For older adults, palliative care may be provided by primary care providers or may involve referral to experts in palliative medicine or geriatrics who can lead or guide complex discussions about goals of care and advanced symptom management. Palliative care can be delivered in the outpatient or inpatient setting as well as in the home or long-term care facilities. Palliative care should be considered in the following situations for older adults:

- Presence of physical, emotional, or spiritual symptom distress
- Increasing frailty and functional dependency
- Symptomatic heart failure, COPD, cancer, dementia, or other serious illness
- Medical plan does not seem to match patient's personal goals

Case Presentation Continued

Mr. K returns a few weeks later with increasing symptom burden due to his progressive malignancy; it is appropriate at this point to involve both oncology and palliative care in the treatment plan. Further disease-modifying therapies such as chemotherapy or radiation should be discussed, as well as symptom-oriented treatments which will address his dyspnea, fatigue, and cough.

After meeting with his oncologist, Mr. K elects not to have further chemotherapy. In his discussions with her, he feels that the benefits of prolonging his life do not outweigh the burden of treatment. He meets with the interdisciplinary palliative care team, and, over time, they address his physical symptoms as well as support and safety at home, functional status, fears and goals for the future, and priorities. When should hospice care be considered for Mr. K?

What Is Hospice Care?

Unlike palliative care, which is appropriate at any point in serious illness, hospice is primarily aimed at end-of-life care. Hospice can be a confusing term as it can be used to refer to a philosophy of care, a care team, a location of care, and a Medicare insurance benefit. The Medicare hospice benefit, which was made permanent in 1986, provides the basis for most insurance agency definitions of hospice care. This benefit, which allows patients with Medicare A the ability to choose the hospice benefit as an alternative to acute care hospitalization, is available to patients who have an estimated life expectancy of 6 months or less as documented by two physicians. At the time it was established, the goal was to allow patients and families access to support at home to enable a comfortable death outside of the hospital. In order to qualify as a hospice agency, Medicare stipulates that hospices must have the following components:

- Medical director
- Nurse
- Social worker
- Chaplain
- Home health aide
- Volunteer program
- Bereavement program
- Access to a nurse by phone 24/7

- Nursing home visits ranging from daily to every 2 weeks depending on need
- Medications for comfort and those related to the hospice diagnosis
- Durable medical equipment including hospital bed, wheelchair, suction, oxygen, and commode

Each hospice agency is independently licensed and can provide different levels of service within these guidelines. While the majority of hospice care is provided in the home, hospice can be provided wherever the patient lives including assisted living and long-term care facilities. Some acute care hospitals have contracts to provide short-stay inpatient hospice care in the hospital for acute symptom management. Additionally, many states have freestanding hospice facilities, which may be short or long stay, and may utilize insurance or private pay for room and board.

Although the hospice philosophy tends to prioritize comfort and quality of life over medical procedures and prolongation of life, there has been a shift toward including "open-access hospice." This approach allows for invasive treatments such as IV medications, artificial nutrition and hydration, palliative radiation and chemotherapy, and short-term ventilator support and other modalities that may provide relief of symptoms associated with a life-limiting disease. Although these treatments may prolong life, they are used primarily to palliate symptoms and, when provided by hospice, are always used in the setting of a terminal illness.

Hospice care most often involves a visiting nurse. The differences between hospice benefits versus visiting nurse services are described in Table 4.1.

Table 4.1 Key Differences Between Visiting Nurse Services and Home Hospice

Visiting nurse	Hospice
Homebound status	Encouraged to "go out"
Focus on rehab or skilled need	Does not require a skilled need
No medication coverage	Medications covered
Standard qualifications for oxygen	No O_2 level to meet oxygen requirement
Co-pays for home DME[a]	DME covered and delivered
Episodic payment	Per diem payment

[a] *DME* durable medical equipment

Case Presentation Continued

You mention the option of hospice care to Mr. K to assist with symptom management and support. He says he's "not ready." You ask him to elaborate. Mr. K tells you that his cousin's wife died with home hospice. "Once the hospice nurse went in, he died in about a month. That will be ok when I'm ready, but I'm not ready yet." You know that Mr. K qualifies for home hospice care based on a prognosis of less than 6 months and that there is no requirement for a *high symptom burden, debility, homebound status, or imminent death. In fact, he can remain active, continue to see his primary care clinician in clinic, and continue to receive most medications while on hospice. You reassure him that hospice assists in living well in the time left and is not only useful at the very end of life. Additionally, you are able to share with him the following benefits of hospice care.*

Hospice has been shown to improve quality of life for both patients and their caregivers in the following ways [2–6]:

- Improved pain assessment and management
- Improved bereavement outcomes
- Overall improved patient and family satisfaction
- Less physical and emotional distress
- Improved quality of life
- Lower risk of post-traumatic stress disorder and prolonged grief disorder among caregivers
- Better caregiver self-reported health
- Lower mortality rates
- Lower cost

Prognosticating for Older Adults

The science and art of prognosticating for older adults continues to grow. Numerous prognosticating tools take into consideration a variety of factors including a patient's underlying disease and comorbidities, functional status, and site of care (inpatient vs community or nursing home) [7]. Specific prognostication tools, such as the Palliative Performance Scale, can be used to help make determinations about hospice eligibility. For older adults, prognostication can be particularly challenging since they may have multiple comorbidities or functional limitations that could affect their prognosis.

An online resource to help clinicians make prognostication determinations and navigate the literature around prognosis is available at *eprognosis.org* [8]. This website provides prognostication calculators and tools, as well as instructional guidance around discussing prognosis with patients. In addition to the use of more sophisticated prognostic tools, a "no" answer to the relatively simple "surprise" question of "Would I be surprised if my patient died in the next year?" has been shown to identify patients with limited prognosis who may benefit from palliative care involvement or may qualify for hospice care [9].

Clinical Pearls: Palliative Care Versus Hospice

Palliative care focuses on providing patients with relief from physical, emotional, and spiritual symptoms associated with a serious illness, regardless of the specific diagnosis. It can be provided at any point in the disease. It is usually provided by specialists and can occur in the hospital, clinic, or at home.
Hospice is care provided by a team during the last 6 months of life which emphasizes symptom management, support for caregivers, quality of life, and bereavement. In the United States, it is most often provided in the home with a team of visiting clinicians. However, it can also be provided in a hospice house, hospital, or wherever the patient lives (i.e., nursing home, assisted living facility, etc.).
Hospice can be provided to patients who are not homebound and focus on improving quality of life, not on hastening death. Two physicians must certify that the patient most likely has a prognosis of 6 months or less.
The "surprise" question, "Would I be surprised if my patient died in the next year?" has been validated as a tool to identify patients who may benefit from palliative care or qualify for hospice.
Patients and families who receive hospice care report improved quality of life and fewer bereavement symptoms than those who do not receive this service.

Case Presentation: Part 2

Mr. K returns to see you in clinic 6 weeks later. He is receiving low-dose morphine for dyspnea and cough. He finds now that he is having trouble walking from the door to the mailbox at the end of the driveway due to progressive fatigue. He is spending more time in the house and spends most of the day in the chair watching TV or reading. He often drifts off to sleep. He is eating less. Hospice nurses are coming to the home to assist with his care.

You decide to perform a home visit. During this visit, Mr. K shares with you that he feels ready to die. He states that he is not depressed, but that he feels that he is just waiting for death, and he cannot do things he used to enjoy like walk to religious services or concentrate on a book. He knows that his functional status will not improve as the natural course of the disease is for him to become more dependent. He asks you if you can "end it with a pill." How should you respond?

Requests for Hastened Death

Requests for hastened death are not uncommon in the palliative care and hospice population [10, 11]. An approach to a request for hastened death has been described in the palliative care literature [12, 13]. First, the clinician must respond in a non-judgmental manner and with respectful curiosity and compassion. The goal is to ask open-ended questions so as to determine the source of the patient's request and, at the same time, to validate and acknowledge the patient's statement. Possible responses could include, "It sounds like this might be important to you. Can we talk more about what you are thinking?" The clinician should confirm a shared understanding. For example, when a patient says he wants to "end it," he could be referring to his life, his treatment, or this clinical encounter. You might say, "What exactly do you mean when you say, 'Can you end it with a pill?'" Once it is confirmed that the patient is talking about hastening death, you must then determine whether the patient is asking you to act on a plan for physician aid-in-dying (PAD), whether he wants to open a dialogue about suffering, or if the desire is to plan more theoretically for the future. It is equally important to discuss the motivation behind this request. Frequent reasons for asking for hastened death include [14–16]:

- Uncontrolled pain or other symptoms
- Concern of being a burden
- Loss of sense of self
- Loss of control
- Fear of the future

Many requests for hastened death are made by patients seeking ways to control the dying process. In these situations, the request for hastening death may reflect a fear of the future and/or a source of unaddressed suffering. It is crucial to partner with the patient to determine whether a trial of treatment may improve quality of life and alleviate suffering. However, in some instances, the patient may continue to request hastened death despite adequate symptom management and spiritual and psychological support. In this situation, the clinician must balance patient autonomy with non-maleficence, the principle of avoiding harm. The ideal approach uses open-ended questions to understand sources of potential suffering. The clinician should express his commitment to the patient and to assisting with alleviating suffering, even if PAD cannot be provided.

Case Presentation Continued

You ask Mr. K what he means by "end it all with a pill." He tells you that he is always short of breath, even at rest. He has no pain. He is worried about burdening his daughter. She is caring for him full time, and he wants to die so that she can get back to her work and family. He feels badly that he continues to live and yet cannot contribute in a meaningful way to the society or his daughter. He used to at least help with the grandchildren but cannot even do that anymore. You ask if it would be acceptable to try a higher dose of opioids for dyspnea, arrange for a meeting with his daughter to discuss these issues, and have the social worker visit to help identify additional resources for support. You confirm with him that he can bring up his feelings about death at any time and that you are willing to continue this discussion. You also offer to have the chaplain visit him to explore the spiritual issues further. You confirm with him *that he was not expecting you to provide a prescription for medication to end his life. Rather, he wanted to be able to express how he feels badly being a burden and feels that his life is not meaningful at this point. He agrees to continue the discussion.*

How would you approach the situation differently if Mr. K had instead said that he was hoping you would give him a prescription to end his life?

Physician-Assisted Dying

Several terms are used to refer to a physician's role in assisting a patient in ending their own life. The most commonly used term is physician-assisted suicide (PAS). PAS is defined by the American Medical Association as occurring "when a physician [or other health-care provider] knowingly facilitates a patient's death by providing the necessary means and/or information to enable the patient to perform the life-ending act (e.g., the physician provides sleeping pills and information about the lethal dose, while aware that the patient may commit suicide)" [17]. Physician-assisted dying is not synonymous with euthanasia. Euthanasia occurs when a third party administers medication or acts directly to end the patient's life. Euthanasia is illegal in every state in the United States.

The term "physician aid-in-dying" is used to describe the practice authorized under the Washington, Oregon, California, and Vermont "Death with Dignity" Acts and is meant to reflect the requirement that patients receiving PAD must have a life expectancy of 6 months or less. The American Academy of Hospice and Palliative Medicine (AAHPM) prefers the term physician-assisted dying (PAD), as it is a more accurate description and is less emotionally charged than physician-assisted suicide. PAD is defined by the AAHPM as a physician providing, at the patient's request, a prescription for a lethal medication that the patient can self-administer by ingestion, with the explicit intention of ending life [18]. Although historically PAD has not been included in the domain of standard medical practice, it is now legally sanctioned in four states. PAD was first legalized in Oregon in 1997 and subsequently in Washington, Vermont, and California. Currently, approximately one-sixth of the US population resides in a state where PAD is legally permitted.

Both the American Academy of Hospice and Palliative Medicine (AAHPM) and the American Geriatric Society (AGS) have published statements on physician-assisted dying [19]. The most recent guideline from AGS, published in 1995, strongly favors aggressive palliation including withholding or withdrawing medical interventions and treating symptoms even if there is an unintended effect of hastening death. The guideline advises that clinicians thoroughly explore the source of the patient's suffering and address all possible avenues to alleviate suffering including the option of palliative sedation (discussed below) and the option to forgo artificial nutrition and hydration. Finally, AGS position statement emphasizes the importance of protection against coercion. At the time of this writing, the AGS statement on PAD is currently undergoing review. The AAHPM statement strongly recommends that medical practitioners approach the request systematically to address all possible causes of fear and suffering and to ensure that quality palliative care is provided. The guidelines state, “The most essential response to the request for PAD in the practice of palliative care is to attempt to clearly understand the request, to intensify palliative care treatments with the intent to relieve suffering, and to search with the patient for mutually acceptable approaches without violating any party’s fundamental values.”

For those who practice in a state where PAD is not legal, the approach to a patient’s request for assistance with ending their life will include active communication, symptom management, and partnering together to determine a mutually agreed upon care plan. In states where PAD is legal, each clinician must decide his or her own position and determine what they find ethically justifiable. A clear consensus is not available from the various professional societies as they disagree on the ethics of PAD. The best practice would support open discussion and respectful, compassionate validation of viewpoints expressed by patients and colleagues. If a provider in a state where PAD is legal is not personally comfortable with this practice, referral to another provider for evaluation around PAD can be offered, but the original physician-patient relationship should not be terminated but should continue to focus on symptom management and emotional support.

In states where PAD is not legal, if the request for PAD persists despite systematic evaluation and optimal palliative care intervention, clinicians and patients may discuss discontinuation of potentially life-prolonging treatments such as steroids, insulin, oxygen, dialysis, or medically assisted hydration or nutrition. In situations with intractable pain or other distressing symptoms persist despite palliative care interventions, palliative sedation may be considered even to the point where the patient is rendered unconscious.

Discontinuation of Treatments at the End of Life

Patients and clinicians must weigh the benefits and burdens of treatments at the end of life. De-prescribing medications whose time frame to benefit exceeds the expected prognosis may provide some improvement in quality of life [20]. Medications to consider in this category may include statins, aspirin, and diabetes medications. Discontinuing antibiotics and other potentially life-prolonging medications also requires a consideration of the patient or surrogate decision-maker’s individual goals, as well as likelihood of benefit compared to burden and risk of, for example, *Clostridium difficile* or other medication-related complications [21].

Other considerations for discontinuation of treatments at the end of life include terminal extubation and withdrawing life-prolonging treatments such as hemodialysis. In these situations, shared decision-making must be used to weight burdens and benefits of the treatment as it pertains to the patient’s goals of care, either currently or as expressed previously to a surrogate decision-maker or in an advanced directive. Withdrawing life-sustaining treatments is considered ethically and legally equivalent to withholding it [22]. When the decision is made to withdrawal of life-sustaining treatments, symptom relief, usually with opioids, and support for the family and patient should always be considered as part of the plan of care.

Patients with automatic implantable cardioverter-defibrillators (AICD), permanent pacemakers (PPM), or other advanced cardiac treatments may wish to consider deactivating these devices at the end of life in order to allow for death to occur or to avoid prolonging the dying process in the setting of underlying life-limiting illness such as advanced heart failure or cancer [23]. The goal in any discussion regarding withdrawing treatments at the end of life should be to elicit the patient's goals and preferences and explore how the treatment in consideration may or may not help the patient reach their goal—of comfort, of life prolongation, or of maximizing function [24].

Palliative Sedation

Palliative sedation is a clinical procedure aimed at relieving refractory symptoms in patients with advanced illness. Most clinical guidelines reserve the option of palliative sedation for patients who are actively dying and who are suffering from refractory symptoms that have failed all other treatments. Symptoms most commonly addressed by palliative sedation include dyspnea, restlessness, pain, and delirium. In most cases, a sedative is administered continuously to lower consciousness and provide relief from symptoms. The primary intention of palliative sedation is to promote comfort, not to hasten death [25]. There is no current available evidence to suggest that palliative sedation to unconsciousness hastens death; in fact, studies have shown the opposite [26]. Despite this evidence, palliative sedation raises ethical concerns when it lowers consciousness to the degree that the patient cannot interact with others, loses the ability to change his or her mind, and is unable to eat or drink.

Several medical societies have published position statements on palliative sedation including the American Academy of Hospice and Palliative Medicine (AAHPM), the American College of Physicians, Hospice and Palliative Nurses Association, American Medical Association, European Association for Palliative Care, National Hospice and Palliative Care Organization, and the National Comprehensive Cancer Network [27]. Although these guidelines differ in some aspects, they agree that palliative sedation is a valid medical procedure to palliate refractory symptoms at the end of life. The AAHPM guidelines specify that, "as with any medical procedure, palliative sedation must satisfy the criteria of having a specific clinical indication, a target outcome and a benefit/risk ratio that is acceptable to both the clinician and patient. Palliative sedation should only be considered after all available expertise to manage the target symptom has been accessed" [28].

There are two main approaches to the ethical dilemma presented above. The goal in this case is to relieve suffering and avoid maleficence, doing harm to a patient.

Case Presentation Continued

Mr. K's functional status has declined further. His daughter has moved into the home to assist with personal care. He can no longer leave his bed and receives sponge baths. He has continuous oxygen at the bedside but, despite this, he appears to be working hard to breathe and seems to be in distress. The hospice nurses call to let you know that they believe he is actively dying and will die in days to a week. They ask for an order for liquid morphine 2.5 mg every hour as needed for dyspnea. His daughter calls you concerned that, given his age and respiratory issues, this dose of morphine could hasten his death.

In hospice and palliative care, clinicians must be aware that the ethical principle of maleficence includes [29]:

- Failing to provide adequate symptom relief
- Insisting that patients confront the reality of their dying
- Failing to offer potentially helpful interventions
- Failing to stop treatments when the burden exceeds the benefit

The Rule of Double Effect

The rule of the double effect has often been used to provide moral justification for treatments at the end of life that may hasten death. This doctrine was developed by Roman Catholic moral theologians in the Middle Ages and is still used in both Catholic and secular bioethics [30]. The doctrine focuses on the intention of the prescribing clinician, rather than the effect of the medication, and validates the use of treatments which are intended to relieve suffering or restore health even if the intervention has potential adverse effects including shortening life. The four elements of the doctrine are:

1. The good effect has to be intended (e.g., relieving pain or dyspnea).
2. The bad effect can be foreseen but not intended (e.g., could possibly shorten life).
3. The bad effect cannot be the means to the good effect (e.g., cannot shorten life in order to relieve pain).
4. The symptom must be severe enough to warrant the risks; this is known as proportionality.

Under the principle of double effect, if the clinician's intent is to relieve dyspnea, prescribing additional opioids is morally and legally acceptable even when the drugs may theoretically shorten the patient's life. The principle of double effect has come under criticism due to the fact that it is rooted in one religious tradition; it assumes that death should never be intentionally hastened; it hinges in the clinician's intent, which cannot be validated; and it cannot be applied to all ethical decisions at the end of life. Furthermore, in clinical practice, the risk of harm is often overestimated. For example, the stated justification for the use of opioids at the end of life is often that the benefit of symptom relief outweighs the risk of hastening death when death is near. However, in most cases, there is a minimal risk of hastening death, and patients often live longer when medicated with opioids at correct doses at the end of life. Nevertheless, the basic tenants of the principle of double effect—to prioritize relief of suffering over a potential yet unguaranteed harm which is proportionally less likely—are grounded in the ethical principles of beneficence and non-maleficence and remain a helpful construct. Although useful, the principle of double effect may not be necessary when a shared decision-making process is utilized. The shared decision-making process, which is described below, focuses on the patient's goals rather than the clinician's intent and includes the ethical principle of autonomy in addition to beneficence and non-maleficence.

Shared Decision-Making Process

In this model, the clinician facilitates communication among the involved parties and uses ethical principles to make a shared decision which incorporates medical knowledge, culture, and values, and weighs possible risks and benefits. Often, perceived disagreements about treatment or goals are due to misinformation or lack of clinical knowledge about the treatments. For example, some clinicians and patients believe that using opioids for dyspnea and pain will often hasten death and therefore wish to reserve opioid use for the active dying stage or avoid them completely. In fact, carefully titrated opioids are not likely to hasten death and may actually lengthen life when provided in a pharmacologically appropriate manner. Similarly, both clinicians and patients may believe that choosing to forgo further chemotherapy may allow for improved quality of life (benefit) with the burden of hastening death. However, studies have shown that for patients considering fourth-line chemotherapy, avoiding chemotherapy may improve both quality of life and survival [31].

The process of shared decision-making requires that both parties fully understand the risks and benefits of the treatments discussed. The impact of these burdens on patients and families is influenced by many factors including prognosis, chance of cure, and impact on others. Thus, when having these discussions, it is important to have a clear understanding of prognosis and to elicit all of the patient's concerns which may extend beyond health-care issues to family, finances, faith, and legacy.

Case Presentation Continued

In the case of Mr. K, an appropriate response to his daughter's concerns regarding prescribing opioids for dyspnea would include the following information:

1. *The opioids, if dosed appropriately, are very unlikely to cause respiratory distress.*
2. *The benefit of the opioids in alleviating shortness of breath, particularly in the setting when there is no cure available, may outweigh any potential risk of hastening death.*

As part of this conversation, it would be appropriate to engage Mr. K and his daughter in a discussion to clarify his goals for care at this time in his illness, reaffirm his priorities, and confirm which risks he is willing to take for which benefits.

After a discussion regarding the above, Mr. K's last days are spent with his family at his bedside. The hospice team teaches them to administer liquid morphine to ease symptoms of dyspnea as well as other medications to ease terminal delirium. Mr. K's breathing becomes more irregular and he eventually becomes apneic and dies. The hospice team provides bereavement care and psychosocial support to the family. His family calls you, grateful for the care you and the oncology, palliative, and hospice teams provided to enable him to die comfortably at home. They share memories from his life and appreciation for his care and his peaceful death.

Conclusion

End-of-life and serious illness situations present ethical challenges for clinicians caring for older adults. By partnering with the patient and family to elicit goals of care, as well as availing themselves of resources such as prognostic indices to help determine reasonable approaches, clinicians can help match treatments given—or withheld or withdrawn—to the patient/family's goals of care as death approaches. Clinicians should be familiar with indications to involve palliative care, including helping with symptoms or suffering in any serious illness situation, as well as those for hospice. Clinicians should be aware of the potential ethical challenges of end-of-life decision-making as it pertains to requests for hastening death. This has become much more of a regular occurrence and will most likely become even more common in the future, as legislation about physician aid-in-dying has been approved in several US states and is under consideration in many others. A focus on symptom relief and shared decision-making is critical to navigating the ethical issues around this issue, and the other challenges related to death and dying, in the older adult population.

Clinical Pearls

Physician aid-in-dying (physician-assisted suicide) occurs when a physician provides, at the patient's request, a prescription for a lethal medication that the patient can self-administer by ingestion with the explicit intention of ending life. PAD is legal in four US states as of this writing.

Euthanasia occurs when a third party administers medication or acts directly to end the patient's life. Euthanasia is illegal in every state.

Palliative sedation is a clinical procedure aimed at relieving refractory symptoms in patients with advanced illness. A sedative is administered continuously to lower consciousness and provide relief from symptoms. The primary intention of palliative sedation is to promote comfort, not to hasten death.

Withdrawal or withholding of treatments at the end of life should use a shared decision-making process around the patient's goals and preferences, balancing benefits and harms.

The rule of double effect refers to treatments intended to relieve suffering or restore health that may have an unintended consequence such as shortening life.

Shared decision-making involves exploring goals of care and weighing risks and benefits of treatments under consideration.

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Special Considerations in Older Surgical Patients

5

Lauren J. Gleason and Angela G. Catic

Case Presentation

A 96-year-old woman with well-controlled diabetes mellitus type 2 on insulin, hypertension, gout, gastroesophageal reflux disease, hearing loss, diastolic heart failure and osteoarthritis presented for preoperative evaluation prior to scheduled left total hip arthroplasty. She reported increasing pain in her groin which has limited her functional abilities. Her review of systems was negative other than pain. She reported that her functional limitations from her hip pain have significantly impacted her life and she was becoming depressed due to her inability to engage in her prior activities. She was independent in her activities of daily living (ADLs), but had been requiring some assistance with independent activities of daily living (IADLs). Discussions were held with the patient and her daughter, and both expressed understanding that there were risks involved with surgery; however, they were willing to take the risk of complications and even death if it meant improvement in current quality of life and provides pain control.

L.J. Gleason, MD, MPH (✉)
Department of Medicine, Section of Geriatrics and Palliative Medicine, The University of Chicago Medicine, Chicago, IL, USA
e-mail: lgleason@medicine.bsd.uchicago.edu

A.G. Catic, MD
Department of Internal Medicine, Section of Geriatrics, Baylor College of Medicine and Michael E. DeBakey VA Medical Center, Houston, TX, USA
e-mail: angela.catic@va.gov

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Introduction

Of the 51.4 million surgeries performed annually in the United States, 19.2 million (37 %) are in individuals 65 years of age or older [1, 2]. With the aging of the population, there will be continued growth in the demand for surgical services in the geriatric population, especially among the oldest old (>85 years of age) [2, 3]. Advances in technology allow surgeons to perform operations even in the most medically complex of the geriatric population with greater safety and improved outcomes [4]. However, with an increased ability to perform surgery in older adults, it is important to pay close attention to the special ethical considerations in this population including (1) appropriateness of the operation, (2) informed consent, (3) advanced directives, and (4) 30-day mortality outcomes.

Appropriateness of the Operation

Physicians are often faced with the challenge of deciding when it is appropriate to proceed with a surgical procedure in an older adult. In each patient, many complex factors can impact this decision. It is essential to consider the unique circumstances of each individual and the specific surgical procedure being considered prior to deciding if it is appropriate to operate. The patient's overall medical goals and their expectations regarding the impact of the surgery should be clearly defined preoperatively. The process of explicitly setting forth these expectations can help determine if the surgical procedure is required for and would result in the desired outcome, as well as deciding if the risk/benefit profile of surgery is acceptable to the patient [5]. For example, in an older adult with multiple medical comorbidities including severe aortic stenosis and moderately advanced dementia, a transcatheter aortic valve replacement may ameliorate cardiac symptoms but may not meet expectations of the patient/family as the concurrent dementia will continue to significantly impact functionality.

Older adults experience the physiologic effects of aging at different rates. Therefore, decisions regarding the appropriateness of surgery should not be based simply on age but should take into account the risk profile of the surgery and the individual patient's physiology, medical comorbidities, and functional status. Multicomponent preoperative geriatric assessments and measurement of frailty should be utilized to determine an individual's operative risk. Components of the assessment should include evaluation of medical comorbidities, functional ability, cognitive ability, and frailty. Frailty is defined as a state of weakness and susceptibility to stress that originates from reduced physiological reserve resulting in diminished resiliency, loss of adaptive capacity, and increased vulnerability to stressors [6, 7]. Understanding the level of frailty of each patient can be instrumental in guiding operative decisions as well as expectations regarding the postoperative course [5, 6].

While there is currently no gold standard for assessing frailty in elderly surgical patients, several studies have demonstrated that increased frailty has a negative impact on surgical outcomes [8–11]. The two most commonly cited tools to measure frailty include the phenotypic [12] and accumulation of deficit models [13]. The frailty phenotype, described by Fried et al. [12], has five criteria: unintentional weight loss, weakness, exhaustion, slow walking speed, and a low level of activity. This definition of frailty has been studied in patients who underwent elective surgery, and increased levels of frailty were associated with an increased risk of postoperative complications, longer length of hospitalization, and a discharge disposition other than home [8]. The accumulation of deficit measure proposes that frailty is a nonspecific, age-associated vulnerability that is reflected in an accumulation of medical, social, and functional deficits which can be measured by counting an individual's health problems or deficits [13]. In the accumulation of deficit model, a patient's frailty index score reflects the proportion of potential deficits present in that specific individual [14]. Increasing number of deficits (i.e., anemia, low serum albumin level, history of falls, functional dependence, cognitive impairment, comorbidity, and mobility impairment) accounted for in a multidomain/accumulated deficit model of frailty has correlated with increased complications, six-month morality, and risk of institutional discharge among colorectal and cardiac surgery patients [11, 15].

A comprehensive preoperative assessment that includes clarification of goals, review of medical comorbidities, evaluation of physical and cognitive function, and frailty assessment can help to determine if a specific surgical procedure is appropriate in a given patient. In addition, the identification of factors associated with specific operative complications and a management plan to minimize these risks can be implemented. For example, a comprehensive assessment might determine that a functionally independent, cognitively intact 95-year-old could undergo surgery with a lower risk than a 65-year-old suffering from symptomatic congestive heart failure and moderate dementia. Based on the results of the comprehensive preoperative assessment, the goals for the surgery and aggressiveness of the procedure can be modified to match the actual physiologic capacity of the patient. Sometimes, a large surgery is not needed to obtain the desired outcome, and a modified or shorter procedure, with lesser surgical insult, can be undertaken to reduce the risk of adverse outcomes. In other cases, the decision may be made to forgo surgery and focus on medical management given the overall goals, medical complexity, functional impairment, or frailty of the patient. However, understanding when modifying or forgoing a surgery is appropriate can only be achieved when a clear understanding of the patient's individual physiology and goals is achieved.

Informed Consent

Clinical communication with patients in the form of informed consent is necessary prior to surgery. Informed consent is the process by which component adults make voluntary decisions following the disclosure of relevant information including review of the medical decision, discussion of the proposed procedure, and disclosure of risk, including any potential complications or disabilities that might occur as a result of the intervention. Additionally, the risks and benefits of not undergoing the procedure should be discussed. There are five identified benefits of informed consent: (1) protecting the patient's right of self-determination, (2) engaging the patient in their health care, (3) enhancing the physician-patient relationship, (4) encouraging physicians to thoroughly review the patient's therapeutic options, and (5) reducing discontent and ligation when there are complications [16].

The full process of informed consent can be challenging to accomplish in the older patient population due to interactions between complex medical comorbidities, cognitive issues, and social barriers. Complications are common in older adults undergoing surgery, and possible adverse effects and future disabilities that may result should be clearly understood prior to proceeding with any procedures [17]. Surgical patients often display suboptimal understanding of the risks and benefits of their upcoming surgery. In a survey of 1,034 preoperative patients, with a mean age of 54.8 years, 13 % did not meet the standards for informed consent [18]. Additionally, this study found that socioeconomic factors including language (non-English) and educational level (lower education) place patients at higher risk for decision-making deficits [18]. Oftentimes, patients do not engage in a thorough discussion of their treatment preferences regarding advanced care planning, particularly preferences about how aggressively care should proceed in the event of significant complications [19]. Therefore, when obtaining preoperative informed consent in older adults, it is critical to ensure that patients have a clear understanding of the limitations of the procedure, complications that might occur, and possible impacts the procedure and resultant complications are anticipated to have on their function and quality of life in the future.

Ensuring that an individual has decision-making capacity is a prerequisite to obtaining legally and morally informed consent for a surgical procedure. Decision-making capacity should be evaluated based on an individual's ability to make a specific medical decision, not their ability to make all general medical decisions. Decision-making capacity describes an individual's ability to understand and utilize information about the proposed treatment options to make a choice that is congruent with their values and preferences. Cognitive decline, with or without meeting the diagnostic criteria for a major neurocognitive disorder, is a significant concern among elderly patients and can complicate the decision-making process [20]. In most cases, the care team can make the proper judgment regarding a patient's decision-making capacity from conversations with the patient regarding their medical situation and possible treatment options. In cases where decision-making capacity is less clear, formal mental status testing can help determine whether a patient is capable of making this type of decision. The Mini-Cog, a brief cognitive screen that tests memory and executive function, can be helpful in determining if the patient has impaired cognitive function [21]. The Mini-Cog is highly sensitive and has advantages over many other formal tests of cognition as it is brief (3–4 min to administer), can be performed by nonphysicians, lacks a language or educational bias, evaluates for the presence of executive dysfunction, and has been used for preoperative assessment [21–23]. However, there is no gold standard for the best cognitive evaluation tool, and the score on a standard examination does not dictate a conclusion about capacity but simply serves as an important data point when making a capacity assessment.

When having informed consent discussions, it is also helpful to engage a patient's surrogate and/or family member in the conversation. As patients may lose decision-making capacity at some point after surgery, conversations between the patient and surrogate prior to the surgery regarding preferences for medical treatment and goals of care are helpful to inform surrogates of patient preferences and improve appropriateness of care in cases where surrogates must assume the role of decision-maker.

If a patient is deemed unable to provide informed consent, then their surrogate decision-maker would be the appropriate individual to make decisions regarding any proposed surgical treatments. It is important to ensure that the surrogate decision-maker understands that decisions should be based on their best knowledge of the patient's expressed wishes and values, not what their personal wishes would be in the same situation. If the patient's wishes and values are not known, the surrogate decision-maker should be guided to make decisions based on what would be in the best interests of the patient. In situations where surrogates are making decisions regarding care, they should be provided with all available details regarding diagnosis, prognosis, and alternative treatments as if they were themselves the patient.

Ideally, documentation of an identified surrogate who was chosen when the patient had capacity to do so should be available. If there is not a designated surrogate, the rules regarding surrogate decision-makers for health care should be reviewed for the state in question. In many cases, family members will be able to take on the role of surrogate, or a guardian may need to be designated.

Do Not Resuscitate and Surgery

A do-not-resuscitate (DNR) order is a legal medical document that reflects an individual's desire to decline resuscitation efforts. Older adults may choose to forgo certain resuscitative procedures because they do not want to accept the possible burdens associated with them. These burdens may be related to either the resuscitation attempt itself or a decline in cognitive and functional capacity following the resuscitation attempt. In the early 1990s, following the passage of the Patient Self-Determination Act which requires facilities receiving Medicare or Medicaid funding to inform patients about their right to refuse medical treatment and the use of advanced directives on admission [24, 25], the American Society of Anesthesiologists, the American College of Surgeons, and the Association of Operating Room Nurses published guidelines declaring that patients with DNR orders should have these reevaluated for the perioperative period. Failure to respect a patient's wishes regarding resuscitation would constitute a violation of the moral and legal right to self-determination [26, 27]. Therefore, a clear and open conversation regarding a patient's wishes around resuscitative efforts and expectations during the pre-, intra-, and postoperative period should occur prior to proceeding with any surgical interventions.

Barriers to Perioperative DNR

Maintaining a DNR order in the operating room is often met with criticism by medical providers as they view the desire to receive surgical therapy as inconsistent with the desire to withhold resuscitation efforts if indicated. Furthermore, a DNR order can be interpreted as a signal that the patient is unwilling to undertake the burdensome interventions and recovery period inherent in high-risk procedures and necessary to achieve the desired surgical outcome. From an anesthesia perspective, resuscitation procedures such as intubation and use of critical care intravenous medication/drips are a standard part of operative care. However, a partial reversal of a DNR order is feasible. This would allow for the administration of regional or general anesthetic treatment while withholding resuscitative measures including chest compressions and/or cardioversion in accordance with patient preferences.

The cause of death has also been a point of controversy in the discussion of perioperative DNR orders. While providers generally understand and accept that patients die from underlying disease, many find it unacceptable to allow an individual to die, without resuscitative efforts, from iatrogenic causes such as anesthesia or surgical complication. In a survey of 2,100 randomly selected vascular, neurologic, and cardiothoracic surgeons conducted in 2010, 912 (54 %) reported that they would decline to operate on patients who have an advance directive limiting postoperative life-supporting therapy [28]. The results of this survey raise a serious question about whether it is ethically permissible for surgeons to decline to operate in individuals who have an advance directive restricting care. In circumstances where providers feel ethically conflicted or that a patient's goals are inconsistent with their personal values, the American Medical Association Code of Ethics states that clinicians are not compelled to perform procedures but should involve a second provider who is willing to comanage the patient by performing the desired procedure [29]. When faced with ethically challenging situations, providers are encouraged to involve the ethics committee of their institution.

Many providers are more comfortable participating in the care of patients with DNR orders who undergo procedures aimed at extending or improving their quality of life [30]. For example, a 90-year-old with a preexisting DNR order who suffers from significant cervical spinal stenosis with neurological sequela impacting functional status might consent to have a high-risk surgery with the hope to regain function of limbs. In this patient, the risk of dying during surgery would be outweighed by the possible benefit of improving function and quality of life. Upon extubation, the patient would like to be do not resuscitate/do not intubate (DNR/DNI). If the surgery was not successful and the patient was to become ventilator dependent, the patient would wish to have comfort-focused care.

In addition to clearly defining a patient's goals of care and ensuring that these are accepted by medical providers, it is helpful to understand the typical outcomes of resuscitative efforts in the elderly. A systematic review found that the overall chance of survival to hospital discharge for in-hospital CPR in adults 70 years and older is low–moderate (11.6–18.7 %), and the percentage of older adults surviving to discharge decreases with advancing age (11.6 % for those age 90 years and older) [31]. A study of noncardiac surgery intraoperative cardiac arrest identified a rate of approximately 7 % per 10,000 noncardiac surgeries with an associated mortality of 44 % within 24 h and 63 % at 30 days [32]. A review of the ACS-NSQIP database of non-trauma patients from 2005–2010 found that, among the more than 1.3 million surgical cases captured in the data set, 6,282 cases of CPR were performed within 30 days of surgery. Of these, 14.1 % occurred intraoperatively and 85.9 % occurred postoperatively. Of the instances of postoperative CPR, 49.8 % occurred within 5 days after surgery. The incidence of CPR varied by specialty with 1:33 for cardiac surgery compared to 1:258 for general surgery [33]. There is limited data regarding functional status in older adults after CPR, although this is often the most important outcome to patients and families. In one study, only 20 % of survivors aged 81 and older who underwent cardiopulmonary resuscitation were capable of independently functioning outside of institutional care [34].

Recommendations

Undesired and unanticipated outcomes can occur during the perioperative period, and advanced directives can provide clarification when navigating decisions regarding treatment. Institutional policies should be implemented in all health-care facilities regarding the need for discussions about advanced directives prior to pursuing any surgical interventions. However, it is often challenging to put theory into clinical practice given the lack of comfort in discussing patient goals and advanced directives, misinformation regarding the utility of advanced directives during the perioperative period, and time constraints. To ease these challenges, these discussions should occur as early as possible in the clinical encounter, ideally when the decision to have surgery or not is still being contemplated. It is best if the discussion is multidisciplinary and includes the patient, family members, anesthesiology, surgery, and the patient's primary care doctor or geriatrician. As part of this discussion, three points should be clarified and clearly documented: (1) existing DNR order that may limit the use of resuscitative procedures and modification of the DNR order if appropriate, (2) exceptions to the DNR order should specific complications occur during the surgery or anesthesia, and (3) explicit plans for reinstating the DNR order, if it has been rescinded for the procedure, when the patient has recovered from the acute effects of anesthesia. In nonelective surgical cases, it would be helpful to have a system that allows for earlier surgeon and anesthesiologist notification of pending cases with existing DNR orders to allow for sufficient time for conversations regarding possible suspension or modifications to the DNR [27].

Public Reporting of 30-Day Mortality

The goal of public reporting regarding health-care outcomes is to provide information regarding quality of care to patients so they can incorporate this into their decision-making process when considering undergoing a particular health-care service. Thirty-day mortality has become an outcome metric commonly used to measure surgical quality. The overall goal is to motivate surgeons and hospitals to improve performance and quality of care as well as allow patients, referring physicians, and health-care purchasers to select higher-quality care.

Clinically oriented outcomes, including postprocedure cognitive and functional status among elderly patients, are vital for assessing the effectiveness of a surgical program. Unfortunately, these measures are not captured if the 30-day mortality statistics are the only data used to assess surgical quality. In addition, reporting and rewarding low 30-day surgical mortality statistics may create a conflict of interest for providers including (1) encouraging providers to preferentially select healthier patients instead of providing care for medically complex older adults, (2) shifting physician focus toward the quality statistics being measured as opposed to what is important to the patient, and (3) supporting life-prolonging measures during the postoperative period which may not be in the best interests of the patient and may result in a prolongation of suffering [35]. In addition, measuring quality of care based on 30-day mortality often fails to account for patient preference and autonomy. Based on these nuances and complexities of the 30-day mortality metric, it is challenging for the public to clearly interpret this data, and information regarding postoperative functional outcomes, length of hospitalization, need for institutionalization, etc. should be considered as surgical outcome measures.

For patients who have operations with palliative intent, the quality should not be judged by mortality but rather by the robustness of the outcomes that reflect high-quality palliative care including symptom management resulting from the procedure. Other metrics of high-quality palliative care include documentation of a preoperative goals-of-care conversation, pain scores, family meetings, and time between a DNR order and death. Although collection of survival rates following palliative operations might help inform future patients about the value of an operation, 30-day mortality rates for these operations should not be interpreted or publicly reported as a quality metric as they can be significantly misleading.

Impact of Mortality Reporting

Several studies have evaluated the practical effects of 30-day mortality reporting which support the ethical concerns raised by this measure. In New York State, thirty-day mortality reporting following coronary artery bypass graft (CABG) surgery in 1989 was initially correlated with a larger decline in mortality rates compared to other states during that same time period [36, 37]. However, studies have determined that the decrease in mortality was correlated with the referral of high-risk patients from New York to out-of-state regional medical centers [38].

When surveyed, 62 % of surgeons in New York State admitted to refusing to operate on at least one high-risk CABG patient over the prior year due to public reporting [39]. Pennsylvania also observed similar changes following the introduction of report cards for CABG surgery. Sixty-four percent of cardiac surgeons admitted to being reluctant to operate on high-risk patients, and more than half of cardiologists reported having increased difficulty finding a surgeon for high-risk patients with coronary artery disease [40]. Analysis of data from fee-for-service Medicare patients from three reporting states (New York, Massachusetts, and Pennsylvania) compared to regional non-reporting states (Maine, Vermont, New Hampshire, Connecticut, Rhode Island, Maryland, and Delaware) indicated that that Medicare beneficiaries with an acute myocardial infarction (MI) were less likely to receive percutaneous coronary intervention in the three states with mortality reporting compared to the seven regional control states (OR 0.82 [95 % CI, 0.71–0.93]) [41].

In addition to resulting in the selection of lower-risk patients for surgical procedures, reporting systems on 30-day surgical mortality can discourage and delay conversations regarding goals of care following surgery. Concerns about adversely impacting the outcome metric may discourage providers from offering palliative care and/or hospice when a procedure has unintended consequences and, in the most extreme cases, may override a patient's previously noted advance directives. This concern was described in a case report where surgeons deferred conversations regarding palliative care options in a 94-year-old woman who sustained cardiopulmonary arrest during a procedure followed by multiple postoperative complications until postoperative day 31 [42]. To meet ethical standards of care, surgeons should offer informed, high-risk patients surgery that is potentially beneficial with the option to refuse aggressive treatments subsequently if they become overly burdensome or when the goals of the surgery are no longer possible [43].

Educational Pearls

1. When considering if a particular surgical procedure is appropriate for an elder, the unique physical, cognitive, and social circumstances and well as the individual goals and expectations of the patient should be considered.
2. The process of ensuring informed consent includes establishing if an elder possesses decision-making capacity. It should start as early as possible in the pre-operative period, ideally when the decision to pursue operative intervention or not is still being considered.
3. The patient's goals of medical care, including the impact of surgical intervention on any existing DNR orders, should be addressed prior to any surgical procedure.
4. While thirty-day mortality has become an outcome metric commonly used to measure for surgical quality, it does not address many of the outcomes which matter most to elders and their families including post procedure cognitive and functional status.

Conclusions

It is important for providers to be aware of the ethical issues commonly encountered during the surgical care of elders. Ensuring that the decision to pursue surgery is in keeping with the patient's overall health goals, that a clear process of informed consent has occurred, and that advanced directives are respected to allow for self-determination and autonomy are critical to providing ethical surgical care in the geriatric population. Throughout the perioperative period, the patient should remain the center of the process, and outside factors, such as 30-day mortality metrics, should not be allowed to adversely influence care decisions. Understanding these complexities of surgical care in the geriatric population can help ensure care that is patient focused with the goal of improving the lives of older adults.

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6

Ethical Issues of Renal Replacement Therapy in the Elderly

Austin Hu and Medha Airy

Case Discussion

Mr. Smith is an 84 year old man with past medical history significant for end-stage renal disease (ESRD), hypertension, coronary artery disease, and mild cognitive impairment who is accompanied to geriatric clinic by his wife and son. The patient requires assistance with bathing secondary to gait instability and prior falls. He relies on family members for assistance with his instrumental activities of daily living. Secondary to worsening renal function, Mr. Smith's nephrologist has initiated a discussion with the patient and his family regarding renal replacement therapy. Mr. Smith is seeking input about this important decision. He and his family questions how mortality and quality of life compare between renal replacement versus conservative therapy. They are also concerned about how his other medical comorbidities may impact his ability to tolerate dialysis if this is the treatment option they decide to pursue.

Introduction

With the rising incidence of diabetes and hypertension, it is not surprising that the United States Renal Data System (USRDS) report for 2015 shows an increasing prevalence of end-stage renal disease (ESRD) in patients over 65 years of age [1]. This follows a steady increase over the last several years, with recent leveling, in incident cases of ESRD among elders. Prior to deciding between conservative

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A. Hu, MD
Internal Medicine, Baylor College of Medicine, Houston, TX, USA
e-mail: Austin.Hu@bcm.edu

M. Airy, MD (✉)
Internal Medicine, Nephrology Section, Baylor College of Medicine, Houston, TX, USA
e-mail: airy@bcm.edu

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management, with medications, and renal replacement therapy, it is important to understand general outcomes and the individual patient characteristics which could impact them. Ethical dilemmas faced in the management of elderly patients requiring dialysis revolve around unique age-related challenges including functional status, multiple medical comorbidities, and impact of the treatment modality on quality of life. The medical subspecialty of nephrology was among the first group of medical providers to grapple with the ethical dilemmas related to the care of patients with ESRD. The Social Security Amendments Act of 1972, which approved coverage for dialysis for everyone who had worked enough to gain social security benefits, initially served as a stimulus to offer dialysis to everyone with ESRD irrespective of age or functional status. This led to a high incidence of dialysis among ESRD patients. However, over the last decade, increasing consideration regarding the outcomes of elderly patients undergoing dialysis has led to higher rates of medical management with resultant stabilization of the incident dialysis rate. To determine the best care options for elders with ESRD, it is necessary to understand current dialysis use patterns, outcomes of the available treatment modalities, and ethical considerations in decision-making for these patients.

Management Considerations in Elderly Patients with ESRD

In caring for elders with ESRD, unique challenges and special considerations must be considered when making treatment decisions. Geriatric patients often suffer from an increased number of medical comorbidities which complicate management. In addition, when considering care options for an individual geriatric patient with ESRD, it is important to understand the general outcomes of elders with ESRD treated with dialysis versus those who receive conservative management.

Comorbidities Impacting Management of ESRD

Important comorbidities which commonly impact elderly patients with ESRD and their management include:

1. *Frailty*: The impact of frailty, defined as "a clinically recognizable state of increased vulnerability resulting from aging-associated decline in reserve and function across multiple physiologic systems such that the ability to cope with everyday or acute stressors is compromised," has been considered at length in the geriatric literature [2]. Fried and colleagues have provided a clinical scale to assess frailty in geriatric patients which includes the following criteria: unintentional weight loss, slow walking speed, weakness, exhaustion, and low physical activity [3]. When treating elders with CKD, it is important to assess for frailty as patients with CKD and ESRD have a higher risk of frailty and subsequent consequences including falls, disability, hospitalization, and death [2, 4].
2. *Falls*: Individuals 65 years of age and older who are on hemodialysis have been shown to have a higher risk of falls as compared to age-matched controls without ESRD (38 % versus 4 %) [5]. In addition, patients on dialysis who suffer at least

one fall have a 1.6 times higher risk of mortality compared to individuals not on dialysis [6]. When considering dialysis in elders with advanced CKD, it is important to consider these outcomes as well as discuss all available treatmetn options and fall prevention measures.

3. *Functional Impairment*: A clear understanding of a patient's functional status is important when considering treatment options for advanced CKD. Functional status is primarily assessed in terms of:
   (a) Activities of daily living (ADLs) which include feeding, dressing, toileting, maintaining personal hygiene, walking, bed mobility, and transferring.
   (b) Instrumental activities of daily living (IADLs) which include maintaining personal finances, cooking, driving/transportation, shopping, telephone use, and medication management [5].

   Risk factors for impaired functional status are many and include poor nutrition, low body weight, decreased mobility, and impaired cognition [7, 8]. In fact, evidence strongly suggests a correlation between the duration of dialysis and the degree of functional decline. This was highlighted in a study of nursing home patients with ESRD focusing on patients with a significant decline in functional status prior to treatment with dialysis. Status post dialysis initiation, only 39 % of subjects maintained their baseline functional status 3 months post initiation and 13 % at the end of 12 months. Subjects had a mortality rate of 58 % one year after initiation of dialysis [9].
4. Cognitive impairment: The Chronic Renal Insufficiency Cohort Study, one of the largest databases for chronic kidney disease patients, established that with increased age (greater 55 years of age), a lower eGFR is associated with cognitive impairment [10]. In addition, the prevalence of cognitive impairment and dementia is far more common in individuals with ESRD compared to age-matched controls, most likely secondary to high rates of cardiovascular risk factors, metabolic derangements, anemia, and polypharmacy [11]. In patients treated with dialysis, it has been determined that cognitive dysfunction worsens over time with increased duration of dialysis [11]. The prevalence of cognitive dysfunction in individuals with ESRD and continued decline with dialysis treatment highlight the need for careful cognitive assessment in this patient population. Further studies are warranted to clarify the optimal cognitive assessment tools in elders with ESRD.

Outcomes in Elders with ESRD Treated with Dialysis Versus Conservative Management

The International Dialysis Outcomes and Practice Patterns Study (DOPPS), conducted over a span of 2 years (2005–2007), represented 295 dialysis facilities in 12 countries across the globe. The purpose of the study was to evaluate the outcomes in patients with ESRD treated with dialysis [12]. In this study, there was decreased median survival with increasing age (≥75 years) across the globe. In North America, median survival by age was reported as follows: 7.9 years if 45 years of age or younger, 4.5 years if 45–74 years of age, and 2.5 years if ≥75 years of age. The association of survival with age was maintained even after adjustment for a variety of comorbidities, excluding diabetes and demographics. The impact of conservative management on outcomes in elders with ESRD has also been evaluated. One study demonstrated improved survival in patients over 70 years of age who received renal replacement therapy compared to those managed with conservative management [13]. However, the survival benefit of dialysis was lost in patients over 80 years of age. The loss of survival benefit with renal replacement therapy as patients age may be secondary to an increasing number of comorbidities. Brown and colleagues found no significant survival advantage among patients age 75 years or older with ESRD and two or more additional comorbidities. [14]. Concurrent cardiovascular disease, in particular, appears to have a considerable effect on survival among elders with ESRD. Murtagh and colleagues determined there was no survival benefit of renal replacement therapy compared to conservative management in patients over 75 years of age when their comorbidities included cardiovascular disease [15]. Based on the available evidence, conservative management is an acceptable alternative to renal replacement therapy in many elders, especially those who suffer from additional comorbidities.

When choosing between renal replacement therapy and conservative management, quality of life is an important outcome measure which must be considered irrespective of survival data. Patients with major comorbid disease that receive dialysis have increased hospitalizations and are more likely to die in the hospital compared to individuals managed conservatively. In contrast, the same patients that undergo conservative management have fewer hospitalizations, are more likely to receive hospice care, and are more likely to pass away at home compared to those being treated with renal replacement therapy [16]. Hence, dialysis may not improve overall quality of life in elders with multiple comorbidities and this must be considered when making treatment decisions.

Decision-Making

An understanding of the epidemiology of ESRD in elders, impact of concurrent comorbidities, and outcomes of renal replacement versus conservative therapy provides the framework for conversations with patients and their families regarding the unique treatment considerations in this population. In addition to these considerations, family support, transportation availability, and financial resources can also be critical considerations in the decision-making process [5]. Figure 6.3 summarizes the management options available during several stages of decision-making in patients with ESRD.

Considerations with Renal Replacement Therapy

If, following a careful conversation with the provider, renal replacement therapy is chosen, there are several important issues to consider.

1. *Does the timing of dialysis initiation make a difference?* Careful evaluation has not found any significant difference in patient outcomes or overall benefits of initiating dialysis early [17, 18]. In fact, patients who start earlier on dialysis spent an average of 6 months longer on dialysis than their nondialysis cohorts [17].

2. *Which modality of dialysis treatment is better?* There are two primary options for renal replacement therapy: hemodialysis (HD) and peritoneal dialysis (PD). The possible pros and cons of each modality should be considered on a case-by-case basis when initiating renal replacement therapy. HD, performed at a dialysis center with assistance from nurses and technical staff, necessitates patients presenting to a facility three times per week. While this often sounds easier than considering home-based renal replacement therapy, patients require adequate social support and transportation to maintain the frequent appointment schedule. Another concern is the need for specialized access to perform HD. Patients will require an arteriovenous fistula (AVF) or arteriovenous graft (AVG) that are created surgically by a vascular surgeon versus placement of a permanent dialysis catheter. An AVF is the preferred access modality, regardless of age, due to a lower incidence of infections compared to the catheters. However, advanced age is recognized as an independent risk factor for primary AVF failure [19]. Additional risk factors for AVF failure in elders include male sex, individual vascular conditions, and the site of vascular access, with radiocephalic fistulas having a higher risk of failure [20]. Due to these issues, staggeringly low numbers of elderly patients initiating dialysis have an AVF despite the higher risk of infection and mortality associated with catheters [21, 22]. In contrast to HD, PD can be performed at home. However, it is important for elders to have a good support system in place as trained medical professionals will not be present to perform or monitor the dialysis sessions. Medically, PD does offer the advantage of a slower rate of ultrafiltration which can be beneficial to elders due to their higher cardiovascular disease risk. Peritonitis, one of the significant risks of PD, is not generally believed to be a greater risk factor among elder patients compared to the younger individuals. Mortality rates and quality of life have not been found to differ significantly between elders receiving HD versus PD [23, 24].
3. *Which vascular access is associated with the best outcomes?* As discussed above, AVF is the preferred access due to lower incidence of infection. However, it is associated with a higher rate of fistula failure in the elderly due to age-related physiologic changes, vasculature issues, and concurrent comorbidities. Catheters have been associated with the higher risk of infectious complications. At this time, there is no consensus statement regarding preference for either type of access in elders pursuing HD given the risks associated with both options. Decisions regarding access should be made on an individual basis and planning for AVF placement should include a surgical opinion.
4. *Does the nephrologist need to individualize the dialysis prescription for elderly patients?* Yes, dialysis treatment needs to be individualized as each elderly patient has unique medical comorbidities requiring careful titration of therapy. In addition, the family and social support, financial situation, availability of transport, and physical and cognitive function of the patient should be assessed on a regular basis as there are often frequent changes as individuals age.
5. *Is renal transplantation an option?* Kidney transplantation has been a preferred modality of treatment for patients with end-stage renal disease due to the survival advantage offered in terms of long-term mortality risk when compared to dialysis. This survival benefit is maintained through all age categories with gain of additional life years (even though it is more evident in the younger age group) [25].

A landmark study by Wolfe et al. [26] found that for patients transplanted between ages 60–74 years the relative risk of mortality was 0.39 (95 % CI, 0.33–0.47) at 18 months status post transplantation compared to those remaining on the wait list. In addition, their projected life span increase was between 6 and 10 years. The annual death rate in the overall dialysis group was reported as 16.1 per 100 patient-years compared to 6.3 per 100 patient-years for the waitlisted dialysis patients. Subsequent to this study [25], the kidney transplantation option was encouraged for the elderly population resulting in longer transplant waiting lists and increased wait periods on the list. With the introduction of expanded criteria donor (ECD) [27] kidneys, a term introduced by the Organ Procurement and Transplant Network in 2002, the waiting period for the elderly population has reduced and beneficial results have been reported. ECD kidney is a term used to describe a kidney obtained from a brain-dead donor ≥60 years of age or a donor 50–59 years with at least two of the following: history of hypertension, terminal serum creatinine >1.5 mg/dl, and cerebrovascular cause of death. ECD kidneys have poorer allograft function and have been associated with higher mortality and risk of allograft loss in patients between 18 and 70 years. However, in recipients above 70 years of age [27], these kidneys did not appear to have a higher mortality risk or allograft loss. One possible explanation is that, since elderly patients generally have more medical comorbidities and shorter remaining life-spans, they may pass away from other causes before the direct complications of an ECD kidney are fully manifested. Even given the possible complications, ECD kidney recipients are reported to have improved survival compared to their matched dialysis-treated counterparts.

Considerations with Conservative and Palliative Care

Since many elders, especially those that are frail and/or suffer from significant comorbidities, have poor outcomes with dialysis, there has been an increasing movement towards managing ESRD with conservative or palliative care. In fact, patients with ESRD have been compared to those with an incurable cancer due to the terminal nature of both illnesses [28]. By extension, dialysis can also be compared to chemotherapy such that it may prolong biological life but the time gained may just be "extending the period of dying" as opposed to gaining a high quality period of life [8, 28]. Just as it is appropriate to involve palliative care experts for patients with metastatic cancer regardless of their decision to pursue chemotherapy or not, nephrologists increasingly agree that palliative care should be integrated into the overall care of all ESRD patients to help manage symptom burden irrespective of which management option they choose (renal replacement versus conservative) [29, 30].

Despite the movement to include palliative care in the management of ESRD, some nephrologists equate dialysis refusal to a death sentence and are uncomfortable with patients not receiving this treatment. This may lead to providers offering dialysis treatment to patients who are elderly, frail, and/or suffer from multiple comorbidities at the cost of increased interventions and suffering. As with other interventions in the geriatric population, this highlights the importance of evaluating treatment options for ESRD not only by how much an intervention can extend life but also by the impact on quality of life. In recent years, many studies have focused not only on the efficacy of conservative care compared to dialysis but also the impact of conservative management on quality of life and functional status [31]. While there are some difficulties in conducting studies of this nature, as patients on conservative management are generally frailer and have more comorbidities compared to their fitter counterparts on dialysis, studies that compared the survival rate of elderly patients with ischemic heart disease or multiple comorbidities receiving conservative care versus dialysis yielded similar results between the two treatment options (Fig. 6.1) [15, 32].

Patients receiving conservative management are often able to maintain their functionality and quality of life for the majority of their remaining duration of life, until experiencing a sharp functional decline within the last month of their life. This was demonstrated in a study using the Karnofsky performance scale, a well-established ten-point scale used to assess functional status with an emphasis on physical performance and dependency, in which functional status was maintained at a moderate level in individuals with ESRD receiving conservative management until late in the course of illness (Fig. 6.2) [33]. In contrast, elderly patients who are initiated on renal replacement therapy often start experiencing a deterioration in functionality soon after going on dialysis that progresses until their eventual demise. As stated earlier, patients with significant comorbid disease who are managed conservatively are also more likely to pass away at home or in hospice and spend fewer days institutionalized than their dialysis-receiving counterparts. Patients on dialysis often spend more time in hospitals due to the many complications associated with dialysis [16]. For instance, the rapid fluid shifts which occur with dialysis often cause derangements in physiology leading to hypotension with subsequent complications of ischemia such as angina and stroke. It is important to determine which of the treatment modalities for ESRD, renal replacement versus conservative, are most consistent with each patient's medical goals. In cases where patients value quality

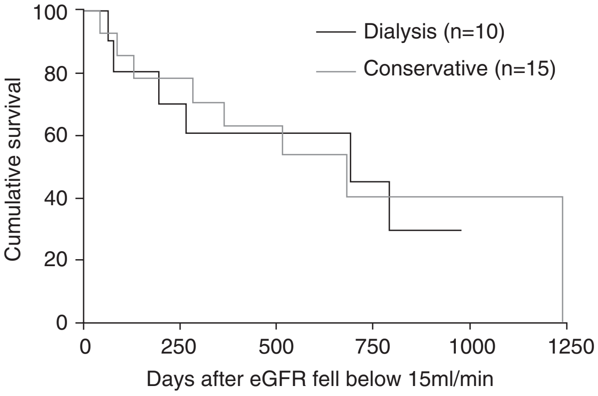

Fig. 6.1 Kaplan-Meier Curve comparing patients (with ischemic heart disease or ≥2 comorbidities) choosing dialysis option versus conservative management (*Source*: Murtagh et al. [15]; Murtagh FE, Marsh JE, Donohoe P, Ekbal NJ, Sheerin NS, Harris FE. Dialysis or not? A comparative survival study of patients over 75 years with chronic kidney disease stage 5. Nephrol Dial Transplant. 2007

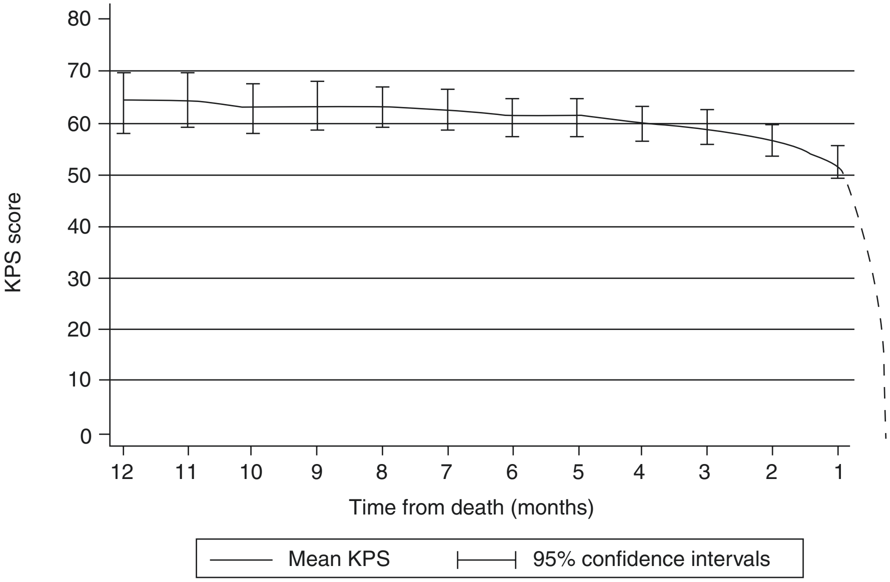

Fig. 6.2 The trajectory of decline in conservatively managed stage 5 CKD patients in the last year of life. *KPS* Karnofsky performance scale (*Source*: Murtagh et al. [33]; Originally from Murtagh FE, Addington-Hall JM, Higginson IJ. End-stage renal disease: a new trajectory of functional decline in the last year of life. *Journal of American Geriatric Society*. 2011)

of life and spending more time at home instead of enduring frequent hospital visits and interventions, conservative management is the appropriate option [30].

The Importance of Advance Care Planning

It is imperative for the nephrologist and other members of the renal care team to facilitate advance care planning early in the course of renal disease, when patients are most capable of making clear decisions regarding their end-of-life care [11]. Advance care planning is a means to assist the patient in understanding their current medical condition and prognosis, to help the renal care team understand the patient/family's wishes and goals, and to plan ahead for scenarios that may occur in the future as the disease progresses. Advance care planning is based on the ethical principle of respect for "self-determination"/patient autonomy and is a series of patient-centered discussions that focus on each individual patient's wishes and treatment preferences as related to their medical situation and prognosis [34]. These discussions should include creating advance directives that can help guide decision-making to best meet the patient's needs in the future. In addition, discussing the anticipated trajectory of care in advance will also help ensure the patient receives care consistent with his/her goals should an acute situation arise that demands prompt decision-making [30]. Similar to other elders or any patient with a significant illness, the patient should designate a single person to be their surrogate decision-maker (i.e., health-care proxy,

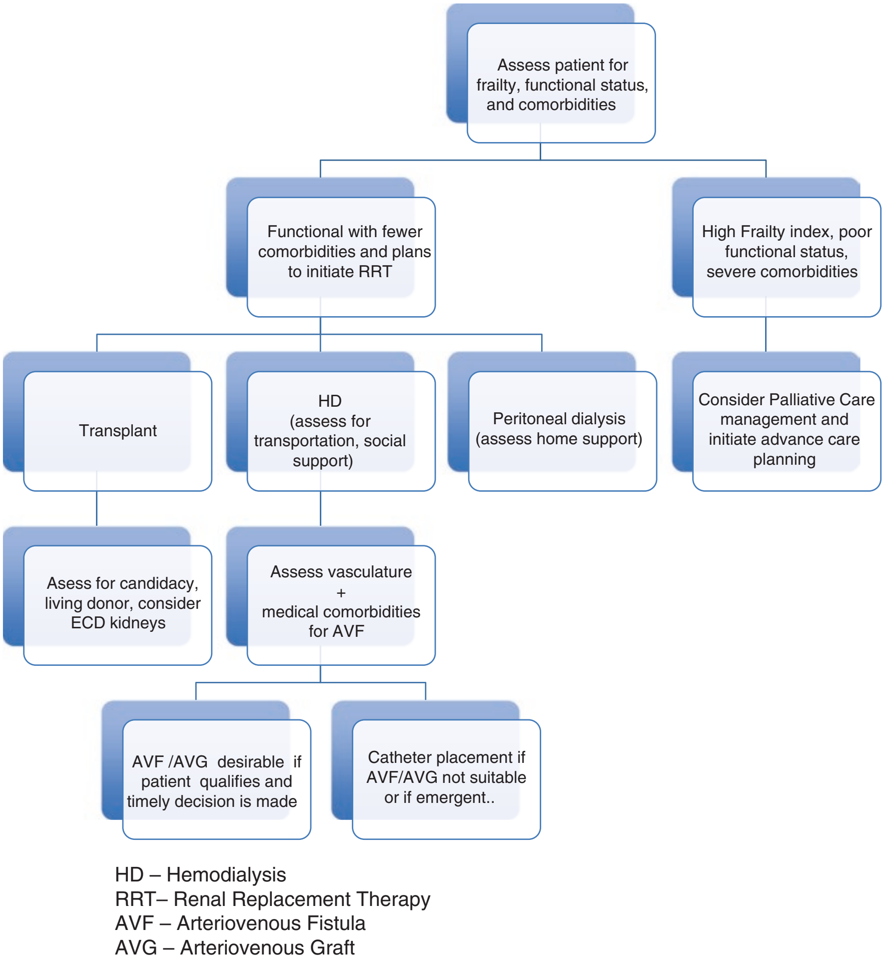

Fig. 6.3 Treatment options for elderly patient diagnosed with end-stage renal disease. *HD* hemodialysis, *RRT* renal replacement therapy, *AVF* arteriovenous fistula, *AVG* arteriovenous graft

medical power of attorney). This individual should be someone who understands the patient's wishes/goals and can make decisions on behalf of the patient if the patient loses capacity [32]. It is important to recognize that advance care planning is a very dynamic process [30]. As the patient's illness progresses, these discussions should be revisited again and again to continually clarify goals and establish tenets of care as the patient/family's views may change over time.

Conclusion

While renal replacement therapy has the ability to extend biological life, it often results in reduced quality of life and, therefore, may not be medically indicated or aligned with a patient's goals. This highlights the importance for open, honest communication between the patient/family and members of the renal care team regarding management options for ESRD as related to the patient's medical wishes. The issue of ESRD care ultimately becomes a process of shared decision-making where the physician and renal care team members, along with a well-informed patient/family, are able to understand each other's positions and mutually establish an appropriate treatment plan. This may or may not involve dialysis, as it depends on the patient's medical prognosis and personal values. Regardless of the specific treatment chosen, the most important aspect in choosing a management plan is ensuring it is patient centered and grounded on the ethical principles of respect for the patient's/family's goals and values while upholding the principles of beneficence, non-maleficence, and professional integrity.

Clinical Pearls

1. Concurrent comorbidities, including frailty, falls, functional status, and cognitive impairment, should be carefully considered when deciding between renal replacement therapy and medical management of ESRD.
2. In elders with multiple comorbidities, conservative management is often an acceptable alternative to renal replacement therapy.
3. Elders in whom CKD is managed conservatively are more likely to die at home or in hospice and spend fewer days institutionalized compared to those receiving renal replacement therapy.
4. Advanced care planning should ideally begin early in the course of renal disease so patients can actively participate in conversations regarding their goals of care and work with their providers to determine how these can best be achieved.

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Ethical Considerations for the Driver with Dementia

7

Geri Adler and Susan J. Rottunda

Case Presentation

Mrs. D is a 78-year-old woman living alone with a two-year history of memory loss and a recent diagnosis of Alzheimer's disease. In addition, Mrs. D has glaucoma, hypertension, and osteoporosis. She is accompanied by her daughter to an appointment with her primary care physician. While meeting with Mrs. D, you learn she still drives, taking short trips to run errands, attend appointments, and visit family and friends. She tells you she is a safe driver and denies recent accidents. After receiving permission from Mrs. D, you meet separately with her daughter. Her daughter describes a different scenario – notably, that her mother was recently pulled over for speeding, that her mother's car has several unexplained dents and scratches, that her mailbox was recently knocked over, and that, due to their concerns about Mrs. D's safety on the road, a few of her mother's friends have tended to assume more of the driving. The daughter pleads, "Please make my mother stop driving."

G. Adler, PhD, MSW (✉)
South Central Mental Illness Research, Education & Clinical Center, Houston VA Health Services Research & Development Center for Innovations in Quality, Effectiveness and Safety, Baylor College of Medicine, Houston, TX, USA
e-mail: geri.adler@va.gov

S.J. Rottunda, BS
Minneapolis VA Health Care System, Geriatric Research, Education and Clinical Center (GRECC), Minneapolis, MN, USA
e-mail: susan.rottunda@va.gov

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Introduction

The challenges associated with the older driver with dementia, such as Mrs. D in the preceding scenario, give rise to the need to address many difficult issues that can impact not only the older driver but also his/her family, physician, and the public. In addition to clinical management and regulatory challenges, driving also presents an ethical dilemma. While most would assume that safety for both the older driver and the public must be a primary concern, when safety and autonomy are at odds, the matter of ethics can pose a challenge to all concerned. This is particularly the case for drivers with dementia, who experience gradually diminishing driving skills but may not recognize that their driving abilities may be compromised.

Currently, approximately 5.2 million older adults in the United States have a diagnosis of Alzheimer's disease (AD), and this number is rising [1]. Most of these individuals are, or were at one time, licensed drivers who use their own vehicle as their primary source of transportation [2]. Being able to drive represents freedom and independence. The loss of driving privileges can dramatically impact both the driver with dementia and his/her family [3–5].

It is estimated that approximately 30–45 % of individuals with AD drive and most drive alone [6–8]. Dementia impairs driving in a number of areas which are required to safely operate a vehicle: visual-spatial abilities, attention, memory, reaction time, and judgment. Not surprisingly, compared with most of the general driving population, drivers with dementia are at increased risk for unsafe motor-vehicle operation and crashes [9–11]. Becoming lost in familiar places is one of the most frequently reported incidents [12, 13]. Other common issues include decreased comprehension of road signs, difficulty with lane positioning, and problems making turns [14–16].

In spite of compromised driving ability, drivers with dementia do not necessarily stop driving, understate their driving difficulties, and overestimate their abilities [17]. Some drivers with dementia modify their driving habits by, for example, not driving at night, during rush hour traffic, or in bad weather – adaptations commonly made by all older drivers [17–19]. Drivers with dementia may have initial success in substituting self-regulation for declining skills; however, given the progressive nature of most dementias, the need for driving cessation is inevitable.

Drivers with dementia, perhaps more than other older adults, need the support and assistance of their family to make driving decisions. Research has shown that families of individuals with dementia are often aware of diminishing driving skills and expect that their relative will need to eventually relinquish his/her license [20]. However, many are reluctant or unprepared to address this topic [20]. They fear alienating their relative and that s/he may become depressed, withdrawn, lonely, or angry [3–5]. Once driving is discontinued, relatives are faced with the added responsibility of providing or securing transportation for the elder with dementia [14].

Drivers and families look to health-care providers, especially physicians, to take an active role and assist with driving concerns [20]. Patients and families often identify physicians as potential decision-makers for this issue [20]. Physicians not only possess the expertise to assess disease-related changes in functioning but also, as trusted members of society, function under the expectation that they will act responsibly toward both their patient and the public at large. As a matter of fact, in a few states, physicians are obligated to report a driver with dementia to the State Department of Motor Vehicles (DMV) and, when not mandated, can report any potentially unsafe driver [21]. However, like family members, physicians and other health-care providers are frequently unprepared to address driving concerns and fear alienating their patient when they do [22, 23]. Nonetheless, their unique position of being a trusted figure of respect and authority enhances the likelihood that their driving recommendations will carry weight, thus providing a critical service to patients, families, and licensing agencies.

As the prevalence of dementia increases, the interest in and concern about drivers with dementia will increase. Dementia affects the ability to drive safely; and driving skills will, predictably, worsen as the disease progresses. Physicians and other health-care providers will be expected to gauge the driving fitness of their patients with dementia. Finding the balance between public safety and the safety, freedom, and independence of the patient poses many challenges for providers. This chapter discusses ethical issues associated with driving and dementia, clarifies ethical responsibilities, and makes recommendations for assessing and managing impaired driving.

Ethical Issues

The responsibility of determining whether someone with dementia can continue to drive raises several ethical challenges for physicians. Physicians are expected to promote the health, well-being, autonomy, and quality of life of their patients. This responsibility extends to respecting patient privacy by safeguarding confidential information and protecting them from harm [24]. At the same time, physicians must consider whether their patient's driving is a potential hazard to public safety. Finally, they must consider whether their driving recommendation is proportionate to the actual risk to patient and public safety. A physician recommending a cognitively impaired patient for a driving evaluation, or in some cases driving cessation, would seem to be a logical and appropriate clinical decision that addresses both patient and public safety. However, in reality, it can lead to conflicts between the physician and the patient, as well as the family.

Mobility is important to the quality of life of many older adults. Driving one's own vehicle provides not only a means of transportation but also a representation of independent status and other positive benefits including choice, the chance to be spontaneous, privacy, and comfort. Driving signifies competence, self-reliance, and vitality. Therefore, drivers with dementia, who are already confronted with multiple losses, may view driving reduction and cessation as a concrete representation of declining function that further threatens their self-esteem and identity [14]. If patients fear that receiving a diagnosis of dementia will lead to immediate revocation of their license or, at a minimum, a referral to the DMV for testing, they may not seek care, disclose information, or trust their physician thus jeopardizing their health [24, 25]. Physicians are aware that a loss of driving privileges may be a hardship for patients. In addition, research has shown that physicians fear that reporting an unsafe driver to authorities could damage their relationship with a patient [23, 26]. A physician who does alert the DMV to a potentially unsafe driver faces the dilemma of alienating the patient versus putting the patient and public at risk if they do not alert the authorities.

Confidentiality is a core value of clinical practice and, for therapeutic compliance and efficacy, it must be safeguarded [25]. However, although there is a clearly defined understanding among physicians that they have an ethical responsibility to ensure that the health-care information of their patients is held in strict confidence, there may be circumstances when the release of this information is necessary. Hughes and Louw suggest that the physician and patient are engaged in a trusting relationship that includes the expectation of confidentiality [27]. However, the authors go on to state that confidentiality is one part of the relationship and that other factors can mitigate it.

The issue of ensuring patient well-being and privacy, versus safeguarding the public, can lead to competing demands being put upon physicians. Under some circumstances, state laws pertaining to operating a motor vehicle require exceptions to maintaining confidentiality. For example, some states mandate that physicians report individuals with certain medical conditions that could compromise driving safety to their DMV [24]. Community members assume that physicians will respect these laws, yet patients also have the right to assume that physicians will respect their right to privacy [28]. Concern about public safety versus patient privacy should not be considered incompatible since situations in which public safety is endangered would also endanger the patient [24, 29]. For example, in 2003, an 86-year-old driver confused the brake and gas pedals, lost control of his car, and, ultimately, killed ten people. This is a rare and an extreme example of the risk the older driver poses to public safety. However, tragedies such as this inevitably generate a public debate about driving restrictions for older adults [30]. Even in the early stages of the disease, drivers with dementia are at increased risk for suffering injuries or even death. Hunt et al., in a 2010 study of 207 drivers with dementia who became lost while driving in familiar locations, found that 70 were not found, 32 were found dead, and 116 were found alive of whom 35 were injured [31].

In the case of older drivers with dementia, where public safety versus patient privacy or confidentiality must be weighed, the principle of proportionality may be a useful concept. Hermerén suggested that proportionality could be applied as a principle of ethics and lists three conditions to consider: importance, relevance of means, and the most favorable option [32]. We can agree that the older driver with dementia merits consideration and, that being the case, actions taken to maintain safety of the patient and public must be achievable and be the least risky method to obtain the desired outcome. The last condition highlights the difficulties with decisions about driving that affect both the patient and the public. While the option of the driver with dementia stopping driving would be the best for public safety, it would not necessarily be the best option for the patient and, in fact, might cause significant difficulties including adverse effects on health. The question could be asked as to whether the risk of the patient's getting lost while driving, being involved in crashes, or having near misses is low enough to be considered acceptable if the loss of driving privileges will result in life-altering changes that involve both the patient and his/her family. It would be very difficult to make that calculation. Instead we can view this element of the principle of proportionality as simply a practical tool to examine means and ends as they relate to driving and dementia.

Driving Situations

The ethical challenges and uncertainty surrounding driving decision-making can make the management of this topic difficult for physicians. However, failure to recognize and address decline in driving skills can have significant and hazardous consequences for the driver, his/her family, and community.

Physicians must use their clinical judgment to determine whether a driver is at risk for being unsafe. A potentially unsafe driver puts both him/herself and the community at risk for sustaining crashes or injury. Once the question of risk is raised, physicians must assess the magnitude of that risk. They must consider the concept of proportionality and weigh competing factors of privacy versus public safety to determine how great a risk the patient's continued driving is to the driver and the public. Finally, after the provider makes a determination as to whether the patient is unsafe to drive, he/she must make a decision as to how best to manage the situation [33].

Clarifying Provider Responsibilities

Assessing fitness to drive is difficult. While researchers and policy makers debate the question, physicians and other health-care providers must determine how to best approach and resolve driving conflicts in their practices. The Veteran's Health Administration National Ethics Committee Report clarifies ethical responsibilities when evaluating and managing impaired driving in older adults and identifies several key areas providers must contemplate when addressing driving [33]. The report recommends that providers be informed about:

1. Warning signs of unsafe driving
2. Actions to take if a driver is suspected of being unsafe, including further evaluation
3. Actions to take in response to an evaluation – be it continued driving or not – including reporting an unsafe driver
4. Strategies for dealing with an unsafe driver who refuses to stop driving

Steps to Take

The AGS recommends that driving be routinely addressed with older patients [24]. Discussing driving early in the dementing process, when the drivers' judgment and cognition are at their best, allows driving plans to be made proactively rather than as a reaction to a driving mishap. Delaying driving discussions means only that the patient will be less able to participate in his or her own care planning once cognition has declined.

Before any decisions about driving can be made, it is necessary that a physician complete a comprehensive assessment that includes a review of medications, mental status testing, estimation of dementia severity, and driving history [34]. In the case of severe deficits or repeated episodes of poor judgment, a recommendation to stop driving can be confidently made. However, in most situations, decisions are less straightforward 24] (Fig. 7.1).

A driving history can be taken in a physician's or other provider's office, in a hospital room, or at an older adult's home. It can be conducted by a physician, a social worker, or other health-care provider [36]. A driving history should include questions about driving habits including frequency, distance, circumstances of travel, and familiarity with roadways used. Inquiries about unsafe driving, such as driving at inappropriate speeds, becoming lost in familiar areas, and a history of accidents or near misses, must also be made. When possible, it is important that the physician or other provider obtain permission from the driver to speak with someone familiar with his/her driving as drivers may lack insight into their limitations or be reluctant to report any problems. If the driving history suggests concern, further evaluation is needed unless the driver indicates that he or she will discontinue driving. A report could be filed with the DMV for reexamination or, if available and the driver agrees, a referral to a driver rehabilitation specialist (DRS) could be placed.

A DRS is an occupational therapist or kineseotherapist with specialized training to assess driving abilities [37]. The DRS conducts a clinical evaluation and, if appropriate, an on-road assessment. Evaluations vary but typically include interviews with the driver and his/her family, some type of cognitive or functional evaluation, vision testing, and rules of the road/sign identification test. Drivers who pass the clinical evaluation, indicating that core abilities meet minimum state licensing standards for vision, cognition, and physical ability, can move on to behind-the-wheel evaluation. The DRS usually provides immediate feedback after the assessment. The DRS can share information about medically correctable interventions, offer driving cessation counseling, and, upon request, will periodically reassess the older adult's driving. The DRS will also send a report to the patient's provider, who may then schedule a follow-up visit to share results and recommendations [24, 38, 39]. A social worker, when available, may join this meeting along with the DRS.

Even if the assessment reveals that the patient is a safe driver, discussions about driving modification and cessation should be regularly revisited. Suggestions for modification can include driving only in familiar areas, avoiding heavy traffic, avoiding driving at night and in bad weather, not driving alone, and driving less altogether, relying more on others for transportation. If the assessment reveals that the patient is an unsafe driver, the driver should receive encouragement to voluntarily stop driving. If the driver has been referred to the DMV or advised to quit driving, his or her compliance with the recommendations needs to be confirmed, reinforcing the notion that these recommendations were made as a matter of safety

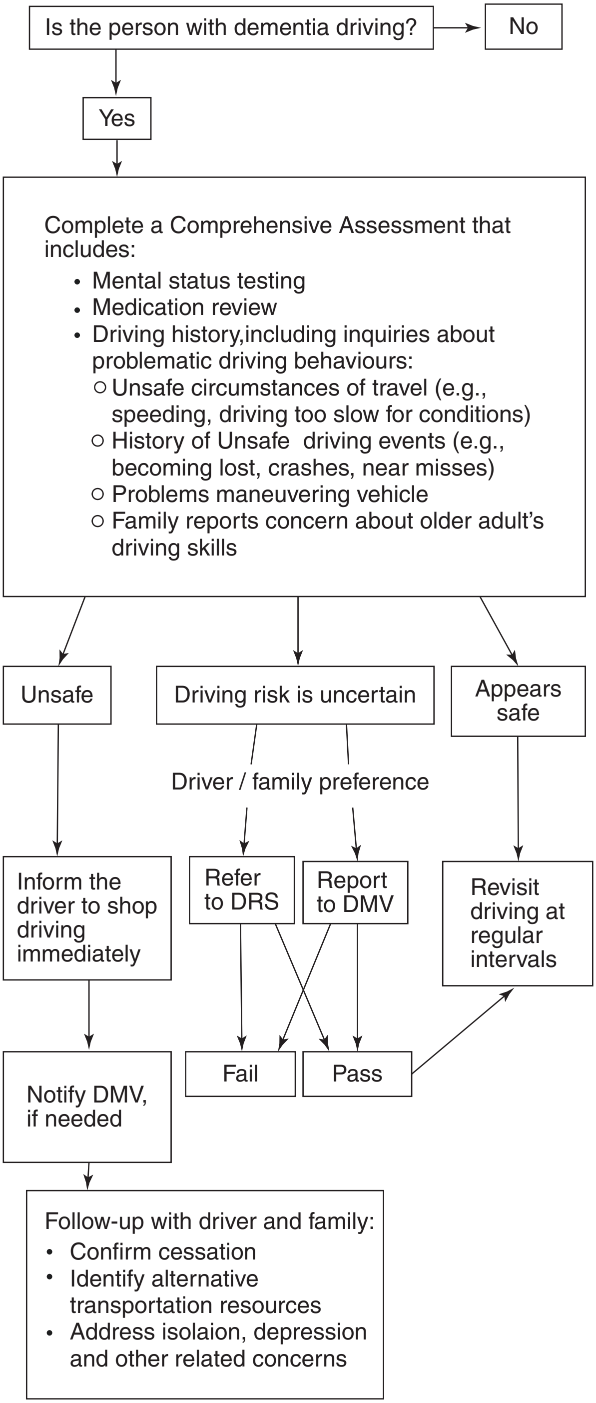

Fig. 7.1 Algorithm for determining driving decision-making for an older person with dementia. Adapted from Bloedow and Adler [35]. *Boxes* indicate key components and sequence of decision points in the driving decision-making process, and *arrows* indicate the direction of flow to the next step

for both the driver and the public. When possible, the family should be involved so that they can support the recommendation and help create a transportation plan.

Some drivers will insist upon driving, even when they have been advised to stop or have had their license revoked. As last-resort efforts, disabling the car, hiding the keys, moving the car to another location, or selling the vehicle may be necessary. A discussion of risk and insurance ramifications can also sometimes persuade the driver to quit. Meeting with an authority figure or someone the driver admired is another approach. Families should be encouraged to try different strategies to find one that works best in their situation. Often support and input from family, physicians, and the DMV are needed for restrictions to be successful.

Conclusion

Finding acceptable solutions for the matters associated with the older driver with dementia necessarily involves the cooperative efforts of patients, physicians, other providers, families, and government agencies. It is a challenge that often does not have a simple answer since the solution that benefits one may not benefit all or, in all likelihood, might adversely affect the other. In addition, because of the progressive nature of dementia, driving discussions should be ongoing and require revisiting as the disease progresses. Since there is currently not a definitive "gold standard" for determining fitness to drive, physicians have to make decisions based on their clinical judgment. Although most can agree that there is a point that a patient is unequivocally unable to safely continue to drive and that recommending driving cessation is absolutely necessary for the sake of patient and public safety, all too often decisions must be made when the best solution is not so clear. Because driving is such an integral part of our culture and quite often essential for obtaining even the most basic needs, many view it as a right rather than a privilege. In addition, a patient does have the right to privacy and confidentiality with regard to his/her relationship with his/her physician. It is this concept that poses one of the greatest ethical dilemmas for physicians and other health-care providers who care for an older driver with dementia as they must balance confidentiality with safety of the patient and public.

Practical Pearls

Common driving errors
Becoming lost in familiar locations
Decreased comprehension of road signs
Difficulty with lane positioning
Problems making turns
Warning signs of unsafe driving
Drives too slowly or too fast
Stops in traffic for no reason or ignores traffic signs

Becomes lost on familiar routes
Has poor judgment
Has difficulty with turns, lane changes, or freeway exits
Drifts into other lanes of traffic or drives on the wrong side of the street
Signals incorrectly or does not signal
Relies on a copilot for driving instructions
Has difficulty seeing pedestrians, objects, or other vehicles
Falls asleep while driving or becomes drowsy
Parks inappropriately
Has frequent traffic violations or episodes of being pulled over by law enforcement
Is nervous or irritated when driving
Has accidents, near misses, fender benders, or unexplained dents and scratches on the vehicle
Has a family member that will not ride with driver or allow other relatives to ride with the driver
Recommended driving modifications
Driving only in familiar areas
Avoiding heavy traffic
Avoiding driving at night and in bad weather
Not driving alone
Driving less altogether
Last-resort efforts
Disabling the car
Hiding the keys
Moving the car to another location
Selling the vehicle

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Medical Futility

8

Gregory A. Holton and Angela G. Catic

Introduction

The concept of medical futility often arises when terminally ill patients, or their surrogate decision-makers, request aggressive interventions that medical professionals view as being without benefit or having a significant risk of causing undue harm. In these cases, the idea of futility is often invoked as a justification to withhold or withdraw care. When patients or surrogates disagree with the presented justification and continue to insist on the requested interventions, tension may arise between the ethical principles of autonomy and those of beneficence, nonmaleficence, and justice. Poor communication and mistrust of the medical profession can increase the complexity and degree of conflict in these challenging situations. Medical providers should employ preventative strategies to minimize conflicts around futility through ensuring patients have advanced directives and maintaining open communication with the patient/surrogate decision-maker throughout the course of illness. While most conflicts regarding potentially inappropriate interventions can be resolved, intractable conflicts do occur. When this is the case, medical staff should turn to hospital ethics committees, policies, and laws for guidance.

G.A. Holton, MD (✉)
Internal Medicine, Baylor College of Medicine, Houston, TX, USA
e-mail: holton@bcm.edu

A.G. Catic, MD
Department of Internal Medicine, Section of Geriatrics, Baylor College of Medicine and
Michael E. DeBakey VA Medical Center, Houston, TX, USA
e-mail: angela.catic@va.gov

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History of Futility

Modern life-support systems, including mechanical ventilation, artificial nutrition, and renal replacement therapy, enable physicians to prolong life substantially. However, the rapid advancement of these technologies has historically outpaced the accompanying ethical considerations and can result in significant negative impacts on quality of life. Early "right-to-die" cases, examining the ethical and legal implications of withdrawing life-sustaining measures, deferred to wishes of the patient or surrogate decision-maker. In the landmark 1976 case of Karen Ann Quinlan, who was in a persistent vegetative state following an anoxic brain injury, the New Jersey Supreme Court ruled in favor of the patient's family and legalized withdrawal of mechanical ventilation [1]. Following this ruling, the primacy of patient autonomy to decline medical treatments gained widespread acceptance. Subsequently, in the 1990s, focus shifted to the legal and ethical implications of withdrawing life-sustaining measures against the wishes of the patient or surrogate decision-maker in cases where healthcare providers viewed the situation as "futile." Much of the early debate regarding futility stemmed from the case of Helga Wanglie, an elderly woman who suffered an anoxic brain injury in May 1990 [2]. Subsequent to this insult, Mrs. Wanglie was in a persistent vegetative state requiring permanent mechanical ventilation. Her husband and children, acting on her behalf, insisted that Mrs. Wanglie valued quantity of life at all costs and requested that she be continued on mechanical ventilation indefinitely. Mrs. Wanglie's physicians disagreed with this request as they felt it was unethical to continue mechanical ventilation given her permanent state of unconsciousness. As no consensus could be reached, this case was heard in court where the judge ruled in favor of Mr. Wanglie, ordering the physicians to continue mechanical ventilation. Mrs. Wanglie died 3 days after the ruling, while still receiving mechanical ventilation.

Following Helga Wanglie's death, the American Thoracic Society published a position statement regarding withholding and withdrawing life-sustaining therapy in *Annals of Internal Medicine* [3]. The authors describe the concept of futility as a justification for withdrawing care, such as mechanical ventilation, in cases similar to Mrs. Wanglie's. They define futility as follows: "A life-sustaining intervention is *futile* if reasoning and experience indicate that the intervention would be highly unlikely to result in a *meaningful survival* for the patient. Here, meaningful survival specifically refers to a quality and duration of survival that would have value to that patient as an individual. Survival in a state with permanent loss of consciousness, that is, completely lacking cognitive and sentient capacity, may be generally regarded as having no value for such a patient."

Following the publication of this statement, a national debate over the concept of medical futility ensued. Robert Truog, a leading ethicist, argued that plurality of values and statistical uncertainties critically undermine the concept of futility [4]. This argument against broad definitions of futility, which attempted to normalize what constituted acceptable risk, suffering, and quality of life, prevailed. Current policy statements focus less on the concept of futility and, instead, provide guidelines for preventing or resolving intractable conflicts regarding potentially inappropriate care.

Futility Versus Potentially Inappropriate Care

Medical professionals should exercise great caution in labeling an intervention as “futile” and using this as a justification to withhold or withdraw care. Ethically, this requires a strict definition of futility which avoids implicit value judgments. Instead, medical professionals should discuss the goals and values of each individual patient explicitly and avoid making implicit assumptions by labeling an intervention as “futile.” In addition, they must recognize and respect that what constitutes an acceptable degree of suffering or quality of life for an individual patient may be very different than their own personal beliefs or values.

If an intervention is to be judged as futile, it should be asked “Futile in regards to what?” The concept of futility is often dichotomized into qualitative and quantitative futility. Qualitative futility refers to interventions that produce benefits considered by the majority of people to be of poor quality. For example, hemodialysis may be considered qualitatively futile if its sole benefit is to prolong the life of a permanently unconscious patient on maximum life support who has no chance of meaningful recovery. In contrast, quantitative futility refers to interventions that have an extremely low probability of achieving success. For example, a fifth line of chemotherapy for a refractory cancer may be considered quantitatively futile because the probability of achieving benefit is extremely low. Both qualitative and quantitative categories of medical futility can be ethically problematic. Differing value systems often undermine qualitative futility. Many individuals would not wish to live in an intensive care unit on life-support machines as they do not view this as a meaningful quality of life. However, some patients value quantity of life at all costs and would wish to be maintained on life support in a high-acuity environment even if there was no probability that their medical situation would improve. The quantitative concept of futility also has inherent difficulties due to medical uncertainty and differing tolerances of low-likelihood interventions. Patients and families often question how accurately medical professionals can predict outcomes, such as the success of cardiopulmonary resuscitation (CPR), and these issues should be discussed explicitly in the context of each individual patient’s goals and wishes.

Due to the challenges of the qualitative and quantitative definitions of futility, many medical organizations have argued for a strict definition whereby an intervention is only considered futile if it cannot accomplish the physiologic goal [5, 6]. For example, chemotherapy would be a futile intervention to eradicate acute bacterial pneumonia, and conventional CPR would be futile in the settings of myocardial free wall rupture because chest compressions would not circulate blood [4]. Healthcare providers have no ethical obligation to comply with requests for interventions that meet the strict definition of physiologic futility.

In situations where an intervention can reasonably accomplish the physiologic goal, but strong ethical arguments can be made against it, the intervention should be termed “potentially inappropriate” [6]. This verbiage makes no paternalistic assumptions and opens the situation up for further discussion. Continuous, open, and honest communication between the patient/surrogate decision-maker and healthcare providers is key to both preventing and resolving conflicts over potentially inappropriate interventions.

Strategies to Prevent Conflict

Strategies including careful advanced care planning, skillful communication, appropriate consultation, and aggressive palliation can be instrumental in preventing conflict and determining an acceptable plan of care in cases of potentially inappropriate interventions.

Advanced Care Planning

Many conflicts regarding what constitutes appropriate care arise when patients are unable to express their wishes but have not established a surrogate decision-maker or documented their healthcare goals. Advanced directive documents allow patients to identify their preferred surrogate decision-maker and communicate their wishes regarding medical goals of care so this information is available if they lose decision-making capacity. These written documents can greatly help treatment teams and families make decisions regarding aggressive interventions near the end of life. Unfortunately, recent studies have determined that only 26.3–42.4 % of adults in the United States have completed advanced directive documents [7, 8]. Those at the upper end of this range are usually elderly or suffer from significant medical illness.

Various federal, state, and local efforts are currently under way to normalize end-of-life planning and increase the prevalence of written advanced directives. Nationally, a measure was passed in 2015 through which Medicare will reimburse physicians and other qualified healthcare providers for providing advanced care planning, including discussing and completing written advanced directives [9]. On the state level, Oregon has been very progressive with development of the physician orders of life-sustaining treatment (POLST) paradigm in 1991 and the incorporation of these forms into a statewide electronic registry for medical providers in 2009 [10, 11]. These forms allow patients or surrogates to sign DNR orders in addition to making decisions regarding aggressiveness of care, antibiotics, and artificial nutrition. On a local level, Gundersen Health System and Franciscan Skemp Healthcare pioneered an innovative advanced care planning program entitled Respecting Choices in La Crosse, Wisconsin, in 1991 [12]. As a result of this program, >80 % of the La Crosse residents who died between April 1995 and March 1996 had written advanced directives. Gundersen Health System subsequently developed a curriculum to teach other healthcare systems the model which has been adopted by Kaiser Permanente Northern California, Australia's National Health Service, and the Minneapolis metropolitan area. Much can be learned from these models regarding maximizing advanced directive discussions and documentation with all patients.

Communication Skills

Suboptimal communication between medical providers and patients/surrogate decision-makers can significantly contribute to conflicts around medical decision-making due to misunderstandings and mistrust. For example, ineffective communication regarding the severity of illness and prognosis can lead to requests for potentially inappropriate interventions in dying patients. Fostering a healthy therapeutic relationship through effective communication with patients and surrogates is key to preventing conflict. Healthcare providers should consciously work to optimize their communication skills and, when communication barriers exist, make every effort to negotiate these barriers and seek the help of experts including ethics teams. Communication should be open, honest, and continuous. Communication strategies, such as the SPIKES protocol, can be used for breaking bad news and focusing on patient values rather than the disease process [13]. This type of focus can help foster healthy therapeutic relationships and prevent conflict regarding potentially inappropriate treatment. Providers should also make a conscious effort to understand prior experiences and perceptions which may be underlying patient/surrogate requests for potentially inappropriate interventions. For example, an elderly patient with multiple organ system dysfunction due to refractory shock may request full resuscitative measures because they fully recovered from a past cardiac arrest, or a patient with widely metastatic cancer may decline hospice treatment because of a traumatic experience with a loved one dying on hospice with inadequate symptom management.

Early Consultation

In situations where there is any anticipated discord regarding appropriate treatment plans, medical teams should obtain consultation from appropriate specialty services prior to recommending a patient not to pursue certain interventions or de-escalate goals of care. For example, a frail elderly patient with severe symptomatic aortic stenosis who wishes to pursue all possible treatment options should be evaluated by cardiology, and possibly cardiothoracic surgery, regarding candidacy for transcatheter aortic valve replacement or surgical valve repair prior to making recommendations for hospice. Specialists are often particularly helpful in clarifying diagnostic and prognostic uncertainties. For example, a patient with persistent obtundation should receive a full neurologic evaluation prior to making any decisions regarding future care and, if uncertainties persist, second opinions should be sought. If providers have different opinions regarding what treatment options are appropriate and inappropriate, they should make every effort to reach a consensus and present a unified, consistent message to the patient and family. Recommending de-escalation of goals of care without appropriate specialist input is inadvisable and can lead to substantial mistrust and conflict.

In situations where there is ongoing conflict within the healthcare team or between providers and the patient/family regarding appropriate care, the hospital ethics committee should be consulted. Ethics committees differ between institutions but often include palliative care experts, geriatricians, ethicists, and senior hospital administrators. As experienced, expert communicators, they are often able to guide all involved parties in reassessing the situation and focusing on the goals of the patient. Ethics committees are also well versed in institutional policies and procedures. In cases of intractable conflict, they can assist in negotiating transfers to outside facilities or initiating legal proceedings in an ethically and legally appropriate manner.

Aggressive Palliation

When withholding or withdrawing life-sustaining interventions is considered, many patients and families fear abandonment from medical providers. This fear can lead to mistrust of the medical team, indecision about the best plan of care to support patient goals, and conflict between caregivers and family members as well as within families. Providers should preempt this by introducing the concepts of palliative care and hospice early in the course of terminal illness, as opposed to waiting until an acute decompensation occurs. Early introduction of palliative care has become much more common in oncology patients with an increase in outpatient palliative care clinics. The success of this model should be replicated for non-oncologic terminal illnesses including dementia and end-stage heart disease. Whenever a transition to palliative care or hospice is considered, providers should reassure patients and families that, while the focus of care may change, the team will continue providing intensive care to ensure the goals of comfort and symptom management are achieved.

Approaching Conflict

Assess Urgency of Decision-Making

In cases of potentially inappropriate care, the first branch point in decision-making is assessing the urgency of the intervention. A formal, process-based approach to conflict takes days to weeks and is not possible when a decision must be made within hours. Therefore, providers should familiarize themselves with the institutional policy for addressing urgent requests for potentially inappropriate interventions. For example, a surrogate decision-maker may request that an elderly patient who has suffered a massive pulmonary embolism to be placed on extracorporeal membrane oxygenation. If the treatment team reaches a consensus that the intervention would not help to facilitate the patient's goals of care and should be withheld, the team should seek the immediate support of specialists and input of senior hospital administrators. In this type of situation, administration may be able to negotiate an expedited transfer to a facility that would be willing to perform the intervention in question. When decisions can be deferred for days to weeks, healthcare teams should consult the hospital ethics committee and begin a formal process of conflict resolution. The patient and/or surrogate decision-maker should be notified of the ethics consultation and informed about the conflict resolution process.

Surrogate Decision-Makers and Substituted Judgment

The ethical principle of patient autonomy plays a key role in medical decision-making in the United States. In cases where patients lack capacity to make their own decisions secondary to severe medical or cognitive compromise, patient autonomy is approximated through the substituted judgment of a surrogate decision-maker. Ideally, surrogate decision-makers should have a close, caring relationship with the patient, understand the patient's values and beliefs, and be willing and capable of making medical decisions based on their best knowledge of the patient's wishes. In situations where a surrogate decision-maker has not been designated, state laws dictate which family member will make decisions for a patient who lacks capacity to do so. If no surrogate or family is available, providers should follow applicable policies and seek a court-appointed guardian.

Conflicts occasionally arise when providers suspect that the surrogate is not acting in the best interest of the patient or blatantly disregarding the patient's values. In rare cases, providers may suspect that the surrogate is seeking secondary gain by artificially prolonging the patient's life or acting with malevolent intent. In these situations, surrogates may exhibit concerning behaviors such as repeatedly missing agreed-upon family meetings, avoiding contact with healthcare providers, or insisting that the patient is improving despite objective data clearly indicating that they are declining. If there are concerns about the intention of surrogates to act in the best interest of the patient, providers should involve the ethics committees to ensure the rights of the patient are being appropriately advocated for and to assist in conflict resolution.

Follow Hospital Policy/State Law

In situations where resolution regarding appropriate treatment cannot be reached, it is important to follow all applicable institutional policies and relevant laws. The 2015 American Thoracic Society policy statement recommends the following steps for addressing intractable conflicts regarding appropriate care [6]:

1. Enlist expert consultation to continue negotiation during the dispute resolution process.
2. Give notice of the process to surrogates.
3. Obtain a second medical opinion.
4. Obtain a review by an interdisciplinary hospital committee.
5. Offer surrogates the opportunity to transfer the patient to an alternate institution.

6. Inform surrogates of the opportunity to pursue extramural appeal.
7. Implement the decision of the resolution process.

These recommendations can serve as a guide for hospitals to develop or review existing policies to ensure systems are in place to provide an explicit, consistent, and fair process for dispute resolution. In most cases, policies regarding conflict resolution around appropriate care are consistent within hospital networks or healthcare systems. It is important to continually review processes and policies around conflict resolution to ensure fairness to all involved parties. For example, in Texas, a process of dispute resolution has been outlined for the entire state through the Texas Advance Directive Act of 1999 [14]. For all intents and purposes, the law provides hospital ethics committees with the final say on withholding or withdrawing interventions. Once this determination is made, the surrogate decision-maker is given 10 days to transfer the patient to another facility before the intervention is withdrawn. In addition, the patient's family may make an appeal to the court for this time to be extended. Although the Texas policy allows for timely resolution of disputes with withdrawal of care or transfer to another facility, critics argue that it places too much power in the hospital ethics committees, which are often composed of colleagues and friends of the treating teams [15]. Providers should familiarize themselves with the policies and laws applicable to their practice and be cognizant of the strengths and weaknesses of these policies in order to act fairly and avoid abuses.

Futility and Do-Not-Resuscitate Orders

Issues around potentially inappropriate patient/surrogate preferences regarding intubation and cardiopulmonary resuscitation (CPR) remain a key paradigm in the concept of medical futility. In the United States, people are assumed to be "full code," meaning that all possible resuscitative measures would be employed, unless explicitly stated otherwise. CPR and intubation, unless attempted too late after irreversible death has occurred, nearly never meet the definition of physiologic futility. Thus, CPR should not be unilaterally withheld without a thoughtful discussion with the patient and surrogates regarding the risks and benefits. If the providers believe that the risks of harm (i.e., broken ribs, impaired neurology state if resuscitation is successful, emotional trauma) outweigh potential benefits, this should be discussed in an empathetic, honest manner with the patient/surrogate in an attempt to reach a consensus. Unfortunately, conversations regarding the probable utility of CPR often occur during periods of acute medical crises and on the first meeting of the care team with the patient/surrogate leading to communication challenges and increased potential for mistrust.

The relative lack of understanding regarding the process and outcomes of CPR by the lay public often contributes to the challenging nature of these conversations. In popular television shows and movies, relatively healthy patients are often portrayed undergoing a short period of shallow chest compressions before regaining a pulse and making an immediate neurologic recovery. In 60 occurrences of CPR on television, 65 % of which were portrayed in youth or young adults, 75 % of patients survived the immediate arrest and 67 % were eventually discharged from the hospital [16]. This is in contrast to real-life resuscitation where approximately 18 % of patients who undergo CPR survive to hospital discharge [17]. Perhaps of even greater importance to patients than initial survival statistics is data regarding long-term outcomes following CPR. In a study of individuals age 65 years and older who were successfully discharged from the hospital following resuscitation, 58.5 % were alive at 1 year and 34.4 % had not been readmitted to the hospital during that time period [18]. Of note, 1-year survival was lower among older patients compared to younger individuals: 63.7 % among patients 65–74 years, 58.6 % among those 75–84 years, and 49.7 % among those ≥85 years. Patients and family members who view CPR from the perspective of popular media, not from the more grim, real-life perspective, may feel deeply offended or abandoned if physicians suggest attempts at CPR are not indicated. Providers should focus on understanding each individual patient's goals of care and, with this at the core of the conversation, attempt to help the patient/family understand the current medical situation and the likely outcomes of any attempts at resuscitation.

The fear that their goals will be misinterpreted or that they will be deprived of life-saving treatments can also be substantial barriers to patients choosing to become "do not resuscitate" (DNR). While some patients may wish to forgo resuscitative efforts including chest compressions and intubation, they would be willing to receive other aggressive treatments such as intensive care unit admission with vasopressors or noninvasive ventilation. In these situations, some providers may be reluctant to provide components of aggressive care in a patient who would ultimately not wish to undergo full resuscitative efforts. In a study of physicians presented with hypothetical medical scenarios, they were less willing to offer certain interventions including central line placement (68 versus 80 %) and blood cultures (91 versus 98 %) for patients who had a DNR order compared to those who did not [19]. Another study evaluated the impact of a recent DNR order on survival among patients undergoing a vascular surgical procedure [20]. Among subjects who had an active DNR order within 30 days prior to surgery, there was a trend toward increased perioperative mortality (21 versus 13 %) compared to matched subjects who had not had a prior DNR suggesting a trend toward reduced cardiopulmonary resuscitation. These studies highlight the need for health professionals to understand patient goals and provide all interventions which would support these without being biased by code status. In addition, frank discussions with patients and families are warranted to assure them that life-saving treatments will be provided to the degree desired irrespective of their wishes regarding resuscitation.

Although the importance of respecting patient/surrogate goals and not imposing personal biases on conversations regarding resuscitation cannot be overstated, there are instances where CPR is clearly inappropriate, and providers should advocate strongly for DNR orders in these situations. For example, a nonverbal 95-year-old with end-stage dementia, contractures, pressure ulcers, and severe malnourishment should not undergo chest compressions as the individual would most certainly suffer pain and other adverse effects of resuscitation efforts if CPR was successful. In these situations, providers should become comfortable in compassionately guiding patients and families toward the decision to forego CPR. Working with expert communicators, such as palliative care providers, can be helpful in learning appropriate communication techniques and specific phrases to use during these conversations. For example, the phrase “do not resuscitate” can be interpreted by families as portraying a sense of abandonment. Alternatively, the phrase “allow natural death” is kinder and may be better received. Another potential strategy which can be employed in cases where CPR is unequivocally inappropriate is to seek a family’s agreement to a DNR through informed assent. In the process of informed assent, if the treatment team is confident that CPR would be unethical based both on patient’s clinical condition and their previously stated values/preferences, they can inform the family of intentions to write a DNR order and allow the family to agree or disagree [21]. The use of informed assent can potentially alleviate fears and moral distress families may experience regarding “giving up” or “abandoning” their loved one as the active decision to forgo CPR rests with the medical team.

Providers who are unsuccessful in obtaining DNR orders for patients in whom CPR is felt to be inappropriate are often tempted to circumvent this problem by offering a “slow code.” In this scenario, the healthcare team may intentionally arrive late to a code situation such that irreversible death sets in or offer weak, inadequate chest compressions for a limited time. The idea behind a “slow code” is to spare a patient’s body from the extremes of a full resuscitative effort. “Slow codes” are clearly unethical and dishonest. The basic premise of the “slow code” is to put on a show of resuscitative attempt in order to satisfy the family. These halfhearted attempts are not designed to restore circulation and oxygenation and, thus, also meet the definition of physiologic futility. Instead of resorting to “slow codes,” providers should pursue more intensive communication regarding the appropriateness of CPR and, if necessary, involve the hospital ethics committees to assist with the process and potentially enact a unilateral DNR order if CPR is unequivocally inappropriate.

The CPR process should be viewed as one in which the providers continuously reassess the appropriateness of resuscitation. The decision to forego or stop a code and declare death is itself a judgment in futility. Providers have no obligation to perform chest compressions on patients without DNR orders who are clearly irreversibly dead, such as those showing signs of livor mortis or rigor mortis. When resuscitative measures are clearly failing and causing grossly excessive bodily harm, providers are required to make judgments regarding the futility of the intervention and when to discontinue efforts. The provider running the code should seek the consensus of the code team prior to termination.

Conscientious Objections

Some providers may feel compelled to refuse certain interventions based on religious or moral convictions. For example, a nurse who is a Jehovah’s Witness may feel religiously proscribed from starting blood transfusions or a provider in Oregon may morally refuse to participate in physician-assisted suicide. Such conscientious objections play an important role in preserving providers' moral integrity, but need to be handled carefully. Accommodating conscientious objections can potentially cause delays or barriers to indicated care leading to excessive hardship on other providers or even discrimination. Recognizing these potential issues, the American Thoracic Society has published recommendations for handling conscientious objections in intensive care units [22]. These include ensuring the following criteria are met: (1) Institutional policies are in place to manage conscientious objections. (2) The accommodation does not impede timely care. (3) The accommodation does not create excessive hardship for other members of the care team. (4) An environment of respect and open discussion around conscientious objections is encouraged.

Case Discussion

The following case is presented to illustrate practical strategies which can be used to guide a patient through decisions around appropriate care. As the case unfolds, you are encouraged to consider how you would interact with the patient and manage his medical care.

Mr. R is a 76-year-old African-American male with severe aortic insufficiency associated with chronic dyspnea on minimal exertion who presents to the hospital from home with a two-day history of fevers, increasing dyspnea, cough, and neck pain. In discussion with Mr. R, it becomes clear that he is not aware of details regarding the prognosis of his aortic valve disease and resultant heart failure. He recalls speaking with a surgeon and a cardiologist a few months ago regarding his "leaky valve" but was not offered surgical intervention at that time. Mr. R has not completed advanced directives in the past. He states that he would like his wife to make medical decisions if he is unable to do so and would wish to have all available treatments, including CPR and intubation.

This case presents the all-too-common scenario where a terminally ill patient does not understand their disease process and has not had prior conversations regarding goals of care. In the setting of clinical decompensation, clinicians are often required to discuss not only the acute presentation but the prognosis as it relates to the underlying chronic condition. In this case, the provider should recognize that Mr. R's symptoms indicate an acute illness that could be reversible or could lead to the patient's death during his hospitalization. In the face of this uncertainty, it would be inadvisable to recommend against full care without learning more about the patient's goals and values since ICU care, including intubation, could potentially save his life, and a premature DNR order could prohibit this possibility. However, once Mr. R is intubated, he would be at high risk of losing decision-making capacity if his condition worsens and he progresses toward death. Therefore, it is important to inquire about his preferences around ongoing life-sustaining measures should he require prolonged intubation.

After Mr. R states that he would want to be full code, the team discusses their concerns regarding a worst-case scenario where he would require prolonged life *support. He answers that "If it looks like you can't get me back, I wouldn't want to be kept alive forever on machines." During the first day of hospitalization, Mr. R rapidly develops neck swelling causing increasing dysphagia and muffled voice. Emergent direct laryngoscopy reveals a compromised airway. The otolaryngologist recommends monitoring in the ICU with difficult intubation and tracheostomy supplies at bedside. Prior to transfer, the patient again consents to intubation, tracheostomy, and CPR if indicated but states that he would want life support withdrawn if he does not recover. He is transferred to the ICU where he is intubated for airway protection and sedated.*

Mr. R has clearly expressed his goals of care and the treatment team should respect these goals. Having a worst-case scenario conversation with patients, such as when the team discussed the need for prolonged life support with Mr. R, is critical in preventing future conflict and moral distress.

Once he is in the ICU, Mr. R is diagnosed with Ludwig's angina with neck imaging revealing a large abscess. The abscess is drained and the patient continues on antibiotic treatment. Over the next few days, Mr. R's condition improves. He is successfully extubated and transferred out of the ICU. Following transfer, Mr. R is severely deconditioned and volume overloaded but has minimal shortness of breath at rest.

Now that the acute crisis has passed, the primary team begins preparing Mr. R for discharge. At this point in his care, the path of least resistance would be to medically optimize him and plan for discharge to a skilled nursing facility where he can receive rehabilitation. However, it would be in Mr. R's best interest for the team to have further conversations with him regarding his medical goals prior to discharge from the hospital. If he is not a candidate for repair of his aortic valve, it is very likely that Mr. R will soon return to the hospital with worsening heart failure symptoms. If repeated hospitalizations are not in keeping with his goals, alternatives such as hospice care could be considered. At this time, it would be helpful for the primary team to enlist the input of cardiology and cardiothoracic surgery to assist Mr. R in understanding possible treatment options and prognosis as related to his aortic valve disease.

Cardiology and cardiothoracic surgery evaluate Mr. R and, unfortunately, are unable to offer him curative intervention as they reach the consensus that the risks of intervention outweigh the possible benefits. They agree that he has end-stage heart disease.

Once the primary team has the input of the cardiology and cardiothoracic surgery, they arrange a multidisciplinary meeting to break the bad news to Mr. R regarding his prognosis using the SPIKES protocol and elicit his end-of-life preferences. Depending on Mr. R's goals, it will most likely be reasonable to discuss home hospice as a discharge option as this could provide supportive services for the patient and his family.

The team discusses the prognosis of his aortic valve condition with Mr. R. He voices his understanding and states "If there is no way to cure it, I don't really see any reason for coming back to the hospital over and over. I would really rather *spend the time I have left at home with my family." Based on his goals, the team arranges for Mr. R to be discharged home with hospice services.*

Conclusion

Given the multiple ethical and clinical challenges associated with the concept of futility, it is helpful to consider interventions in terms of being appropriate or potentially inappropriate. Clinicians should employ strategies to prevent potentially inappropriate care including advanced care planning, open communication, early consultation, and education about palliative care and hospice. If intractable conflicts regarding requests for potentially inappropriate treatments occur, these should be handled through the hospital ethics committee and should follow a fair process of dispute resolution. Decisions regarding resuscitation are often challenging. It is important for clinicians to elicit patient goals and provide accurate information regarding the risks and benefits of CPR during conversations around resuscitation. In patients for whom CPR is unequivocally inappropriate, providers should advocate for DNR orders or consider using informed assent.

Practical Pearls

Continuous, open communication is key to building trust and preventing conflict
Providers should seek to understand each patient's life outside the context of illness including understanding their values, hopes, and fears and how these relate to goals of care
Providers should refrain from prematurely labeling interventions as futile or using this as justification for withholding or withdrawing care. Instead, they should first ensure a clear understanding of the patient's medical goals and elicit input from relevant specialists to ensure a clear understanding of the clinical situation
Teams should involve communication experts, such as palliative care providers or hospital ethics committees, when faced with conflict around appropriate care
Institutions should have policies regarding conscientious objections. These should ensure that conscientious objections do not impede timely patient care or create excessive hardship for members of the medical team

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Feeding Issues in Advanced Dementia

9

Nicolin Neal and Angela G. Catic

Case Discussion

During a hospitalization for pneumonia, the daughter/surrogate decision-maker of an 88-year-old lady with dementia is approached by the treating physician to discuss options to address feeding issues and associated aspiration. The patient has been hospitalized three times in the past 8 months secondary to aspiration pneumonia and has been steadily losing weight. At her care facility, it is noted that she often pockets food in her cheeks and appears to have forgotten how to feed herself. The physician discusses with her daughter that feeding issues are common in dementia and a hallmark of the later stages of the disease. She reviews that feeding tubes do not prevent aspiration and that tube feeds have not been shown to improve outcomes in elders with advanced dementia. The patient's daughter states that her mother has always enjoyed the taste of food and interacting socially around meals. She does not believe her mother would wish to have a feeding tube or other artificial interventions for nutrition. The decision is made to pursue hand-feeding, so she can taste food and interact with caregivers, without a focus on nutritional intake. The patient returns to her long-term care facility where she appears to enjoy interacting with caregivers around meals until the end of her life 6 months later.

N. Neal, MD (✉)
Post Acute Care, IPC Healthcare, Houston, TX, USA
e-mail: Nineal@ipc-hub.com

A.G. Catic, MD
Department of Internal Medicine, Section of Geriatrics, Baylor College of Medicine and
Michael E. DeBakey VA Medical Center, Houston, TX, USA
e-mail: angela.catic@va.gov

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Introduction

Enteral nutrition, providing food through a tube in the nose, stomach, or small intestine, is often offered to those with inadequate oral intake of nutrients and hydration. It has been considered as a treatment option for elders with advanced dementia who develop feeding issues as part of their disease progression. However, in this population, there is no evidence that tube feeding improves comfort or outcomes and it can result in significant adverse effects. Despite this, enteral feeding continues to be offered for a variety of reasons including hospital- and long-term care-related factors. In contrast to enteral feeding, there are multiple documented benefits to hand-feeding in individuals with advanced dementia. Ideally, discussions regarding feeding issues and options to address these should be held early in the course of dementia when the patient is able to express their wishes regarding the topic [1].

Feeding Tubes

Enteral nutrition may be provided through a variety of techniques, all of which bypass the mouth and esophagus, providing nutrition directly into the stomach or intestine. Nasoenteric tubes that pass from the nasal cavity directly into the stomach or intestine are generally indicated for enteric feeding duration of less than 30 days. For enteral nutrition requirements beyond 30 days, percutaneous gastrostomy tubes (direct communication between the abdominal wall and stomach) are preferred over nasoenteric tubes as they are associated with lower rates of complications including mucosal ulceration, bleeding, aspiration pneumonia, and esophageal reflux. In addition, they are generally more comfortable for the patient. The percutaneous endoscopic gastrostomy (PEG) tube placement technique emerged in the 1980s and is now the preferred method for gastrostomy tube placement. In contrast to other surgical tube placement techniques, it is more cost-efficient, less invasive, and can often be performed without general anesthesia [2]. Due to the perceived low risk and relative in-expense, this procedure is often extended to a wide variety of populations for nutritional support, including individuals with advanced dementia [3].

Advanced Dementia and Feeding Issues

Feeding issues, including loss of interest in eating, dysphagia, or both, occur in 90 % of individuals with advanced dementia and is typically the last activity of daily living (ADL) lost prior to death [3–6]. Other issues which may impact feeding at various stages of dementia include loss of appetite; medication side effects; depression; poor oral health (broken teeth, ill-fitting dentures); forgetting to eat; inability to recognize food (agnosia); inability to go through the steps of eating including using utensils, chewing, and swallowing (apraxia); delusional thoughts (someone poisoning the food); and true dysphagia [7]. When feeding issues occur, the option of nutritional augmentation through a PEG tube is often offered as a solution. While using a PEG tube to provide nutrition may seem like a reasonable solution, evidence suggests that artificial feeding does not improve patient outcomes in advanced dementia and may cause increased harm. Despite evidence to the contrary, common misperceptions persist regarding the use of and outcomes associated with artificial nutrition in patients with advanced dementia. In a survey of 195 physicians, 90 % believed enteral feeding would improve nutritional status, 75 % believed it would decrease the risk of aspiration pneumonia, and almost 40 % believed it would alleviate discomfort from thirst and hunger in patients with advanced dementia [8]. Families also often believe that PEG feeding will prevent discomfort or pain from thirst and hunger in their loved ones with dementia [9]. Despite evidence to the contrary, the perceived benefits and ease of PEG tube placement have contributed to feeding tube placement in elders with dementia approaching 40 % nationwide in long-term care facilities [3, 10, 11].

Evidence Regarding PEG Tubes in Advanced Dementia

PEG Tubes and Nutrition

Despite common perceptions, tube feeds do not improve the nutritional status of individuals with advanced dementia. In a study of 40 long-term care residents with poor cognitive and functional status who were receiving optimal enteric feedings over a 3-month period, subjects continued to lose weight and laboratory measures of nutrition (serum protein, hemoglobin, and zinc) were in the low normal to below normal range [12]. In fact, the extent of weight loss and malnutrition increased over time, despite enteric nutrition, in individuals with advanced dementia [13]. Complications from enteral feeding, including diarrhea and electrolyte disturbances, can result in further declines of nutritional status.

PEG Tubes and Aspiration

Although feeding tubes are commonly placed with the misperception that they will prevent aspiration, aspiration of oral secretions and regurgitated gastric contents commonly occur in elders with PEG tubes [14]. In fact, insertion of a PEG tube may cause relaxation of the lower esophageal sphincter leading to an even greater risk for aspiration of gastric contents following the procedure. Among elders with advanced dementia being fed by PEG or NG tube, no studies have demonstrated a reduced risk of aspiration, and there is evidence that the risk of aspiration pneumonia actually increases [13]. In a comparison of enterically and non-enterically fed patients with advanced dementia, 40 % of subjects receiving enteric feedings developed aspiration pneumonia versus 12.8 % of subjects in the oral feeding arm [15].

PEG Tubes and Pressure Ulcers

While attempting to increase nutrition through enteral feeding may seem beneficial in promoting wound healing, studies examining this theory indicate otherwise [3, 16]. In a large propensity-matched study, nursing home patients with advanced cognitive impairment and recent hospitalization were analyzed for differences in pressure ulcer development and pressure ulcer healing in those who received PEG tubes while in the hospital versus those who did not [16]. Patients who were admitted without a pressure ulcer and received a PEG tube during hospitalization were 2.27 times more likely to have developed a pressure ulcer by their next nursing home Minimum Data Set assessment compared to those who did not receive a PEG tube. Additionally, those admitted with an existing pressure ulcer who had a PEG tube inserted during admission were less likely than their non-PEG tube counterparts to demonstrate pressure ulcer healing. Possible reasons for these outcomes include the increased use of physical and chemical restraints in those with advanced dementia and PEG tubes, the propensity for enteral feeding to cause diarrhea with subsequent skin irritation and breakdown, and reduced personal attention from nursing staff compared to patients who were hand-fed [13].

PEG Tubes and Survival

Post-PEG tube insertion survival in individuals with advanced dementia tends to be quite poor. In a large study of long-term care residents with advanced dementia, median survival was only 56 days following PEG tube placement, and overall data suggests a 1-year post-procedure mortality between 39 and 90 % [3]. When mortality is compared between elders with advanced dementia who undergo enteral feeding and those who are hand-fed, no mortality benefit is conferred by the PEG feeds [17–19]. Post-PEG tube placement survival has also been evaluated in patients with dementia compared to those with other diagnoses including oropharyngeal cancers, dysphagia after stroke, motor neuron disease, Parkinsonism, and multiple sclerosis [17]. On assessment after PEG placement, the dementia cohort demonstrated significantly increased mortality compared to the other subjects at 3 and 12 months (78 vs 44 % and 90 vs 63 %).

PEG Tubes and Comfort

A major concern for the medical providers and family members of elders with advanced dementia and feeding issues is the prevention of suffering due to feelings of hunger and thirst. However, studies suggest that elders with advanced dementia can live a relatively long time with poor oral intake secondary to an altered state of homeostasis with reduced metabolic rates and lower caloric requirements [20]. In addition, reduced oral intake is part of the natural progression toward the end of life [9].

Although it is impossible to definitively assess hunger and thirst at the end of life among elders with advanced dementia, studies in other terminally ill populations lend insight into these issues and can be extrapolated to late-stage dementia. In a study of 32 terminally ill patients, who ate and drink at will but received no artificial nutrition or hydration, 20 subjects reported no hunger on admission while 11 lost the sensation of hunger as they approached death [21]. Only one subject's appetite remained active until death. In the 12 subjects who reported the sensation of thirst until their death, this was relieved with small amounts of food/liquids, ice chips, and oral care. The small amount of oral intake observed in this study, far less than would be needed to maintain weight or prevent dehydration, in conjunction with oral care, prevented suffering from the sensations of hunger and thirst in all of the terminally ill patients. Of note, nine subjects reported abdominal pain and nausea when they ate not to satisfy the sensation of hunger but to please their family. In a similar study involving elders with advanced dementia, an observational scale was used to assess for discomfort related to the decision to forgo artificial nutrition and hydration [22]. Subjects, who were offered small amounts of food and liquid by mouth, demonstrated no signs of significant discomfort.

Adverse Effects of PEG Tubes in Advanced Dementia

In addition to a lack of evidence to support the benefit of enteral feeding in advanced dementia, tube feeding in this population is associated with increased restraint use, acute care encounters, and adverse medical side effects. As they are unable to understand the reason for the intervention, the use of PEG feeding tubes in individuals with advanced dementia has been associated with an increased use of both chemical and mechanical restraints [1, 13, 23]. For example, the use of mitten restraints were 90 % more likely among elders with advanced dementia who had a feeding tube in place compared to those who did not [23]. The use of feeding tubes and associated complications, including tube dislodgement, malfunction, and blockage, has been associated with increased emergency department visits, hospitalizations, and days spent in the hospital both on the floor and in the intensive care unit [13, 19, 24]. In a prospective cohort study of nursing home residents with advanced dementia, 47 % of all emergency department visits were secondary to feeding tube complications, accounting for more visits than falls, fractures, and infections combined [24]. In addition to feeding tube-related complications requiring acute care, 20 % of PEG tubes required replacement within the first year [3]. The increased acute care episodes can be very distressing in this patient population and are often not aligned with their goals of care. PEG tube insertion and complications in individuals with advanced dementia also are associated with significant financial cost. The annual inpatient expenses increase from $7,967 to $10,191 in elders with dementia who receive enteral feeding [19]. Other potential adverse effects of feeding tubes in elders with dementia include skin breakdown, cellulitis at the tube site, and GI side effects of gas, nausea, vomiting, diarrhea, and gastroesophageal reflux [13].

Factors Driving Feeding Tube Placement

Misperceptions regarding the risks and benefits of feeding tubes in those with advanced dementia are one of the impetuses for PEG tube placement in this population. Forces within hospitals and long-term care facilities also drive PEG tube placement in this population. Specific hospital factors associated with higher rates of PEG tube placement include a for-profit status and larger bed capacity (>310 beds) [10]. In hospitals, an increased focus on reducing length of stay appears to be a significant contributor to PEG tube placement as patients with feeding tubes are often more readily accepted to the next level of care (i.e., nursing home, rehabilitation center) [25]. This was supported by a survey of hospital physicians in which almost 50 % of respondents stated that nursing facilities have requested PEG placement in residents prior to discharge and 65 % stated that nursing facility concerns influenced their decision to place a PEG tube [8]. Nursing home characteristics associated with higher numbers of residents with advanced cognitive impairment receiving enteral feeding included for-profit status, location in an urban area, >100 beds in the facility, and lack of a dedicated memory care unit [11]. Reasons which may lead nursing facilities to encourage enteral feeding include fear of regulatory sanctions secondary to weight loss in residents for whom they cannot document appropriate caloric intake, increased reimbursement, and reduced personal care time compared to hand-feeding [8, 25]. Certain characteristics of individuals with advanced dementia are also predictive of increased rates of tube feeding: younger age, nonwhite race, male gender, divorced marital status, lack of an advanced directive, and recent decline in functional status [11, 26, 27]. Despite certain characteristics being generally predictive of higher enteral feeding rates, it is notable that the rate of feeding tube placement in nursing home residents with severe cognitive impairment varies widely between states from a low of 3.8 % in Nebraska to a high of 44.8 % in the District of Columbia [27]. This variation correlates inversely with the rate of do not resuscitate orders [28].

Alternatives to Feeding Tubes in Advanced Dementia

As there is no evidence to support benefits of tube feeding in elders with advanced dementia and significant adverse outcomes can occur, hand-feeding is preferred in this population [1]. Benefits of hand-feeding include providing the individual with dementia quality personal interaction with others, enjoyment of food and drink, and continued dignity as they approach the end of life. Calories and other nutritional markers should not be monitored when hand-feeding individuals with advanced dementia. In contrast to being fed by hand, the act of tube feeding can be very instrumental without the benefits of personal care, touch, and interaction [29]. To ensure optimal benefits from hand-feeding, diets should be liberalized and elders should be offered their favorite foods by individuals trained in feeding [1, 29]. Appropriate oral hygiene should be maintained and, if the elder wears dentures, it should be ensured that these are fitting properly [29]. As with tube feeding, the possibility of aspiration exists and this should be disclosed to family members. Methods to minimize aspiration with hand-feeding include sitting the person up at a ≥45° angle while eating, providing small bites of food (less than a teaspoon in size), encouraging coughs after each swallow, and encouraging the person to swallow multiple times after each bite to assure clearance of food [13]. Providing quality hand-feeding is time intensive requiring 35–40 minutes per meal [25].

Surrogate decision-makers for individuals with dementia perceived multiple benefits of hand-feeding: enjoyment of food and drink, improved nutrition, effective in ensuring food is provided, increased dignity, feeling of being cared for, and extra interaction with caregivers [30]. Perceived disadvantages included finding the experience unpleasant (does not like offered food, being overfed, messy), concern for loss of independence, concern for choking, uncertainty regarding amount of food (might not get enough to maintain weight and nutrition), and the time-intensive nature of this method [30]. However, these perceived disadvantages can be overcome through education regarding feeding issues and close attention to signals from the person with dementia regarding likes and dislikes. Surrogates can be educated regarding the expected course of dementia, with the onset of feeding issues often signifying the transition to the end stages of the disease, and terms such as "comfort feeding only" can clarify the goals of hand-feeding [5, 9]. If the elder with dementia exhibits discomfort or other signs of distress with hand-feeding as the end of life approaches, it should be discontinued and positive human interactions including touch and reassuring speech continued [9].

Conclusions

Feeding issues are a hallmark of advancing dementia. Evidence suggests that enteral feeding does not improve outcomes and can result in significant adverse effects. In contrast, hand-feeding has been found to be enjoyable for both the individual with dementia and the caregiver. When counseling families regarding options for feeding their loved one with advanced dementia, it is important to educate them regarding these findings and to support them in making decisions regarding feeding issues with the best interest of the patient in mind.

Practical Pearls

- Feeding issues occur in 90 % of individuals with advanced dementia and is typically the last activity of daily living (ADL) lost prior to death
- Enteral feeding in elders with advanced dementia has not been shown to
  - Prolong survival
  - Increase comfort
  - Improve nutrition
  - Prevent aspiration
- Adverse effects of feeding tubes include
  - Increased use of chemical and physical restraints

Tube dislodgement, malfunction, and blockage
Skin breakdown and cellulitis at tube site
GI side effects – nausea, gas, vomiting, diarrhea, and gastroesophageal reflux
Benefits of hand-feeding
Increased caregiver interaction
Ability to enjoy the taste of food and drink
Increased satisfaction among family of elders in long-term care with advanced dementia

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Intimacy in the Long-Term Care Setting

John W. Culberson, Totini Chatterjee, and Fiona Prabhu

Introduction

Sexual needs of the elderly have historically been misunderstood and ignored. Younger, healthier people tend to believe that sexual desire and activity normally cease with advancing age [1]. In reality, the sexual needs of the elderly are similar to those of younger individuals, but with variations in frequency, intensity, and mode of expression [2]. Social connection and human touch are essential ways of avoiding the depression and loneliness that inevitably abound when an elderly individual becomes isolated by losses or illness in advancing age [1]. Sexuality is often considered in the context of youth when, in reality, intimacy in the long-term care environment often takes the form of affection, romance, companionship, touch, and the need to feel attractive, even in the absence of overt sexual or coital activity [2]. Admission into a long-term care facility does not automatically diminish these basic needs and desires, although it often includes the loss of personal freedom, especially involving sexual fulfillment [3]. The communal atmosphere and environment necessarily leads to additional restrictions to individual autonomy, privacy, and expression of these behaviors. However, it is important to recognize that the Patient's Bill of Rights mandates that a resident has the right to associate and communicate privately with persons of his or her choice, including other patients [4].

J.W. Culberson, MD (✉) • F. Prabhu, MD
Department of Family and Community Medicine, Texas Tech University School of Medicine,
Lubbock, TX, USA
e-mail: john.culberson@ttuhsc.edu

T. Chatterjee, BS
Internal Medicine, Texas Tech University Health Sciences Center, Amarillo, TX, USA

Family and Community Medicine, Texas Tech University Health Sciences Center,
Lubbock, TX, USA

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The architectural features of a long-term care facility are specifically designed to allow for easy access and observation. Although federal regulations mandate privacy as a given right of residents, interviews with staff indicate that there is general agreement that compromising resident privacy is justifiable if physical health can be enhanced [5]. Privacy of information is an often overlooked concern when it relates to a resident's personal activities. Regulations require that private resident information may not be discussed, documented, or judged, unless it is directly required to the provision of care [2]. The evolution of the long-term care environment has created a resident-centric culture in which the facility may be viewed more as a home, where privacy permits an individual to function within "a place of choice, a place of pleasure" [1]. Individual choice includes both aspects of a resident's previous life, such as cultural and religious beliefs, and a resident's current sexual needs and expressions. It seems only logical to recognize and respect the highly individualized character of sexuality [6].

In the majority of long-term care facilities, the medical model receives emphasis, while the basic human right of loving and being loved is overlooked. This, in turn, determines operational norms and values of the community. In such a model, the nursing staff plays a central role in the care of institutionalized elderly. Sexuality is often not considered to be part of the primary caregiving role, largely because it is not vital to the maintenance of bodily functions [7]. In their desire to provide care, staff may inadvertently treat adult residents in an infantilized manner, making it difficult to contemplate them as sexual beings [8]. Additionally, many staff members have only a vague understanding of the sexual needs of their elderly residents. As the typical curriculum provided in healthcare professional education sends a message that sexuality is not an important aspect of geriatric health, there is often a sense of unease among physicians, administrators, and staff when considering these issues [9]. There is often a perception that residents' sexual interests represent behavioral problems, rather than expressions of need for love and intimacy, and staff indirectly determine whether and which sexual acts are tolerated [10]. The most commonly observed sexual behaviors in nursing homes include hand-holding, kissing, petting, and masturbation. The impetus for policies concerning intimate relations in the long-term care facility setting is often a sexual violation, or perceived "inappropriate behavior," committed by a resident [11].

In order for long-term facilities to care for each resident in a holistic fashion, they must expand their definition of basic human needs including the need for sexuality and touch. Regardless of whether this topic is brought to the forefront of societal and medical discussions, residents are finding ways to meet these needs. Studies have found that 25 % of patients were seen as "causing problems" due to sexual behavior or talk [12]. Staff felt uncomfortable in the face of what they considered to be "problem" sexual behavior and were unsure of what to do or say. Therefore, they typically fail to acknowledge residents' sexual comments, touching, self-exposure, or masturbation [11]. The tension between an ethical responsibility to provide privacy, autonomy, and self-expression, while meeting the requirement to ensure a safe living environment that respects family values and cultural beliefs of each resident, creates a challenge for administrators and staff which must be considered on a case-by-case basis.

A Culture of Intimacy in Long-Term Care

Two nursing home residents with no cognitive impairments become attracted to one another and would like to initiate a relationship, including an intimate sexual component. While both are currently married, neither spouse has maintained an intimate relationship and they rarely visit. Their families are opposed to their relationship based upon differing cultural and religious beliefs and their intact marriages. Several staff members have expressed concern based upon their personal belief systems and point out that both residents have multiple debilitating illnesses and functional disabilities.

Benefits and Challenges of Intimacy in Long-Term Care

Essential to the ethical treatment of sexuality in long-term care is a process that allows the complex situation to be reduced into its basic components. Provided that all safety concerns are identified and addressed, residents of long-term care facilities should not be made to feel as if they "are being forced to hide in fear of having the enjoyment of sexual activity taken away from them" [1]. Residents retain a right to privacy and to express themselves as autonomous adults. In addition to the sense of control provided by their right to expression, developing and maintaining an intimate relationship has additional benefits. In an interview of residents of a long-term care facility, 73 % of the residents reported that sexual activity improves quality of life and 95 % viewed sexual expression as a way to promote a sense of well-being [13]. These health benefits can ease feelings of loneliness and despair that may lead to depression, clinical decline, and even suicidal ideations. Most long-term care residents also view sexual activity positively as a stress reliever [13]. It is likely that being involved in an intimate relationship makes residents feel more connected to their surroundings and allows them to confide in another, sharing similar joys and challenges of living in a long-term care setting.

While advantages have been noted, an intimate relationship can also be challenging for older adults. Only 1 of the 13 residents believed that "sexual activities are common in long-term care facilities," and, therefore, they may feel isolated in their desire for intimacy [13]. The significant shift in cultural norms over the lifetime of many current nursing home residents contributes to the uncertainty around intimate relationships. Most residents began their sexual experience at a time of conservative norms and double standards when "Pleasurable sex was for men only, and women engaged in sexual activity to satisfy their husbands and to make babies" [9]. Additional feelings of guilt can arise when either or both partners are married. However, residents may wish to pursue intimacy outside of their marriage for a variety of reasons including physical separation from their spouses as well as significant differences in cognitive and physical function. The decision to remain faithful or not to the spouse, whatever the conditions of the relationship, lies exclusively on the resident. Regardless of the beliefs or opinions of staff or family members, the long-term care facility has an obligation to "address residents' needs and interests and uphold residents' legitimate rights" [14].

Cultural Support of Intimacy

In order to meet the needs of residents in a long-term care facility, the cultural circumstances of each individual should be recognized and respected by all interdisciplinary professionals. A popular nursing theory states that "culture is the broadest, most comprehensive, holistic, and universal feature of human beings; and care is embedded in culture."[15] In the context of intimacy, this concept extends its meaning to include the fact that human touch and intimacy are expressed differently in individual cultural contexts. Interdisciplinary professionals should engage themselves in an active process of attempting to understand why residents hold certain beliefs or act in a particular manner. It is only through this process of understanding that long-term care staff will be able to address the unique background and basic human needs of each resident [2]. An important part of understanding intimate relationships in long-term care is determining what benefits are being provided by the relationship. For example, an individual's selection of a specific partner is often based upon a need that is missing in their life at the facility, be that a desire for quiet conversation, human touch, or someone with whom to share activities. If residents express feelings of guilt regarding intimate relationships, these should be addressed in a manner that examines the cause and identifies methods by which it may be productively managed [16].

Due to the complex interaction between facility staff, residents, and family members in situations of intimacy in long-term care facilities, it is helpful to consciously consider facility culture and policy regarding these issues. Currently, over two-thirds of facilities do not have any policy regarding sexual activity between residents and only one in five has written policies [17]. However, written facility policies can be very useful as they help to guide the actions of administration and staff, provide an awareness and openness to the sexual health of residents, and encourage an atmosphere where privacy is respected. Such policies should be reviewed through regular trainings, and interdisciplinary case discussions regarding issues around sexuality should be encouraged. When a couple begins an intimate relationship, it is appropriate for interdisciplinary professionals within the facility, including administrators and physicians, to initiate a dialogue concerning how the couple intends to proceed with their relationship. This conversation is meant to facilitate a safe place for the residents to express themselves and their desires [18]. Occupational therapists, who often interact with patient's function, and other staff members closely involved in care can also help elicit a patient's sexual goals and desires. Intimate encounters can be planned for a time of day when energy levels are highest or physical symptoms are less troublesome. In addition, trained assistants can assist couples in experimenting with different sexual positions and assistive devices (i.e., pillows) to maximize comfort [19].

There is ongoing debate regarding the need to involve family members in intimate relationships within long-term care facilities. A survey of directors of nursing at skilled facilities indicated that more than half require family or a designated representative to approve sexual activity between residents, regardless of cognitive status, and one in eight still requires permission even when both individuals are cognitively intact. Less than 5 % require a physician order [17]. In general, even in cases where residents have cognitive impairment, it is not always necessary to require permission from family members if the partners are deriving benefit from the relationship.

Intimacy and Cognitive Impairment

An 82-year-old male nursing home resident with mild cognitive impairment is flirtatious and often makes sexually provocative comments to female staff, indicating that he likes to "play the field." He has been observed spending increasing time with a 79-year-old female resident with mild to moderate dementia. She is largely independent for most ADL's but requires assistance with dressing and toileting. She has severe osteoarthritis of the hips and is largely wheelchair-bound. The couple has frequently been observed in a quiet corner of the facility, and their intimacy has advanced to hugging and kissing. Although most behavior is initiated by the male resident, his advances are encouraged by his female partner. He tells staff that they need a private place where they can "make love." He adds that he understands that he must be gentle with her due to her arthritis pain. She independently assures staff that she desires to be intimate in a private place and that they are in love. She adds that she does not want her family to be informed because "they will not approve."

Recent national news headlines highlighted an Iowa court case in which an older man was charged with sexually abusing his elderly wife, an Alzheimer's patient living in a nursing home. The case was complicated by family tension between adult stepdaughters and focused on the question of whether an individual with dementia can give consent for intimacy. In this situation, the man was acquitted following testimony that he and his wife had shared a loving, consensual relationship [20]. This case highlights the struggle long-term care facilities face in balancing the right of cognitively impaired residents to engage in intimate activities versus their right to be protected from actions for which they may lack ability to consent [21]. This tension is clear in the wide variety of personal attitudes and reactions demonstrated by administration, staff, and families to sexual behavior between individuals with cognitive impairment. In one study of sexual behavior in residents with dementia, long-term care staff were supportive and accepting of "caring acts" and "compared romantic behavior to puppy love" [16]. In contrast, overtly sexual behavior generated "anger and efforts to protect a resident whom they perceived as being coerced into sexual activity" [16]. From a legal standpoint, engaging in sexual activity with someone who is unable to consent is a sexual offense, which clearly has significant implications for facilities which are ultimately responsible for the safety of residents [6]. Given these issues, it is important to have a clear understanding of the impact of intimacy on residents with dementia, capacity as related to sexuality, and resources for mediating possible conflicts.

In caring for individuals with dementia, the prevailing attitude is that all elements of risk must be removed in order to satisfy the duty of caring. Therefore, these residents are often perceived as "being in need of" protection from their own impaired memory and judgment [22]. While care facilities have an obligation to acknowledge the potential risks and difficult questions surrounding a sexually friendly policy, they should resist focusing on legal and ethical debates which reinforce the medicalization of dementia. Overprotection of the vulnerable blurs the lines between duty of care and social control, resulting in a failure to recognize the ethical concept of "dignity of risk" [23]. Succinctly, one cannot eliminate risk without eliminating the person. Although permitting residents with various levels of cognitive impairment to make autonomous decisions about their sexuality may expose them to some level of risk, these are risks that any sexually active person faces throughout his or her life, and an unwise decision should not be confused with incompetence. Restricting an intimate sexual relationship in an attempt to protect an individual with dementia denies an individual their autonomy and is a violation of the fundamental human right to be recognized and appear as a person before the law. This is itself a failure of duty to care [6]. Instead, facilities should develop policies and a culture that emphasizes solutions to make sexual relationships safe and possible for all residents who desire such opportunities, including those with cognitive impairment, rather than trying to control/limit sexual behavior or becoming bogged down in the definition of capacity [24].

If a determination of capacity as pertains to intimacy was desired, it is important to recognize that there is currently no universally accepted criterion for capacity to consent in sexual relations. A semi-structured interview approach described by Lichtenberg and Strzepek remains the only formal capacity assessment tool in this area [25]. The assessment evaluates:

1. Choice and understanding: awareness of the relationship, including knowing who the partner is and whether or not it is their spouse, awareness of who is initiating sexual contact, and ability to state the level of intimacy with which they are comfortable
2. Reasoning and rationale: ability to avoid exploitation by knowing what is desired from the relationship and the ability to set limits
3. Awareness of consequences: possible reactions from family/spouse regarding relationship, awareness that relationship may be time limited, and consideration of the possible implications of the relationship ending

The tool assumes an interviewer of the same gender and a basic level of cognitive functioning (designated as a Folstein Mini Mental Status Exam score of 14/30) [26]. Of note, having a guardian does not rule out the possibility that the older adult can consent to engage in intimate relationships. However, if the court has included decisions around sexual activity under the preview of the guardian, this person would serve as the decision-maker.

In the event of discrepancy or disagreement between the resident, family members, staff, and facility administration, an interdisciplinary ethics committee meeting or consultation may be warranted. The ethicists would evaluate the relationship in detail including assessing the impact of this new relationship on any existing spouse, the facility's role in judging the wishes and understanding of the two residents, the presence or absence of coercion, whether either resident is mistaking the other for his or her spouse, and the extent to which the relationship reflects an authentic value expressed in the past by the residents [9]. An additional resource is The Administration on Aging's Long-Term Care Ombudsman. Ombudsmen, individuals who are trained to suspend their personal values and to consider a situation from the resident's perspective, can serve as an advocate for their best interest of the resident. This includes acting on behalf of a resident in dealing with those who are concerned or upset by a resident's actions [27].

Disruptive Sexuality in Long-Term Care

A nursing assistant files a complaint with facility administration regarding the behavior of a 73-year-old male resident with moderate dementia. She states that he is a "dirty old man" and is "always trying to touch me." In addition to this complaint, the resident frequently makes overtly sexual comments to female staff and has been found masturbating in his room while looking at pornography. While he is not aggressive toward female residents, he does occasionally expose himself in public areas. Family members of other residents have complained to staff and indicated that "someone has to do something about this."

Nurses often report feelings of anger, embarrassment, confusion, helplessness, and rejection when they encounter sexual incidents within a nursing home environment. Sexual behaviors, such as exposure of genitalia and masturbation, are often considered "seriously disturbing" [28]. While sexual acts may make some staff uncomfortable, to consider them "seriously disturbing" is indicative of the significant taboo many consider sex in the elderly. Staff should recognize that most sexual behaviors in the institutionalized older individual, including masturbation, are closely related to their historical attitudes and prior level of sexual activity [12]. Similarly, the reactions of older co-residents and their families to sexual behavior are more closely linked to the perceived cultural and religious appropriateness of the behavior, rather than emotional discomfort that results from witnessing the behavior [29]. Staff education of co-residents and families regarding the sexual policies of the facility and normalization of behaviors can be reassuring.

When caring for residents with various sexual behaviors, staff can reduce tension related to the behaviors by identifying them as an expression of psychosocial needs and functional dependence rather than a deviant behavior directed toward other individuals [30]. Sexual behaviors should be evaluated through an interdisciplinary sexual assessment including the patient's treating physician and involved nurses, aides, and other appropriate staff. The purpose of the assessment is to determine the underlying need the resident is expressing through their sexual behavior and how it can best be addressed in a fashion which ensures privacy, autonomy, and safety while protecting the cultural values and safety of other residents and their families. For example, psychological needs including boredom, loneliness, and the need for reassurance can lead to sexualized behavior [9]. In other instances, increased genital self-manipulation can occur secondary to urinary or vaginal symptomatology.

Evaluation of behaviors within an interdisciplinary team also ensures that sexual behaviors are not being unfairly judged or limited by individual moral values. While it is necessary to provide protection and boundaries for all residents in a community living environment, overreaction to behaviors is not constructive for either the resident or community. Importantly, the use of shame or guilt works no better for the regressing adult then for the developing child [31].

Staff should also recognize that miscommunications may arise due to the fact that the act of caregiving itself is a type of intimacy. Task and non-task-related touching (stroking a resident's cheek or holding their hand) may be misinterpreted. Depending upon a person's cultural background and their cognitive state, these actions may be viewed as assaultive, erotic, comforting, or presumptuous. In addition, residents who are functionally dependent on caregivers may have a fear of abandonment should they reject non-task-related touch [9]. These issues demonstrate the critical need for staff education in negotiating the often blurred boundaries between caregiving, intimacy, and sexuality.

LGBT Intimacy in Long-Term Care

Christine is a 75-year-old woman who has recently entered the nursing home due to increasing physical frailty. She has been with her life partner Jane for 50 years. They have no children but they have many friends both their age and younger. Christine has been asked many times about whether she has been married and if the visitors that she receives are her children from both staff members and from other residents. She has overheard the staff make many negative comments about gay people. She is worried about displaying her many photos of herself and Jane so she has not done so.

Compared to their heterosexual contemporaries, lesbian, gay, bisexual, and transgender (LGBT) elders are more likely to be single, childless, estranged from their biological family, and reliant on families of choice. These circumstances can lead to unique challenges within long-term care. In a survey undertaken by multiple organizations to better understand the experiences of LGBT older adults in long-term care settings, a number of specific forms of discrimination were identified which are common to this vulnerable population [32]. These included:

1. Verbal or physical harassment from other residents
2. Refused admission or readmission and/or attempted or abrupt discharge
3. Verbal or physical harassment from staff
4. Staff refusal to accept medical power of attorney from residents' spouse or partner
5. Restriction of visitors
6. Staff refusal to refer to transgender resident by preferred name or pronoun
7. Staff refusal to provide basic services or care (e.g., assistance with bathing, isolation of transgender staff from the dining table)
8. Staff denial of medical treatment (e.g., giving medications) [32]

Recognizing the right of all long-term care residents to the highest practicable mental, physical, and psychosocial well-being, the Nursing Home Reform Act (NHRA) was passed in 1987. The Act protects residents regardless of sexual orientation or gender identity. It creates a minimum set of standards for care and rights including the right to be treated with dignity and respect, to be free from physical or mental abuse or involuntary seclusion, and to make personal decisions as to what to wear [4]. To ensure optimal care of LGBT elders in long-term care, advocacy groups recommend that facilities raise staff awareness and conduct self-assessments of their facility's culture and quality of care involving LGBT residents, their intimate partner, their family, and community [32].

Summary

Long-term care environments are rapidly evolving to meet resident-centric basic human needs. Sexuality is an essential part of the past and present lives of aging adults, and facilities have a duty to protect the rights of these individuals to participate and express their personal sexual identities in a way that ensures the privacy and safety of the community. The presence of cognitive impairment can make it difficult to determine whether an individual can understand the benefits and potential consequences of becoming involved in an intimate relationship. Written policies and staff education programs can clarify the role of each interdisciplinary team member and help to avoid bias in their interpretation of behaviors and feelings of residents and their families. Beyond the walls of facilities that many older individuals call "home," society is clarifying its definition of sexuality. Within a long-term care facility, individuals with varied historical and cultural experiences must live together in a community that requires tolerance and respect. Human sexual needs do not lessen with age or loss of independence. Often, they are simply expressed in different ways. Despite progression of chronic illness and functional losses, human touch and intimacy remain the essence of humanity and healthy aging.

Educational Pearls

- While intimate acts are often considered in the context of youth, in the long-term care environment, intimacy is common and takes the form of affection, romance, companionship, touch, as well as more overt sexual behaviors.
- Privacy of information is an often overlooked concern as it relates to a resident's intimate activities. Regulations clearly indicate that private resident information, including sexual activities, may not be discussed, documented, or judged unless it is directly required for provision of care.
- Caution should be employed when considering or administering assessment of sexual decision-making capacity. These assessments sometimes ignore the ethical and legal rule that capacity should be assumed until

proven otherwise and that decisions regarding intimacy are highly individualized.
- Written facility policies regarding intimacy and sexuality provide important guidance to administration and staff as well as encouraging an atmosphere of awareness and openness regarding the sexual health of residents. Policies should be reviewed through regular trainings, and related interdisciplinary case discussions should occur as appropriate.
- Involving family members in honest discussions can allow them to better understand how the facility supports the autonomy, privacy, and safety of its residents in meeting their individual needs for intimacy and sexual expression.

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Elder Abuse and Neglect

11

John M. Halphen and Carmel B. Dyer

Introduction

Elder abuse, neglect, exploitation, and self-neglect are significant problems around the world, resulting in increased morbidity and mortality among those elders who are reported as victims [1, 2]. Because of this, physicians and other health-care workers have the duty to (1) be aware of these harmful conditions, (2) know how to identify elders in these conditions, (3) perform proper screening and assessments that are likely to reveal these problems, and (4) make the necessary interventions, including reporting to the appropriate governmental agencies. This chapter will provide definitions and give information to aid in fulfilling these duties. In addition, hypothetical cases that illustrate ethical issues and concerns medical providers may encounter will be presented.

Definitions

The conditions of abuse, neglect, exploitation, and self-neglect described in this chapter are defined by civil laws, and the remedies are designed to extricate the elder from the condition. However, the abuse, neglect, and exploitation can also amount to violations of criminal statutes where punishment for the perpetrator may

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J.M. Halphen, JD, MD (✉)
Department of Internal Medicine, Division of Geriatrics and Palliative Medicine, McGovern Medical School, University of Texas Health Science Center at Houston, Houston, TX, USA
e-mail: John.M.Halphen@uth.tmc.edu

C.B. Dyer, MD, FACP, AGSF
Department of Internal Medicine, Division of Geriatric and Palliative Medicine, University of Texas Health Science Center at Houston, Houston, TX, USA
e-mail: Carmel.B.Dyer@uth.tmc.edu

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be sought. Abuse, neglect, and exploitation refer to the acts or omissions of a person who has an ongoing relationship with and would be expected to care for the needs of the elder involved. The person who would be reasonably expected to have a duty to care for and protect the elder is usually referred to as a caretaker or caregiver. When the caretaker abuses the elder or neglects the needs of the elder they are expected to support, they are referred to as a perpetrator.

The actions of the caretaker are what create that expectation. For example, the son or daughter of an elder who is estranged and refuses to handle that elder's finances or help care for them in any way is not a caretaker. However, if that offspring handles some aspects of the elder's care, especially handling the elder's finances, he or she creates an expectation that they will also make sure that the elder has enough help during the day, gets food, is kept safe, and that other needs are met. Facility owners and employees of facilities where the elder resident lives are considered caretakers and have an expected duty of care and protection for their elderly residents.

The definition of an elder varies among jurisdictions, but is usually someone 60–65 years or older. Persons who are 60 or 65 are a diverse group and certainly not uniformly unable to take care of themselves independently in the community. A vulnerable elder might be defined as one who is unable to self-care and self-protect because of functional disabilities which often include one of a cognitive nature [3].

Elder abuse includes physical abuse, psychological abuse, sexual abuse, and financial exploitation by a caretaker as above described. Elder neglect refers to situations where the caretaker does not take care of the needs of the elder. Financial exploitation refers to a caretaker appropriating an elder's resources for the use of the caretaker without the consent of the elder. In situations where consent is required, such as sex with the elder or use of the elder's resources, the consent is not valid if it is not freely and knowingly made by an elder who is able to make the decision to consent. If the will of the elder is overcome by another person, undue influence or coercion may have been exerted and the consent may not have been valid.

Situations of self-neglect are those where the person is unable to provide for their own needs, yet does not have another person who has a duty to provide the support and protection needed. There is no identified caretaker in these cases. Self-neglect referred to here is not voluntary self-neglect. This self-neglector has not chosen to neglect their needs. Instead, they may not have the insight to realize that they are unable to meet their own needs and their failure to thrive in their environment is not intended [4].

At times, it can be difficult to identify with certainty a case of elder abuse, neglect, or self-neglect. In some families, shouting at each other may be a normal, long-standing behavior yet considered psychological abuse by an observer. In cases of alleged self-neglect, there may be varying cultural expectations for cleanliness of the person or clothing. Some families or individuals tolerate more clutter and dirt than others. Also, some persons with full mental capacity may choose to live in conditions thought to be intolerable to others. Therefore, a determination of the presence of a state of elder abuse, neglect, and self-neglect can be subjective. When considering possible elder abuse, neglect, or self-neglect, cultural and personal preferences of the elder should be noticed and honored in support of autonomy.

Reporting to Governmental Agencies and Other Interventions

All jurisdictions in the United States, and in many developed nations around the world, have agencies that are mandated to protect their elderly and vulnerable adult populations. The agencies that deal with community-dwelling elders are usually called Adult Protective Services agencies in the United States. The agency is set up to receive reports of suspected elder abuse, neglect, exploitation, and self-neglect and investigate them. The agency then offers services to the victims which are designed to ameliorate the condition of concern [5]. These jurisdictions also have Long-Term Care Ombudsman programs. These programs take complaints regarding persons in long-term care facilities and help mediate problems or direct the complaints toward the appropriate state agency that regulates that facility [6].

In almost all jurisdictions, health-care workers are mandated to report concerns of elder abuse, neglect, or self-neglect to the appropriate governmental agency. In addition, there is often a criminal penalty possible if there is a failure to report as required. Once the case is reported to APS, or another responsible agency when the suspected victim is a facility resident, the governmental agency will perform the subsequent detailed investigation. The health-care worker is protected from liability for reporting so long as they are acting in good faith. In situations where the victim is suspected of being at risk for immediate harm, the police should also be contacted.

The types of protective services offered may include assisting the elder in finding another place to live, arranging for provider services (a provider is usually a non-licensed helper who assists with activities of daily living), helping to ensure an acceptable living environment by cleaning or doing home repairs, or taking the elder to a clinic for medical evaluation. These protective services may be rejected if the elder has the capacity to refuse the intervention. If the agency believes that the elder does not have the capacity to refuse the intervention, the government may seek to have the elder evaluated by a physician and ask a court to force the intervention if the elder is found to lack that capacity [7].

Since adults are generally presumed to have the capacity to make their own decisions, their decisions to reject services, live in poor conditions, or allow others to use their resources are usually respected. This is supported by the ethical principle of autonomy which respects the right of competent adults to make their own decisions. However, if the government through the courts determines that the elder does not have the capacity to make their own decisions regarding their care and protection, the government will interfere with the autonomy or liberty of the elder. This interference should only be to the extent that it is the least restrictive alternative to meet the elder's care and safety needs [8]. For example, an elder that is found to be in a state of self-neglect in their home may be lacking the capacity to refuse interventions. However, if a relative is able to supply the support needed, the agency will not pursue a declaration of incapacity by a court and the appointment of a guardian.

Statistics of Elder Abuse and Neglect

It is estimated that 2–10 % of the community-dwelling elderly population in this country are subjected to elder abuse, neglect, exploitation, or self-neglect at any time [1]. The cases reported to adult protective services are less than what actually occur, and it is thought that the reported cases are only the tip of the iceberg [3, 9]. Elder abuse, neglect, exploitation, and self-neglect are major public health problems with a large impact on the well-being of the elders affected.

Morbidity and Mortality

Elders who are reported to Adult Protective Services are at increased morbidity and mortality risk [2, 10]. The elder may be injured, emotionally distressed, and not getting their basic needs for food, shelter, and medical care met. All forms of elder abuse, exploitation, neglect, and self-neglect can have severe consequences for the physical and emotional well-being of an elderly person who often does not have much physical or financial reserve [11].

Risk Factors

Some characteristics of the elder that place them more at risk for being the victim of elder abuse, neglect, financial exploitation, and self-neglect are cognitive impairment, disability in self-care functions, depression, and social isolation [1, 9, 11–17]. Characteristics of a caregiver or a facility that are associated with an increased risk of elder abuse or neglect are financial dependence on the elder, caregiver mental illness, caregiver drug or alcohol abuse, and caregiver overburden or staffing shortages [1, 15, 18].

Red Flags

Some indicators that an elderly person may be in a state of elder abuse, neglect, financial exploitation, or self-neglect include fear of the caretaker; injuries in unusual locations or that are inadequately explained; dehydration, malnutrition, or wounds that can best be explained by neglect or abuse; medical conditions or medication effects that are poorly monitored or addressed; an elder that should have money for what they need, but is now unable to afford food, bills, utilities, and medications; and transfers of property by those with a doubtful ability to consent to the transfer [11, 19, 20].

Screening and Assessment

Due to the severe impact on the victim of elder abuse, neglect, financial exploitation, and self-neglect, screening for these conditions is suggested as the duty of medical providers by multiple health-care organizations including the American

Medical Association [21, 22]. It is suggested that the elder be questioned alone using questions such as whether or not they feel safe where they live, who prepares their meals, and who handles their checkbook [18].

A comprehensive history and physical examination including a cognitive and functional assessment should be done. This, along with consideration of risk factors and red flags, enables the medical provider to form a suspicion of whether the elder is in a state of abuse, neglect, financial exploitation, or self-neglect [3, 23–25]. Checking the information gathered against observations and reports of credible persons who have knowledge of the elder and their situation is often necessary.

Ethical Principles as Applied to Elder Abuse, Neglect, and Self-neglect

The dominant model of bioethics has been described as a method of problem solving based on principles. Primarily these principles are autonomy, beneficence, and distributive justice. In cases of elder abuse, neglect, exploitation, and self-neglect, the tension between the principles of autonomy and beneficence is central. At times distributive justice may be a principle that is part of the analysis, but this would normally be overshadowed by the other principles in the setting of elder abuse or neglect. Social and cultural norms, as well as legal rights and responsibilities rooted in public policy, help to give detail to what autonomy and beneficence require in specific cases [26]. Legal concepts and rules such as informed consent, presumption of the capacity of adults to make decisions, governmental use of the least restrictive alternative, duty to report suspected abuse, and the responsibilities of health-care providers to patients shape how our society interprets the principles of autonomy and beneficence and what weight each may be given in specific circumstances.

Hypothetical Cases

We will now discuss some hypothetical cases that illustrate ethical issues that arise in cases of elder abuse, neglect, exploitation, and self-neglect. These cases are based upon a mixture of different situations encountered. In one hypothetical case, the medical providers involved exercised their duties to the elder, and, in the second case presented, a different set of medical providers did not perform as well.

First Case

A 68-year-old woman who previously ambulated in her trailer using a walker was hospitalized following a fall. During the hospitalization, she was determined to have a urinary tract infection which was treated and she was subsequently discharged back to her trailer in July. The trailer was extremely dilapidated. There were holes in the walls and floor. Dirt and cobwebs were all over the home. After that hospital stay, the woman was unable to get around the trailer on her own and was lying on a mattress next to a large metal sheet that covered a hole in the floor. In August, a doctor and a home health company visited and found that the woman was unable to get up for toileting, food, or water. She was dependent on her daughter who lived there with her. The daughter was about 30 years old and would leave daily for a part-time job. It appeared that the daughter was intellectually disabled. Both the mother and the daughter used the funds from the mother's social security check.

Adult protective services became involved and found that the mother resisted any provider or cleanup assistance in the home. She did not want to be moved out of her home despite the fact that the trailer was not habitable and too dilapidated to repair. The woman tried to move across the room and ended up face down on the metal sheet covering the hole in the floor. She stayed there for a week, despite the daughter coming in and out of the trailer during that time. The daughter did not call for help to get the mother up off of the floor. On the next visit by adult protective services, an ambulance was called. The ambulance took the elderly lady to the hospital where she was kept for over a week and received antibiotics for another urinary tract infection. When she was medically improved, the patient insisted on returning to her trailer. The hospital personnel believed that she was able to make her own decisions. Again at home, she was not taking any medications prescribed, was bedbound, was refusing provider services, and again was dependent upon her intellectually disabled daughter for care.

In April, a geriatric physician with experience in evaluating the various forms of abuse and neglect was brought to the home by adult protective services to assess the ability of this woman to choose to stay there. Despite the conditions remaining the same, the mother insisted that she was doing well, getting her needs met, and not in danger. When the physician was introduced to the mother, the physician explained that he was there to evaluate her and make a report to adult protective services. The woman agreed to let the physician ask questions and examine her.

It was learned that the mother had two older children who had been removed and adopted by her sister-in-law. Her husband had been dead for about 20 years, which is how long she and her daughter had been living in the trailer. She said that her sister-in-law spies on her and arranged to have her kept for a prolonged time during her last hospital stay. She said that she had not seen her sister-in-law for many years, but that the sister-in-law continues to watch her and cause her trouble.

Her person and clothing were dirty, her teeth were rotting, and she was lying on her back on the bed, unable to move about well enough to retrieve a spoon that she was laying on. Her short-term recall was good. She had trouble with simple math problems and was wrong on the date and year. She did not seem to have delirium, which is a state of acute confusion and considered a medical emergency.

Issues Raised

There is a presumption in our culture and law that an adult has the capacity to live independently without supervision. Although various types of dementia are more frequently encountered in older populations, to presume that a person in advanced age is incapable of living in the community without supervision is inappropriate, and an example of the prejudice referred to as ageism. Respect for the autonomy of elders requires that we not deem them unable to make their own decisions without good reason.

When an elderly person seems to be making decisions and taking actions that result in a failure to provide for their own care or protection, beneficence requires some action on the part of the medical provider and government agency charged with the protection of elders. The capacity of the elder to take care of themselves without supervision needs to be evaluated. To care for themselves and protect themselves, the elder must be able to both make and carry out decisions regarding their needs and safety [27, 28]. In Texas, where the lady in this case lives, a person is deemed to be incapacitated and unable to take care of themselves without supervision to the extent that they are "substantially unable to: provide food, clothing, or shelter for himself or herself; care for the person's own physical health; or manage the person's own financial affairs" [29]. To make decisions about these needs, they must be able to (1) understand and remember relevant information, (2) appreciate their circumstances, (3) reason about options, and (4) make choices [30]. Then they need to be able to carry out their decisions, which requires a cognitive ability called executive function. Executive function allows a person to plan, monitor circumstances, and make goal-directed adjustments in behavior [27, 28].

It may be that the elder is actually able to make a choice to not have their needs met and to not be protected from harm. If that is the case, autonomy would predominate in the balance with beneficence, and our respect for autonomy would require that the government not interfere. People are allowed to make inadvisable decisions.

In the case of this 68-year-old woman, there was no indication that she actually wanted to have her needs neglected. She did not appreciate that that was the case. Her ability to make decisions was impaired because she could not appreciate her circumstances. Without the ability to make decisions about her needs and protection, she could be found to be incapacitated by an appropriate court. The autonomy rights of the woman could no longer be fully exercised by her secondary to her dementia and psychotic delusions. In this situation, the duty of the governmental agency and medical provider was to become more protective. Beneficence toward the elderly person required the consideration of a need for government imposed supervision if the needs of the elder could not be provided for otherwise. As discussed previously in this chapter, the least restrictive alternative must be employed by the government. In this case, a declaration of mental incapacity was made and a guardian was appointed because this was required to meet the needs of the elderly person.

Second Case

A 94-year-old woman lived alone in her home in the city, having been widowed 20 years before. In the neighborhood where she lived, she owned her own home plus seven other properties which provided rental income. She also received a small social security check. Most of her family and friends had passed away. She still maintained contact with her two middle-aged nephews in town and an elderly cousin who lived in another city. These were her closest living relatives. One nephew, who we will call Carl, had been named previously as her agent through a durable power of attorney for health care and a durable power of attorney for her estate. The other nephew and a cousin were named as alternate agents in these documents. One day she was found on the floor in her home and was taken to the hospital where she was treated for pneumonia. She was confused and unable to make her own decisions. Carl started making treatment decisions and handling financial affairs on her behalf.

The lady remained debilitated after the hospital stay and transitioned to a skilled nursing facility. Although she received therapy in the skilled nursing unit, she was still unable to live independently. She was confused and dependent on others for assistance with transfers, walking, grooming, bathing, toileting, and dressing. She was not qualified for government funded nursing home care because her assets exceeded the limits required to qualify. Her nephew Carl arranged for her transfer to a small unlicensed personal care home that would use less of her funds than a nursing home. The owner had one other resident and had no special training in taking care of frail elders.

Once there, the aunt did not like the care she was receiving and complained to the two other family members with whom she was still in contact. Carl instructed the owner of the home to only allow visitors when he or the owner could be present. The lady's other nephew and cousin subsequently found it difficult to visit the patient and soon began visiting less frequently. They noted that she seemed sedated whenever they saw her.

A nurse practitioner and physician team made occasional visits to the personal care home. The patient was developing pressure sores. The owner was asked to have the woman repositioned often to prevent prolonged pressure on vulnerable areas on the patient's body such as her sacrum, hips, and heals. However, the caretakers at the home were not able to reposition her as often as needed. In addition, the home was not taking the necessary time to help her eat and drink. This resulted in weight loss, malnutrition, and weakness. By late November, the nurse practitioner was expressing alarm at the condition of the patient and reported that she was in danger of dying. She informed both the physician she worked with and Carl that the patient needed to go to the hospital. Carl rejected this idea. Home health started visiting the aunt in late December and noted that the wounds were large, painful, and draining pus. The home health nurse recommended that the aunt be sent to the hospital. Again the nephew refused to allow a transfer to the hospital, insisting that she be taken care of in the home. At one point he mentioned that his aunt was old and just needed to pass on. Carl was in favor of enrolling her in a hospice program to be carried out at the home.

Issues Raised

In this case, the patient had provided for a surrogate to manage her affairs and make medical decisions in case she was unable to do so. Designating a surrogate to make her decisions was an exercise of her autonomy and should have been honored. However, the role of surrogate was not appropriately carried out and, as a result, her autonomy was ultimately not respected.

The powers of the agent appointed through power of attorney documents are defined and restricted by the terms of the documents creating them. These powers are also limited by the laws that authorize the creation of this agency relationship. For example, in Texas, the statute that provides for the durable power of attorney for health care allows it to be revoked by even a confused patient. In the case of both the durable power of attorney for health care and the durable power of attorney for finances, the agent is required to act as a fiduciary with respect to the principal. Also, in situations where the law establishes a surrogate for the incapacitated elderly person in the absence of a document appointing an agent, it is required that the surrogate act as a fiduciary for the person represented. This means that Carl was required to carry out the wishes of his aunt if he knew what she would want in the situation and, if he did not know what she would want, he was required to act in her best interests. These documents, as well as other advance directive instruments such as directives to physicians, are meant to promote the autonomy of the principal (patient) on whose behalf they are written. In this case, there is no indication that the patient would have wanted to be kept in a facility where her needs would be neglected. In the case of Carl, he violated his fiduciary duty to his aunt and was therefore potentially subject to removal as her agent [31–33].

The health-care providers were aware that this patient was residing in a personal care home that was not equipped to meet her needs. They also noted that she was suffering, not being cared for appropriately, and that the nephew stated that she should just pass away. Perhaps the medical team did not realize that the instructions of the nephew should be challenged when he was not acting in the best interests of his aunt.

When the medical providers had reason to believe that the patient was not getting her needs met, they were obligated by law to report the situation to adult protective services [34]. Even if they did not have the legal mandate to report, they had an ethical obligation to respect the interests of their patient to be treated humanely and have her needs addressed. The aunt's autonomy was being disregarded in the most fundamental way. Her right to life was being challenged. The level of disregard for her needs demonstrated by her surrogate (Carl) might have been a criminal offence and require a report to the police.

Enrollment of the patient in hospice would help make it seem that the death was expected and natural. However, even without the involvement of hospice, when an elder dies there is a lowered scrutiny regarding the cause of death being unnatural. The police, medical examiner, first responders, and hospital personnel are less likely to suspect unnatural causes of death, such as abuse or neglect, when the deceased is elderly [11]. Certain circumstances, wounds, or lab results may trigger a suspicion of unnatural death. Education regarding those red flags is important for those who investigate the deaths of elders. Medical providers are in a good position to distinguish the effects of normal aging and illness from the effects of neglect and abuse [1]. The most important indicator of abuse and neglect may be that the condition of the patient may not fit with the story given by the caretaker. For example, the caregiver may report that the elder stopped eating and drinking 2 days before yet the sodium is extremely high at 156 or the caregiver says that the patient developed some pressure sores over a week when the wounds are obviously a few months old.

Did ageism play a role in this disregard for the autonomy of the patient presented in this case? Ageism is, according to the Merriam-Webster dictionary, "prejudice or discrimination against a particular age-group and especially the elderly" [35]. Common prejudices against the elderly include the beliefs that (1) they are confused and cannot make their own decisions, (2) what they say is not reliable, (3) they cannot manage their own affairs, and (4) they do not have a good quality of life. Did the people taking care of the patient see her as a person with a right to autonomy or did they assume that her age precluded autonomy?

Medical providers sometimes depend on a facility, or a group of facilities, for referrals of patients, director fees, or other financial benefits. If the medical provider notices that one or more of the patients in the facility are not getting their needs met and this situation is not remedied by discussions with the appropriate persons, the physician has a duty to report the situation to the agency which licenses and regulates the facility in that jurisdiction. In situations like our hypothetical case where the facility is not licensed, APS might be the appropriate agency. In most jurisdictions, the health-care provider is required to report elder abuse, neglect, or self-neglect whether they have a physician-patient relationship with the patient or not. Any real or perceived duty toward the facility is overridden by the duty to obey the law and protect vulnerable elders. Beneficence requires this pursuit of the interests of the patient, not the facility.

Second Case Continued

A few weeks later, the owner of the facility called an ambulance for the patient. The aunt had become unresponsive and the owner did not want her to die in the home. She was not yet enrolled in hospice. In the hospital, the patient was found to be dehydrated, malnourished, and with over 20 pressure sores, some of which were infected. She was septic from the wounds. The nurses were alarmed at her condition, and the hospital social worker reported her case to adult protective services. The patient was treated with intravenous fluids, antibiotics, and surgical debridement of the wounds. She improved in the acute care hospital and was able to report to the social work case manager that she had not been getting fed well and was having pain from the wounds in the personal care home.

After 11 days in the hospital, she was transferred to a long-term acute care hospital for continued treatment of her wounds and infections. A month later, still in that long-term acute care hospital, she developed fluid overload and respiratory failure. The patient's nephew Carl was still recognized as the surrogate for his aunt, and he insisted that she not be moved to the intensive care unit and resuscitated. Morphine was administered for comfort and she expired.

Issues Raised

The nurses and social work case manager in the acute care hospital recognized that the aunt had most likely been the victim of neglect and reported the case to adult protective services. The aunt communicated with the social worker there regarding not being fed well and having been in pain at the personal care home. What if in this hypothetical case the patient did not want to get her nephew in trouble and so did not want the social worker to make a report to adult protective services? Patients do have an interest in confidentiality and this should be respected. However, social workers and medical providers have an obligation to obey the law, and the law requires that suspected elder abuse be reported even if the alleged victim is not in agreement [36].

Carl was still seen as her agent when another health crisis occurred at the long-term acute care hospital. Was a report to adult protective services enough to protect this patient? Could the social worker or the medical team at the acute care hospital have done more to protect this woman from a surrogate who had not acted in her best interests? Protection of the aunt's interest in autonomy should have prompted a termination of Carl's agency and this fact should have been made evident in the medical record. In the state of Texas, a principal on a durable power of attorney for health care may terminate the agency relationship no matter what the mental state of the principal. The aunt probably needed assistance and guidance from the social worker or medical team to have a more appropriate surrogate identified and engaged. The other nephew and the cousin were not contacted to take over as alternate surrogates either. She did not get the advocacy that she needed to protect her interests.

Conclusion

Elder abuse, neglect, exploitation, and self-neglect affect up to 10 % of elders in the United States, and these problems are associated with increased morbidity and mortality. Identification of cases and intervention to reduce harm to the affected elders is an important effort. Ongoing education of health-care workers, as well as others in the community who come into contact with the potential victims, regarding these issues and appropriate interventions is needed. Balancing the principals of autonomy and beneficence is required to resolve ethical conflicts arising in the case of elder mistreatment or self-neglect. Social and cultural norms, as expressed in laws and other codes of behavior, help guide what autonomy and beneficence mean in specific cases. The goal is to respect and promote individual choice to the extent possible while protecting elders who are unable to provide self-care and self-protection.

Practice Pearls

- The main duties of medical providers are to protect the interests of vulnerable elderly patients by
  - Knowing the statistics, morbidity, mortality, and red flags of elder abuse, neglect, financial exploitation, and self-neglect
  - Screening for these conditions in inpatient, outpatient, and long-term care settings
  - Performing appropriate assessment histories and physicals
  - Keeping the elder safe through appropriate interventions including reporting to appropriate governmental agencies and ensuring medical treatment
- In cases of elder abuse, neglect, exploitation, and self-neglect, the tension between the principles of autonomy and beneficence is important
  - Autonomy should be respected and overrides the requirement that the medical provider protects or acts beneficently regarding the elder. To care for and protect themselves, the elder must be able to both make and carry out decisions about their needs and safety. To make decisions about their needs and safety, they must be able to appreciate their circumstances. They must also be able to take goal-directed action toward carrying out these decisions. The autonomy interest of the elder with capacity to take care of and protect themselves allows them to make decisions that seem unwise to others
  - When the elder is unable to take care of or protect themselves, and so is unable to exercise their autonomy, beneficence requires that the medical provider work with the appropriate government agencies to help protect the interests of that vulnerable elder
  - The autonomy interests of the vulnerable elder may be furthered by the use of advance directives such as durable powers of attorney for health care, directives to physicians, and other durable powers of attorney. The agents or surrogates established in such documents have a fiduciary duty to the elder and so are required to carry out their wishes if known and act in their best interests otherwise. When this trust is violated, the vulnerable elder may need the assistance of the medical provider to oppose the agent or surrogate. The medical provider has a duty of beneficence toward the patient, and this requires them to put the interests of the patient before the interests of the agent or a facility

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Hospital and Physician Rating Websites: Ethical Challenges Without Context

12

George E. Taffet

Case Discussion

You are on call for the geriatric primary care practice. You receive a call from an anxious sounding daughter that her mother, your patient, has fallen. From the description, it sounds as if the patient has a fractured hip. The daughter asks you which hospital emergency room to go to and you pause. You cover two hospitals and could see your patient as a consultant in either place. Hospital A has a one-star rating on Healthgrades for hip fracture. Hospital B has a five-star rating. Which hospital would you suggest to the daughter? Is this a difficult choice? The daughter states that she has already looked at Healthgrades and Zocdoc but, as her mother's long-time physician, she values your input in making this decision.

Introduction

Questions regarding the utility and reliability of healthcare rating systems are not uncommon and pose ethical challenges. Ratings are, of course, not new and clearly predate the ubiquity of the Internet. However, multiple review sites on the web allow for easily accessible, unfiltered, and anonymous rating systems of physicians as well as opaque and frequently contradictory ratings of hospitals. This often leads to significant uncertainty among healthcare consumers who are presented this information without context.

In the example of the two hospitals above, your advice to the patient's daughter would be easier if there were no differences in the ratings between the facilities. In that case, you could respond that the care at either institution would be fine for a

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G.E. Taffet, MD
Chief Geriatrics, Geriatrics and Cardiovascular Sciences, Robert J. Luchi, M.D. Chair in Geriatric Medicine, Head of the Division of Geriatric Medicine, The Methodist Hospital, Baylor College of Medicine, Houston, TX, USA
e-mail: gtaffet@bcm.edu

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relatively common issue like a hip fracture repair. The daughter could then decide based on other personal factors such as her proximity to the hospitals. However, disparities in the ratings, with the representation of enhanced or worse quality of care and outcomes, are critical to your dilemma. Before providers, patients, and families can rely on information from healthcare rating systems such as Healthgrades and other consumer guides, they first must understand these systems including the basis of ratings and potential biases.

Hospital Ratings

Hospital ratings have proliferated over the past decade. These ratings systems have been stimulated by the movement for improved patient satisfaction and safety, increased accountability, greater transparency, and reduced costs. Many of the rating systems are governmental or from not-for-profit foundations, while others are from the private sector [1]. Those which are active across the United States include Hospitalsafetyscore.org, healthgrades.com, Medicare.gov:Hospital Compare, WhyNottheBest.org, CareChex.com, Leapfroggroup.org, Healthinsight.org, ratemds.com, and health.USnews.com (http://health.usnews.com/best-hospitals/rankings). Many individual states and professional societies have established ratings or comparison sites for hospitals as well.

Unfortunately, it is often difficult to fully understand the data presented on individual facilities and compare between facilities secondary to inconsistencies in the rating systems. The data driving the ratings, frequency of publication, and updating of the ratings vary widely. In addition, the various rating sites often include contradictory information on facilities. Sites also use a variety of different rating systems, including stars, numerical, and A through F grading, which makes comparing between the sites challenging.

In 2013, the Healthcare Association of New York State (HANYS) responded to these challenges by creating criteria upon which to judge the rating scales and publishing their findings in the “Report on Report Cards” [2]. This attempt at standardization was prompted by the recognition that individual hospitals were top rated within some systems and received low ratings from others. The HANYS called for (1) transparent methods; (2) evidence-based measures; (3) appropriate data source(s); (4) use of current, risk-adjusted, high-quality data; and (5) allowing the hospitals to preview their findings to correct errors prior to publication. The HANYS also tracked the financial implications of the rating systems in the hopes that financial drivers of the given models would also be made as transparent. In investigating this issue, HANYS determined that the financial models varied widely between the systems and raised the concern that money might influence the awarding of ratings. For example, the Leapfrog group required a licensing fee, not to participate in their assessment but to publicize the scores in advertisements for marketing purposes. Truven Health Analytics and CMP Healthgrades sell business tools to help improve scores on their respective rating scales.

One ratings scale which scored poorly on analysis by HANYS was that from the widely respected consumer group, *Consumer Reports (CR)*. CR was penalized for not allowing hospitals to preview the findings to correct errors, for using data from an inconsistent time frame, and for using criteria that were not endorsed by the National Quality Forum or CMS. Leapfrog, Trumen, Healthgrades, and US News and World Report shared the one-star rating with CR. Consumer Reports recognized the challenges that consumers face in understanding and interpreting the hospital ratings. Dr. John Santa, medical director of Consumer Reports Health, was quoted in a 2015 modernhealthcare.com article, “The science of (Hospital) performance management is still in the early stages and we have not all come together and agreed on an evaluating (sic.) system. It’s a chaotic picture. But if we want to get to knowledge, we have to go through that stage of confusion” [3]. Given this degree of confusion, it might be reasonable to explain to your patient’s daughter “We are still working through that stage of confusion in regards to the healthcare rating systems.”

Similar in concept to HANYS, the Informed Patient Institute (IPI) is a consumer-oriented, not-for-profit group that rates the usefulness of hospital ratings from A for “outstanding” to F for “not worth your time” [4]. In some instances, the state-specific rating scales are included, and they generally fare better on hospital ratings evaluations than the national scales. Unfortunately, many states do not provide the state ratings scales. One recurring critique that IPI raised was difficulty in understanding the data presented on the ratings pages, including the use of jargon. As might be expected given the wide variety of data and disparities between the rating systems, despite having a similar mission, there is little agreement between the IPI and HANYS regarding the most helpful rating systems.

The Advisory Board has also evaluated a variety of ratings groups: independent organizations such as Leapfrog, news organizations including US News and World Report, government measures such as CMS’ Hospital Compare and the Agency for Healthcare Research and Quality’s Patient Safety Indicators, and accreditation groups like the Joint Commission [5]. In their in-depth assessment of five different ratings groups, they noted that a major reason for the discrepancies among the ratings is that they include different foci [6]. While all five ratings scales focus on processes and outcomes, some gave greater weight to the process variables while others put more emphasis on outcomes. Additionally, Healthgrades adds the patient experience and US News includes the reputation of the institution among peers.

In an attempt to better understand and compare consumer-focused rating systems, Austin and colleagues looked at four national ratings systems focusing only on the top hospitals [7]. Over 800 hospitals were “high performers” on at least one of the ratings scales. Amazingly, not one hospital was ranked as a high performer in all four systems. In addition, only 10 % of hospitals were “high performers” on even two ratings systems. This analysis highlights the significant disparities between the variables measured and weight given to each within the ratings scales.

The Association of American Medical Colleges (AAMC) issued a set of guiding principles for academic medical centers to use in evaluating quality reports. They noted that the “differences in the measures, data sources, and scoring methodologies produce contradictory results that lead to confusion for the public, providers, and governing bodies and impair the ability to make well-informed choices" [8]. The three principles they underscored as critical to interpreting the reports were to "make sure a ratings group (1) offers a clear and concise purpose statement, (2) explicitly describes the intended audience, and (3) offers transparent methodology." They recognized that metrics could be influenced by a variety of factors including small sample sizes, non-validated data, and differences in patient populations, especially socioeconomic differences. The AAMC's principles were endorsed by a number of hospital organizations and provide a good deal of guidance for what the ratings scales need to consider before they will have impact within academic circles.

In contrast to the AAMC's recommendations, some ratings groups do not offer transparent methodology. Instead, they use proprietary algorithms, prompting criticism from the hospitals and experts. "If a rating program isn't willing to make its methodology completely transparent, then no one should use it," said Dr. Ashish Jha, a Harvard University professor of health policy who is on the advisory committee for the Leapfrog Group [9]. It is difficult to imagine how a hospital might improve its rating and, more importantly, quality of care, if the scoring is opaque. Not surprisingly, many groups using the proprietary algorithms are the same ones that will provide advice for a fee [7]. Transparency seems to be critical to understand and interpret the rating systems.

While the multiple ratings are a challenge, making it more difficult for hospitals to know which areas to prioritize to improve their quality of care and rankings, the multiplicity of ratings and methodologies does have a benefit for some hospitals. The multiple rating websites and data points included allow almost all hospitals to be above average on at least one site, enabling hospitals to choose favorable ratings for marketing purposes, independent of the validity or rigor of the ratings system.

Ratings systems have become part of our modern healthcare climate and increased rating scrutiny is anticipated as consumers, facing higher cost-sharing, increasingly attempt to shop and compare healthcare venues in an attempt to balance quality, service, and price. As long as hospitals do not directly provide this type of information to consumers, disparate ratings scales will continue to proliferate resulting in increased complexity and confusion for hospital leaders, direct care providers, and healthcare consumers. While searching through multiple Internet-based rating systems presenting contrasting information may feel familiar to consumers making decisions about products such as new cars, using a similar system to make healthcare decisions is fundamentally different as users may not have the opportunity to test drive their choices before making this critical decision.

Returning to the case, it is important for the patient's daughter to understand that each of the rating sites integrate different information in varying fashions to determine their final rating. In addition, the quality of the data utilized is variable. It is very difficult to know how their rules and ratings, designed for general populations, will predict the outcomes her mom would experience in each hospital. It would be reasonable to discuss that most large hospitals are well equipped to handle an older person with a hip fracture, to recommend a surgeon if there were compelling reasons to do so, and then allow her to make the final decision.

Practitioner Ratings

While rating systems are starting to focus more on individual providers, rather than hospitals, this may be out of touch with prevailing trends. The Advisory Group's Alicia Daugherty, who has followed ratings websites for almost a decade, noted, "There's some data suggesting that while baby boomers choose their doctor first and then will go to the hospital that their doctor recommends, younger generations are more likely to choose a hospital first and then find a doctor affiliated with that hospital" [10]. That does not diminish the potential role for physician ratings websites; it just modifies whether they are primary or secondary.

There are more than 60 physician review websites available for US consumers to get information on their health providers [11]. These include Healthgrades.com, Vitals.com, WebMD.com, RateMD.com, Yelp.com, AngiesList.com, Checkbook.org, EverydayHealth.com, Kudzu.com, RevolutionHealth.com, ThirdAge.com, UCompare.com, Healthcare.com, ZocDoc.com, RealSelf.com, Google.com, BetterDoctor.com, and Sharecare.com. Some, like RealSelf.com, seem to focus on aesthetic procedures or other narrow areas of care rather than more general overall care.

In recent national consumer surveys, up to 75 % of consumers reported doing some research before choosing a doctor. Preferred methods included asking friends/family or visiting a provider's or insurer's website. However, less than 10 % used third-party physician rating sites. This was due, in part, to lack of knowledge about the available ratings sites and finding them difficult to navigate [12]. When patients do use the rating websites to choose physicians, they avoid physicians based on negative reviews more than one-third of the time. However, at this time, websites and the individuals who post negative reviews have been immune to slander and other charges including damages for posting fraudulent or inaccurate reviews. This presents a real problem as there is no way to confirm the accuracy of reviews and physicians have no recourse to rebut those that are incorrect.

Much as with the hospital ratings sites, there are significant ethical challenges raised by practitioner ratings websites. The principles presented by the AAMC regarding hospital ratings are likely to be the best rule of thumb for these sites as well: (1) states a clear and concise purpose statement, (2) explicitly describes the intended audience, and (3) offers transparent methodology. Unfortunately, at the present time, practitioner ratings websites can be manipulated, and the ability to influence what appears on the site is a growing industry that works by multiple strategies, all independent of modifying quality of care. Since there are frequently very small numbers of reviews for any given individual practitioner or practice, the impact of even a small amount of manipulation can be dramatic. Entities are available that will monitor, help clean up negative reviews, and assist in reputation management for a fee. Interestingly, these entities use testimonials to validate their impact [13].

Reports of practitioners or practices paying for good reviews are not infrequent, with some of the payments being as little as 25 cents per review [11]. Bing Liu, a data-mining expert at the University of Illinois, Chicago, estimated that about one-third of all consumer reviews on the Internet are "fake" [14]. However, because consumer reviews offer the illusion of truth as testimonials of real people, they are more powerful than old-style advertising and marketing. In the case of online book reviews, Mr. Liu thought it was difficult to discriminate real reviews from those written by marketers or retailers, by the book authors themselves, by customers getting a deal for giving a good review, or by a hired third-party service. The same probably holds true for reviews of practitioners and practices. All of those "fake" would be expected to be positive. For negative reviews, the same challenges exist as they could be inaccurate reports posted by disgruntled patients or former employees, those angry for getting appropriate care (i.e., not ordering a MRI to work up a benign presentation of low back pain), or the competition. Secondary to the unique protection available to "patients" under HIPPA, all reviews can be anonymous making false reports easy to post and very difficult to confirm. All of these issues contribute to the compromised validity of the information available to consumers trying to decide which physician to use.

Physicians who have been unfairly given inaccurate and factually incorrect reviews have found they have no recourse to correct or counter the false claims. Many websites make no effort to verify correctness or legitimacy of posted reviews. Some of the ratings websites charge a fee to modify a report but have no accountability or responsibility for repercussions of the reviews. The lack of accountability by the ratings websites has caused increasing frustration on the part of many practitioners and helped spur the growth of reputation management services. In an attempt to prevent negative reviews, some physicians ask patients to sign waivers precluding them from submitting negative reviews or any reviews at all. While one might think this approach is useful, it will not stop patients from submitting anonymous reviews and may create a strained component to the nascent physician-patient relationship which is built on trust. Others have taken different approaches. In Samora's survey, she found physicians that would no longer perform "back-to-work" or court-ordered "independent medical examinations" because those patients, when given news other than what they desired, were frequent sources of bad reviews [11]. Other practitioners in that same survey seemed to have modified their screening so that "difficult patients" would not be admitted into the practice. Some physicians admitted to considering placating unreasonable patients because of the threat of the bad reviews [11, 15]. The association between increased patient satisfaction/positive reviews and better patient care quality/outcomes is debatable at present [15, 16].

One popular review website, Yelp, helps illustrate many of the concerns raised regarding the challenges of physician ratings websites. Yelp originated in 2004 as a physician recommendation service when one if its creators was trying to find a physician in San Francisco. Today, it has grown into a site where millions of users share information and access reviews on a wide variety of goods and services, including doctors. A Freedom of Information Act request unearthed hundreds of complaints filed with the Federal Trade Commission against Yelp. The most common complaints purport that Yelp filters out positive reviews and allows negative reviews through, especially in cases where the vendor in question did not purchase advertising [17]. Thus, the ratings algorithms were manipulated to encourage financial support for Yelp. A second challenge faced by Yelp was documented in a study from Harvard Business School that suggested nearly 20 % of Yelp restaurant reviews were "fake." The reviews were assessed using a screening algorithm, rather than being researched individually. The "fake" reviews included reviews that were paid for, solicited, written by competitors, and written by the restaurants themselves [18]. While Luca and Zervas, the investigators, focused on restaurant reviews rather than physician reviews, there is no obvious reason that their reasoning and approach would not generalize to all types of reviews.

Some practitioners have recoiled at being rated like restaurants or car washes. Medicine is complicated and even the best care does not always lead to wanted outcomes. Furthermore, the general public can tell if their car is clean or food hot, but judging appropriate medical care may not be so obvious. Confusing a confident bedside manner with competence is one obvious trap [19]. Consumers may base their ratings on what they understand best, customer service, which may not be what is medically most important. Therefore, the impact of a rude receptionist or inadequate parking on these ratings cannot be overestimated. Reviews based on customer service, not medical care, are just another reason physicians have become disenchanted with these sites but also highlight possible ways to improve ratings without any impact on patient care.

Conclusion

Ratings systems for physicians and hospitals can be helpful if used in certain ways. Most of the review sites provide practical information such as phone numbers and addresses, physicians' credentials, and what insurances are accepted. However, it is unlikely that today's rating systems can provide what our patient and her daughter want and need – unbiased, transparent, timely, and relevant information to help make educated healthcare choices. Samora and colleagues suggested creation of a task force to assess the professional, ethical, and legal implications of the ratings websites [11]. At the same time, the task force could work to improve the accuracy of the information, oversight, and feedback mechanisms. Perhaps that will come with future iterations of rating websites. However, in the interim, it is reasonable for practitioners to monitor their presence on these sites and make an effort to correct incorrect information. They should realize that a few negative comments should not be a surprise, especially because the physician is seen as responsible for the actions of the nurse, billing personnel, and parking attendant. Simple steps taken to correct customer service concerns at these levels can increase ratings, if not improve patient care. Rating sites have resulted in a new dynamic and possibly irreversible shift in balance in the physician-patient relationship. Hopefully this can be countered by increased accountability, reliability, and utility of medical rating sites in the future.

Practical Pearls

The utility and reliability of hospital and practitioner rating systems is currently limited due to the use of various, often unclear criteria

It is important to be aware that some sites will assist hospitals in improving their rating for a fee

Practitioners should actively review their presence on rating sites as many, but not all, encourage correction of inaccurate information

Customer service aspects visits (parking issues, interaction with receptionist, etc.) often impact practitioner ratings by patients

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Considerations and Challenges in Information and Communication Technology

13

Bradley H. Crotty

Case Presentation

Addie is an 86-year-old woman who, accompanied by her daugher Melanie, comes for a new geriatrics visit with Dr. Smith. Addie was previously living independently out of state but, after a series of falls and some increased forgetfulness, Melanie convinced her mother to move into senior housing nearby in her town. Melanie, who is the mother of two teenagers, is an executive at a local nonprofit organization with full working days of her own. Addie prefers to be responsible for managing her affairs, but she is agreeable to having Melanie participate.

Melanie, dealing with her own very busy life, is looking for easier ways to communicate with clinicians about her mother. She is particularly interested in communication through texting, if possible, and to find a way to easily obtain information from visits that she can't personally attend because of work. She often lives in social media as part of her work and has naturally turned to this for information about caregiving. For the most part, Addie does not use computers, but she does have a tablet computer that she uses for video chatting and Facebook® to connect with her grandchildren.

Addie wishes to be in charge of her medical care, but, acknowledging her new forgetfulness, she is agreeable to Melanie helping out as long as she doesn't "take over." Though Addie is now closer, Melanie is still nervous about her mother living by herself and is interested in seeing what technology can be used to give her a "heads-up" if Addie has a problem. The geriatrician, whose practice does have a portal for patients to communicate with their clinicians and read their records, meets with both Addie and Melanie and begins the conversation.

B.H. Crotty, MD, MPH
Department of Medicine, Medical College of Wisconsin and Froedtert Hospital,
Milwaukee, WI, USA
e-mail: bcrotty@mcw.edu

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Introduction

The case above is becoming a common scenario in the offices of many geriatricians and primary care clinicians. While family members assisting their aging parents are not new, the information and communication technology landscape is rapidly changing and offering new and creative ways to enhance communication among families and their clinicians. As commonly occurs in real life, Melanie is busy with her own responsibilities and would like to apply the technology she uses everyday to help her in the coordination of care for her mother. Within the case, we see foreshadows of conflict regarding autonomy of the elderly woman and the helpful intentions of her daughter. We can also envision challenges for the geriatrician that include decisions about methods of communication between the patient and family, decisions around competency, challenges of information access, and assistance in the implementation of monitoring technology to alert caregivers about problems, such as falls and missed medication doses.

Technology and Healthcare

In the information age, people increasingly have several "always-on" communication and information channels, such as voice, text messaging, e-mail, and social media that are supported by fast mobile and home Internet connection [1]. The proportion of older people with these devices and capabilities is also increasing. In 2013, 68 % of individuals between 70 and 74 years of age and 47 % of those 75–79 years of age were online [2]. Baby boomers, the generation born between 1946 and 1964, are now caring for aging parents. This generation is accustomed to using the Internet, with 72 % of caregivers spending time online gathering health information [3, 4]. Over time, and with people living longer, the curve of older people using technology will continue to rise.

Technology has helped to break down many barriers and democratize information. Partly due to the widespread use of technology, the information asymmetry between patients and clinicians is shrinking. Patients and, by proxy, their families increasingly have access to their own medical data and records including clinician notes [5]. In addition, websites, ranging from the National Library of Medicine to Wikipedia, are offering helpful information and educational resources to patients and caregivers. Motivated patients can also access professional content. Patient-focused communities and message boards bring together people with similar conditions, struggles, and needs. Increasingly, we will see patients, especially those with more rare or nuanced conditions, be more informed than clinicians about their medical conditions.

Developing technology also brings new challenges, both to families and to healthcare professionals. Challenges can be separated into ethical ("Should I perform an action?"), technical ("Can I perform an action?"), and social/legal ("Is it acceptable to perform an action?"). Additionally, information and communication technology opens new risks, such as loss or theft of information, and this may be particularly relevant to older people online. When considering the increasing use of technology in healthcare and the challenges that geriatricians are likely to encounter in their clinics, it is helpful to apply existing ethical frameworks when possible. It is important to realize, however, that these frameworks are not exclusive to technology but can be applied to many of the interactions that occur between patients, their families, and their healthcare providers.

Principles, Concepts, and Tools

The rapid pace of change in technology that we use for communication, as well as the diversity in circumstances for its use, precludes hard and fast rules about its acceptable use in clinical care. Rather, geriatricians should become familiar with principles and tools to help resolve any ethical dilemmas. The "Georgetown Mantra" of Bioethics lists the principles of beneficence (in the interest of helping the elderly person), non-malfeasance (do no harm), autonomy (respect the individual), and justice or farness for all. Not infrequently, ethical principles may appear to be at odds with one another, and as we shall see, it is important to understand the decision-making capacity of the elderly person, to weigh risks and benefits, and to ensure that goals and perspectives are aligned with the patient's interests (Tables 13.1 and 13.2).

Here, we will discuss ethical principles related to the use of technology in healthcare: protection of autonomy and respect for the individual, issues of consent and assent, beneficence, and principles of privacy and security [6].

Table 13.1 Ethical principles applied to technology

Principle	Definition
Autonomy and respect for the individual	A person's ability to preserve decision-making and exert independence
Consent and assent	A person's ability to give permission while understanding the trade-offs of a particular decision. Assent refers to the ability of a person, who is deemed unable to consent, to voice willingness to adhere to a particular decision
Beneficence	A principle to act to benefit others
Privacy and security	The protection of personal information from public accessibility

Table 13.2 Practical pearls for navigating technology

When possible, use communication channels dedicated for patient care and available to all patients
Be aware that unintended consequences of sharing health information, including disclosure of information previously kept private, may occur with proxy access to portals or records
Encourage patients to discuss information stewardship and management in the context of advance care planning
Periodically enquire about online activities
Discuss limitations of using technology with patients and families when appropriate

Autonomy and Respect for the Individual

Autonomy, perhaps one of the most central tenets in ethics related to aging, refers to the older person's ability to preserve decision-making rather than to relinquish it to another person. In the context of technology, autonomy may relate to a person's ability to have control over information flow and communication. The use of social and communication/information technologies creates needs for decisions about access and privacy. For example, can a family member read the elder's chart? Also, with whom should the doctor communicate – only with the patient or also with family members and, if so, which family members in particular?

Teachings from Immanuel Kant and other philosophers have taught us to think about respect for people and their autonomy as a process [7]. Put another way, the ends may not justify the means if the elderly person's preferences are not being honored. One example that we will come back to is the use of technology to monitor elderly people in their homes. While these signals may be helpful for early detection of problems, such as falls, they may not be acceptable if they result in loss of privacy for the elder. Data from focus groups of elderly people and caregivers provide rich food for thought. As one older gentleman noted, "we want technology to rescue us, not spy on us" [8].

For elderly people, autonomy is likely to diminish as cognition declines. Making prearranged plans for information control and sharing may be helpful for preserving and honoring peoples' wishes, even when they are unable to make decisions for themselves.

Consent and Assent

Consent refers to a person's ability to give permission while understanding the trade-offs of a particular decision. Assent refers to the ability of a person who is deemed unable to consent, often due to cognitive impairment, to voice willingness to adhere to a particular decision [9]. In the context of information and communication technologies, consent and assent may be most frequently applied when using patient portals or communicating with electronic tools, including the delegation of family as proxy users, or when using technology to monitor elderly people at home. If a patient with some level of cognitive impairment dissents with sound reason to the use of a technology, such as a home-monitoring device, this should be incorporated into the decision-making. Patients with cognitive impairments may have difficulty understanding some of the discussions regarding consent for online services, such as risks to privacy, but even when patients have some cognitive impairment, their wishes and preferences about how communication occurs should be respected.

In our case of Melanie and Addie, Addie has some form of forgetfulness that could represent mild cognitive impairment. At this time, however, she appears to have the ability to represent her interests and preferences for communication flow. She acknowledges that she wishes Melanie to be involved. Our geriatrician may go on to ask if it is okay for Melanie to have access to Addie's records and under what circumstances, if any, it would be acceptable to be in touch with Melanie directly.

Beneficence

Another vector in ethical frameworks is that of beneficence or benefit. We assume that patients, families, and clinicians are using technology to help improve or optimize health on the older person's behalf. In some cases, however, beneficence from the perspective of the family members or clinician may be at odds with the perspective of the patient when it interferes with the patient's autonomy. Put another way, what benefits one person may not benefit the other, and therefore beneficence depends on values, goals, and perspectives [10, 11]. Let's return to the example of home monitoring. Melanie may suggest that a home-monitoring device be used by Addie that would provide warnings for falls or untaken medications (putative benefit for the health and well-being of Addie). Addie may find, however, that such a device is not acceptable because it is too intrusive (autonomy – she has the right to decide). In such a scenario, beneficence and autonomy are potentially at odds. In these circumstances, determining the goals of the intervention is important; what is beneficial to Melanie (peace of mind) may not provide any benefit to Addie. In these cases, it can be challenging for all parties involved to navigate what should happen, and intra-family negotiations are often required. Ultimately, centering discussions around the goals of the patient will likely bring some clarity to the conversation.

Privacy and Security

Clinicians have a duty to safeguard patient information, but the use of information technology provides some inherent risks. These risks can be managed with good information habits and by following best practices. However, we sometimes will see where security is at odds with usability, especially in the consumer space. Clinicians and supporters of elderly people, such as family members, will need to consider trade-offs of optimal usability with privacy and security and often have to balance the privacy risks to the elderly person with the benefit of the service [12]. A common example is the use of traditional e-mail, which is typically not secured or encrypted, compared with the use of a dedicated and secured patient portal for messaging. E-mail is available to nearly all – most individuals are using it already for other purposes – and many people may feel comfortable with this technology. In contrast, a portal requires additional steps to use including a distinct visit and log-in to the site using a separate username and password. Some elders, who are comfortable with traditional e-mail, may find this confusing or cumbersome.

Elderly people may be especially vulnerable to breaches in security. The Federal Trade Commission has noted that about a fifth of identity theft complaints reported to the agency were for people over the age of 60 [13]. In particular, the most common type of fraud focuses on healthcare or health insurance. Elderly people may have less facility with technology and, as such, be potentially be more trusting of nefarious e-mails and content such as phishing attacks, where an e-mail or website purports to ask for information for legitimate purposes but instead collects and uses the information for malicious purposes. Elders may be more susceptible to scams from the phone, web, social media, and e-mail. Funds, including savings and social security payments, may be at risk.

Technologies and Communication Channels

It is important to understand how to apply the above principles to scenarios clinicians may encounter. For each medium, we will (1) review the context and frame the issues, (2) consider issues in the context of the guiding principles, and (3) provide practical suggestions for geriatricians.

Patient/Family and Clinician Messaging

Technology has facilitated the proliferation of communication channels. Clinicians now try to balance in person meetings, phone calls, and e-mails and secure patient portal messages. They may even have requests, such as in our case, to use text messaging. In the ever-changing landscape of communication media, clinicians caring for elderly patients are likely to encounter new dilemmas and challenges. Does the elderly patient provide consent or assent for proxies or other family members to communicate with the clinicians? How do clinicians balance their communication with patients and the family members? When is it appropriate for clinicians to raise concerns directly with the patient's family members?

The guiding principle of autonomy encourages clinicians to ensure that they communicate directly with the patient in so far as possible, in the manner in which he or she prefers. Acknowledging that family members may wish to communicate directly with them, clinicians should ask patients when and under what circumstances this would be acceptable or preferable. They should also clarify which family members are to be involved in the communication. In our case, Melanie, the daughter of Addie, wishes to develop communication channels directly with Dr. Smith. This makes sense for several reasons including being able to communicate concerns and questions as well as being able to alert Dr. Smith of important changes. We also see that Addie does not want Melanie to "take control." Geriatricians will often need to balance competing interests of the patient and family, but being transparent and forthright in asking the patient about preferences is an important first step in helping to prevent downstream conflict.

Where possible, clinicians will want to use communication channels that are dedicated for patient care and available to all patients. For example, communication through secure messaging in a patient portal is preferable to e-mail because of security and self-documentation in the permanent medical record [14]. Since a patient's clinician may not be readily available to receive an important message (in the middle of the night, on vacation, or during a busy clinic session), it would be particularly helpful if the patient's messages could be directed as well to appropriate clinic members who will be available around the clock.

Health Information, Patient Portals, and Open Notes

Access to information can be a boon to family caregivers [15, 16]. Especially when they cannot attend an appointment, for them to have summary information available from the visit can help with providing care and reduce their stress [17]. Patients and families may wish to sign up for dedicated patient portals for a variety of reasons, such as communicating with clinicians, viewing lab results, accessing other test results, and facilitating medication refill requests. Increasingly, clinicians are also making their medical notes available to patients through portals [5]. These notes are referred to as "open notes," named after the large demonstration project in 2012 at three major medical centers [18]. Open notes have been linked with patients feeling more in control of their health. Recently, attention has been directed to sharing open notes with family members and other caregivers [19, 20]. Open notes provide a way for family members, such as Melanie who cannot attend clinic visits because of her working schedule, to know what was discussed and the plans that were made.

While most early portals were not designed with caregiving in mind, some allow for proxy access, meaning a family caregiver can use their own log-in credentials to access the site [21]. It may become complicated, however, if the elderly patient wishes to keep some specific information in the past medical chart private. Proxy access to health records through a patient portal may unintentionally disclose information about sensitive matters previously undisclosed, such as abortions, sexually transmitted infections, or past diagnoses. In situations where there is information patients would not want revealed, clinicians should tend toward protecting the autonomy of the individual patient. The ability of patients to manage their information, however, is dynamic and depends on the health and functional status of the patient. In cases where patients can no longer manage their health affairs on their own and the proxy is provided access to the medical record, clinicians should be aware that unintended consequences of sharing health information, including disclosure of information previously kept private, may occur. In anticipation of this issue, clinicians would be wise to discuss issues of information stewardship and management in the context of advance care planning early on with their patients. For example, should the proxy have access to all historical information or only be provided with information moving forward? Patients should be encouraged to consider such discussions and to share their preferences with their proxy.

In our case, Melanie and Addie need to discuss Melanie's access to the portal and to clinical notes. Addie may wish to have sole access to the portal in order to keep control of her information or she may wish to delegate permission for Melanie to access the portal as well. If Addie wishes to have sole access at this time, she and Melanie should be encouraged to have a discussion about those circumstances in the future when Melanie would have access to the health records in order to be an informed proxy and surrogate decision-maker.

Social Media

Patients and families are likely to use social media to connect with one another as well as to seek information from others with similar experiences in aging. Offline social integration and networks have been related to improved health [22–24]. Higher social integration leads to becoming better informed, helping with decisions, and helping to access tangible resources. Evidence is building that online networks and communities are translating into improved health and reduced caregiving burden [25–27].

If clinicians do not have a channel available for electronic communication with patients, such as a patient portal, patients may be more likely to attempt to communicate through more personal channels, such as personal e-mail, Facebook, or other social networking sites that may be retrieved through a web search [28]. Social media channels such as these should, however, be discouraged as communication channels for patient care because of concerns about security, confidentiality, ownership of content, and reliability. Additionally, patients may read blogs or information that has not been vetted or does not apply to their particular circumstances. Clinicians should periodically enquire about patients' online activities to determine if their use is helpful or a source of misinformation or stress. Learning what types of health-related information patients may be reading can help the clinician, when appropriate, recommend better sources of information. If clinicians become concerned that elderly patients have been the victim of a scam or elder abuse through online tools, they should respond appropriately as for any other form of abuse, including mandated reporting where applicable.

Melanie and Addie may use social media to connect with friends and others with similar situations to seek support. Social media is becoming an important channel to learn about new information and learn how others have responded to similar challenges. It is likely that over time they will bring questions and ideas from social media to Dr. Smith, who will play an important role in helping the family navigate this information.

Remote Monitoring

As consumer devices, appliances, and other objects gain connections to the Internet, in the so-called Internet-of-things, technology could increasingly be deployed to the home environment to help monitor for safety problems. Connected sensors are currently able to send alerts in situations where a fall occurs or medications go untaken. On the horizon are sensors and algorithms that can monitor changes, such as in gait or voice, of relevance to changes in health that could initiate alerts leading to prompt interventions that might prevent falls or the need for late-night trips to the emergency department. Studies have demonstrated that elderly people are accepting technology in the home, as long as it better helps them remain independent and preserve their autonomy [29]. Although one report has suggested that in the future the acceptability of monitoring technology may decrease with use due to false alarms or concerns around issues of privacy, there is little evidence at this juncture to discourage the use of these types of assistive technology in the home [30, 31]. Geriatricians may be asked about the use of assistive technology by patients and families, and it is important for all parties involved to be sure they understand what problem is being addressed, who will monitor the alerts, what will be done when an alert occurs, and what contingency plans are available if the technology fails to work properly. Further, the family and healthcare team need to determine if the technology is acceptable to the particular elderly person in the home. Additionally, and also from an ethical perspective, the limitations of the technology should be fully discussed such that the technology is not being relied upon in lieu of other home safety plans, such as visits by family, nurses, or personal care attendants.

In our case, the geriatrician and team may wish to recommend some basic technology to help with Addie's independence in her home, this could include alert devices that when pressed can call family or emergency services. In the future, it will be important for patients and their families to discuss with their clinicians what other technologies could be helpful and acceptable in their homes.

Summary

Technology offers promise to make lives better, but also introduces new challenges to patients, families, and clinicians. Many of these challenges, however, are not unique to technology and ethical dilemmas about information sharing, autonomy, and privacy existed before patient portals and social media. Clinicians can apply existing ethical frameworks and approaches to most of these new challenges when conflicts arise.

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Ethical Issues in Geriatric Research

14

Lisa Boss, Sandy Branson, and Sabrina Pickens

Case Presentation

Imagine yourself as a new research investigator conducting your first pilot study. Your ultimate goal is to develop an intervention that will alleviate detrimental health outcomes in the older adult population. In your first interaction with a potential study participant, Mrs. S., you suspect she may have dementia because she has asked the same question about the study at least five times. How should you proceed with the informed consent process? Should you enroll Mrs. S, despite your suspicion that she may not understand your study? Both new research investigators and experienced investigators will face ethical dilemmas like this one with Mrs. S. on a regular basis.

Introduction

Adults 65 years of age and older are the fastest-growing segment of the US population and, due to longer life spans and the aging of the baby boomers, are expected to double to 72 million by 2030 [1]. With greater longevity, older adults incur multiple chronic conditions which contribute to the leading causes of death and 66 % of the healthcare budget [1]. Despite these impressive statistics, older adults are frequently underrepresented or completely excluded from clinical trials without adequate justification [2]. This lack of inclusion is alarming given the fact that many prescription drugs and medical procedures have not been properly evaluated in the population in whom they are most likely to be used.

L. Boss, PhD, RN, ACNS, CEN (✉) • S. Branson, PhD, RN • S. Pickens, PhD, MSN, GNP-BC, ANP-BC
School of Nursing, The University of Texas Health Science Center at Houston,
Houston, TX, USA
e-mail: Lisa.Boss@uth.tmc.edu; Sandra.M.Branson@uth.tmc.edu; Sabrina.L.Pickens@uth.tmc.edu

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In the early 1990s, the International Conference on Harmonisation (ICH) attempted to address this issue by issuing guidance regarding inclusion of older adults in clinical trials of study drugs likely to be used in this population [3]. It was recommended that this guideline, which stated the following, be adopted by regulatory agencies in the United States, Japan, and the European Union:

> The geriatric population is arbitrarily defined, for the purpose of this guideline, as comprising patients aged 65 years or older. It is important, however, to seek patients in the older age range, 75 and above, to the extent possible. Protocols should not ordinarily include arbitrary cutoffs. It is also import not to exclude unnecessarily patients with concomitant illnesses; it is only by observing such patients that drug-disease interactions can be detected. The older the population likely to use the drug, the more important it is to include the very old (pg. 2) [3].

Despite this and other efforts from regulatory agencies, the widespread exclusion of the geriatric population is still evident among clinical intervention trials [2, 4]. For example, studies on hypertension and heart failure tend to include older adults who are younger, healthier, and cognitively intact, thus making it difficult to generalize the results to more complex individuals. The more complex cases, including those normally cared for in geriatric medicine clinics, typically include individuals over 80 years of age with multiple comorbidities, polypharmacy, functional decline, cognitive impairment, and inadequate social support networks [2]. The exclusion of this more complex, real-life population from research is widespread. For example, only a small percentage of older adults discharged from an acute hospitalization with the primary diagnosis of heart failure meet eligibility criteria for heart failure trials [5]. Similarly, in a systematic review of clinical trials for cancer treatment, less than a third of possibly eligible older adults were recruited [6]. In a review of 440 clinical trials regarding type 2 diabetes mellitus, Cruz-Jentoft and colleagues found that only 1.4 % are designed for older adults [7]. In this review, the majority of the trials excluded older adults for the following reasons: 65.7 % based on an arbitrary upper age limit, 76.8 % on comorbidity, 29.5 % for polypharmacy, 18.4 % for

Table 14.1 Educational pearls regarding research in older adults: connecting ethical issues to daily dilemmas

Use good clinical acumen when evaluating new drug therapy for older adults when this population is not representative of the study sample
If engaging in clinical research, adequately justify exclusion of subjects 75 years of age and older with comorbid conditions
Be aware of the challenges, and possible solutions, in research involving older adults
For potential research participants, assess decision-making capacity prior to obtaining informed consent, particularly in vulnerable populations
As there is currently no general consensus, be aware of laws regarding surrogate consent for research in the state in which you practice
Regarding surrogate consent, be aware of the ethical principles of substituted judgment, pure autonomy, and best interest for the older adult who lacks decision-making capacity
Encourage older adult to complete research advance directives to resolve potential ethical dilemmas

cognitive impairment, 8.9 % for short life expectancy, and other poorly justified reasons.

To increase representation of the geriatric population in clinical trials, researchers must understand and be comfortable with the ethical challenges which may arise in this population. Familiarity with basic educational pearls regarding research in geriatric subjects can help researchers safely and ethically include older adults in their studies (Table 14.1). In addition, to minimize the exclusion of older patients from appropriate clinical trials, researchers should be well versed in appropriate informed consent procedures, strategies to prevent under-recruitment, and information security risks.

Informed Consent Issues in Geriatric Research

Informed consent is a process that is intended to ensure human research subjects are provided with the necessary information to make an informed decision to voluntarily participate in research. Agencies and regulations including the Food and Drug Administration (FDA), the Federal Policy for the Protection of Human Subjects (commonly called the Common Rule), the Office for Human Research Protections (OHRP), and the Institutional Review Boards (IRB) require informed consent for human research subjects in research studies. Based on ethical principles delineated in the *Belmont Report*, the informed consent process is intended to ensure that the autonomy of potential research subjects is protected by ensuring that they have decisional capacity and are free from coercion to participate [8].

Decisional Capacity

Decisional capacity is the ability to understand and process information and make judgments based on rational understanding of choosing one alternative instead of another [9, 10]. Hence, decisional capacity is the first requirement of informed consent. A consistent set of criteria for assessing decisional capacity has not been published; however, standards of incapacity include the inability to: express or communicate a preference or choice; understand one's situation and its consequences; understand relevant information; give a rational reason, give risk- or benefit-related reasons, and/or to reach a reasonable decision [11]. Individuals who are capable of demonstrating understanding of the presented information, ability to reason, and consent or refusal to participate may be able to consent and participate in research.

Cognitively and mentally impaired persons are the most challenging to assess in terms of decisional capacity [12]. In some situations, individuals who are cognitively or mentally impaired have substantial impairment to decisional capacity, whereas in other situations individuals may be able to provide consent [13]. For example, older adults who are diagnosed with mental disorders, neurological disorders such as stroke and dementia, and metabolic disorders may retain decisional capacity, but these conditions can cause transient or persistent impairment in individual's capacity to consent [13]. Not only can medical conditions affect decisional capacity, but the complexity of a research study may hinder the older person's ability to fully comprehend the study and consent to participate [14]. For example, a potential subject may not be able to understand the implications of a randomized control drug trial, whereas they are able to understand and consent to a simple observational study [14]. Determining an individual's capacity for consent and conveying information in an organized, understandable manner that allows for questioning and full consideration of all possible options are important ethical principles of the informed consent process [8].

Procedures for assessing decision-making capacity are defined by the research protocol and may include standardized and validated instruments with cutoff scores for participation, post-consent quizzes documenting the critical elements of the research, or alternative procedures [15]. Although decisional capacity is assessed during the recruitment and the enrollment phase of research, researchers must continue to assess for decisional capacity throughout the duration of the study. If participants lose the ability to consent after enrolling, the participation should be placed on hold for IRB review [16].

In the United States, additional protections of vulnerable research subjects are regulated by federal regulations and state statute. Federal regulations include cognitively impaired persons as "vulnerable" research populations that require additional consideration or protection. This may include individuals with Alzheimer's disease, dementia, mental illness, and developmental disabilities [17]. Consequently, detailed procedures to determine decisional capacity and the ability to consent must be reviewed by the IRB when recruiting subjects with cognitive impairment [17].

Consensus is lacking on the degree of protection that should be afforded to individuals enrolled in surrogate-based research [18, 19]. In certain situations, federal regulations and state statute allow surrogate consent from a legally authorized representative. However, states define legally authorized representatives differently, and many states have no laws regarding surrogate consent for research [20]. Not surprisingly, the role of surrogate consent is contentious, and judgment on the part of all involved in conducting the research is required [21].

Competency

Although the terms are often used interchangeably, the legal concept of competency is not synonymous with decisional capacity. Competency refers to a court decision, usually by state probate court, which determines if an individual has the ability to make competent decisions [22]. In the case of an older person who is determined to be incompetent, a guardian (or conservator) may be appointed as the legally responsible decision-maker through the process of guardianship. The guardian is usually a family member, but can also be a court-appointed friend or impartial person [23]. Legal guardians have the authority to make decisions on behalf of the individual who was deemed incompetent, including participation in research as a legally authorized representative via surrogate consent. In situations where a guardianship is in place, obtaining proof of guardianship status and following strict research protocols to comply with guardianship requirements are important to conducting ethical research and protecting human subjects [23].

Surrogate Consent

Surrogate consent is based upon the ethical principles of *substituted judgment*, *pure autonomy*, and *best interest* standards of the research subject [24, 25]. According to the *substituted judgment* standard of surrogate consent, the exact preferences of the incapacitated person are unknown, and a surrogate determines these preferences based upon preexisting knowledge through understanding of the participant's life history, values, and beliefs [25, 26]. The *pure autonomy* standard requires prior and formal prospective authorization of the incapacitated person to participate in research [25]. Lack of prior communication between an incapacitated person and a surrogate regarding the incapacitated person's desire to participate in research is based upon the *best interest* principle whereby the surrogate makes decisions based upon what he/she judges to be the best for the incapacitated person [25, 27]. The *best interest* standard has been criticized in part because prior studies have demonstrated discordant judgments made by surrogates pertaining to an individual's desire to participate in future research [18]. Without the *pure autonomy* standard of surrogate consent being met, the *substituted judgment* standard has been considered to be the only ethically permissible method of surrogate consent that demonstrates true respect [27].

The NIH and the National Bioethics Advisory Commission have proposed safeguards which are concomitant with the risk-benefit ratio. The required evidence from surrogate decision-makers increases as the risk-benefit ratio for the participant becomes less favorable. For example, in cases where research has the potential to directly benefit the subject, no positive evidence from the past is required as long as the research does not conflict with the person's remaining preferences and interests. However, in cases of research studies that do not have a potential for direct benefit, it is suggested that participation be supported by positive evidence from the past [16]. When working with research participants who have diminished decisional capacity and require surrogate consent, researchers should respect the ethical framework laid out in the Belmont Report based on the tenets of respect, beneficence, and justice. Equal moral force of each principle is required to conduct ethical research, meaning that in certain situations, ethical principles will conflict and one principle should not outweigh another. In addition, from a practical perspective, researchers should clarify the current regulations and seek guidance from their IRB for each proposed research study to prevent adverse consequences for incapacitated adults [28].

Research Advance Directives

Bioethics researchers have maintained the best way to ensure respect for incapacitated participants (i.e., research participants with dementia) when subjects grant advance permission in a research advance directive [27]. However, few competent adults complete research advance directives, while the majority of those who do not complete research advance directives are willing to participate in research that may provide them with benefit [29]. As such, some researchers believe that requirement of formal research advance directives may hinder important research in dementia [29]. Suggestions have been made to develop advanced directives to encompass both medical and research directives and to require research advance directives for subjects who are competent, but at high risk for losing decisional capacity, such as individuals with mild Alzheimer's disease who are enrolled in longitudinal studies [29].

Overcoming Challenges of Under-Recruitment of Older Adults in Research

Investigators are faced with many challenges in engaging older adults in clinical trials. One of the challenges is recruiting a homogenous sample to reduce confounding variables. However, older adults are a very heterogeneous sample, depending on the number and type of comorbid conditions, their cognitive and functional status, and whether they reside in the community or long-term care settings. Therefore, investigators need to simplify inclusion and exclusion criteria, but also include older adults from different ethnicities and lower socioeconomic classes to ensure the results are generalizable [30, 31]. High attrition rates, whether due to an acute hospitalization, loss to follow-up (i.e., relocated to long-term care), or death, present an additional challenge to the participation of older adults in research. Attrition rates have an effect on statistical power as well as generalization of study results. A suggested solution is to shorten the length of the study (i.e., 3–6 months versus 1–2 years), if possible, for interventional trials using study treatments [30]. A third challenge in enrolling large numbers of older adults in research studies is the consent process. Often, this process is too complex and time intensive secondary to the language level used and highly detailed explanation of the study protocol and risk-benefit ratio. One way to overcome this challenge is to use terminology at the fifth-grade education level which will benefit many older adults without a high school education. In addition, consent forms should detail only the essential components of the study, thereby reducing the amount of paperwork involved with the usual consent forms. If the older adult has impaired cognition, a legally authorized representative needs to be present during the consent process unless information is included in the older adult's advanced directives stating a desire to participate in research. Investigators should detail this process for consenting subjects with cognitive impairment in the study design section of the proposal [32]. More detailed information on impaired cognition in research can be found elsewhere in this chapter.

Privacy and Information Security Risks

Ensuring privacy and information security is a priority for anyone working in healthcare, including researchers. Specific requirements for security of personal information in healthcare are outlined by federal legislation in the United States and are included in the Health Insurance Portability and Accountability Act of 1996 [33]. According to the federal guidelines, all health-related information concerning any identifiable person is considered sensitive. In addition, only those healthcare professionals who have a professional relationship with the identified person should have access to that person's health information, unless the person has given consent for others to access the information [33].

The International Organization for Standardization (ISO) is an independent, non-government international organization with over 162 national standards bodies. Through the members, ISO brings experts together to share knowledge and develop voluntary, consensus-based international standards that support quality, safety, and efficiency. According to ISO, essential elements of information security include confidentiality, integrity, and availability [34]. These are defined as follows:

- *Confidentiality* refers to the idea that information is not made available for or disclosed to unauthorized persons, entities, or processes.
- *Integrity* refers to the trustworthiness of the information. Specifically, that data have not been deliberately tampered with or accidentally changed.
- *Availability* refers to the idea that information is accessible and usable when needed by authorized personnel or entity.

Due to the sensitivity of personal health information, all three of these essential elements are important in any aspect of healthcare, including research. Researchers must take steps to ensure all subject names, birthdates, addresses, phone numbers, and any other identifying personal information are secure at all times. Whether the personal health information is maintained in paper documents or electronic records, researchers should store personal health information in a locked and secured location. This includes not leaving personal health information at the data collection site, including the hospital, clinic, or car. Additionally, storage of personal health information in an office or computer should occur in a locked area or room with restricted access. The storage method of protected health information should be approved by the appropriate institutional IRB.

Cyber-Crime

Not surprisingly, one of the biggest threats to security of personal information in recent years is cyber-crime. Cyber-crime is a crime that involves a computer and a network. It is defined as "Offenses that are committed against individuals or groups of individuals with a criminal motive to intentionally harm the reputation of the victim or cause physical or mental harm, or loss, to the victim directly or indirectly, using modern telecommunication networks such as Internet and mobile phones" [35].

Cyber-crime is a real and significant threat to governments in every country, their citizens, businesses, and overall economy [36]. The impact of cyber-crime is staggering and includes billions of dollars lost and the risk of disrupting or disabling entire businesses, hospital systems, and banks [37]. Motivations to launch a cyber-attack vary and can include stealing personal information to sell on the black market; spies and terrorists look for vital information related to national security; and even kids that are known as hackers [37]. Unfortunately, security of personal health information stored electronically for the purpose of research is not immune to this threat. Methods of cyber-attack have evolved and become more sophisticated. Some of the most common types of threats are:

- *Hacking*: Breaking into a computer or network to gain some form of control
- *Malware*: Software designed to infiltrate or damage a computer system without the owner's knowledge or consent
- *Misuse*: Abuse of computer systems, abuse of personal privileges for malicious intent, and abuse of system privileges
- *Deception*: Manipulating an individual to gain unauthorized access to a computer system or network
- *Physical*: Trespass or threat to gain unauthorized access to a computer system or network

The methods can also be combined resulting in a multifaceted and intricate attack.

How to Protect Your Computer-Stored Data and Personal Health Information

The same advice parents might deliver to young drivers on their first solo journey was mirrored by suggestions from a special agent in the Federal Bureau of Investigation's Cyber Division regarding navigating safely online [37].

- "Don't drive in bad neighborhoods."
- "If you don't lock your car, it's vulnerable; if you don't secure your computer, it's vulnerable."
- "Reduce your vulnerability, and you reduce the threat."

Additional steps to protect your computer from intrusion include [37]:

- *Keep your fire wall turned on:* A firewall helps protect your computer from hackers who might try to gain access to crash it, delete information, or even steal passwords or other sensitive information. Software firewalls are widely recommended for single computers. The software is prepackaged on some operating systems or can be purchased for individual computers. For multiple networked computers, hardware routers typically provide firewall protection.
- *Install or update your antivirus software:* Antivirus software is designed to prevent malicious software programs from embedding on your computer. If it detects malicious code, like a virus or a worm, it works to disarm or remove it. Viruses can infect computers without users' knowledge. Most types of antivirus software can be set up to update automatically.
- *Install or update your antispyware technology:* Spyware is just what it sounds like – software that is surreptitiously installed on your computer to let others peer

into your activities on the computer. Some spyware collects information about you without your consent or produces unwanted pop-up ads on your web browser. Some operating systems offer free spyware protection, and inexpensive software is readily available for download on the Internet or at your local computer store. Be wary of ads on the Internet offering downloadable antispyware – in some cases these products may be fake and may actually contain spyware or other malicious code. It's like buying groceries – shop where you trust.

- *Keep your operating system up to date:* Computer operating systems are periodically updated to stay in tune with technology requirements and to fix security holes. Be sure to install the updates to ensure your computer has the latest protection.
- *Be careful what you download:* Carelessly downloading e-mail attachments can circumvent even the most vigilant antivirus software. Never open an e-mail attachment from someone you don't know, and be wary of forwarded attachments from people you do know. They may have unwittingly advanced malicious code.
- *Turn off your computer:* With the growth of high-speed Internet connections, many opt to leave their computers on and ready for action. The downside is that being "always on" renders computers more susceptible. Beyond fire wall protection, which is designed to fend off unwanted attacks, turning the computer off effectively severs an attacker's connection – be it spyware or a botnet that employs your computer's resources to reach out to other unwitting users.

Conclusions

Ethics is the study of conduct and character and is an integral component when interacting with clients in any capacity, including research. In this chapter we described basic ethical issues in geriatric research including ageism, informed consent concerns, challenges of under-recruitment, and information security risks that concern geriatric researchers. Whether you are a new research investigator or a senior scientist, the goal is for all geriatric researchers to understand and consider the complexities of the aging population in order to make the best decisions when ethical dilemmas present themselves.

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