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Aging and End-of-Life Care

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Traditional medical

education created the impression that aging was an illness and that all means should be applied to extend life as long as possible, regardless of its quality. Anything less was regarded as a physician's failure. As a result, many physicians share the attitudes of society at large and are uncomfortable with old age and dying. The practice of caring for the elderly and dying in our current health care system often fails to provide comfort and a positive experience for terminally ill persons and their families.

Also, despite broad consensus on the need to integrate a psychosocial perspective into medical care for older Americans and persons at the end of life, there are not enough psychiatrists and other behavioral health providers to approach the need. Further barriers to quality care occur due to fragmentation of communication across the acute, rehabilitative, long-term, and community-based care systems. Mental health issues in older adults make needed communication and continuity of care even less likely. Poorly connected and coordinated proprietary electronic health records can make

efforts to communicate between the systems frustrating, if not impossible. Patients receiving primary care at one medical center may not have their records accessible at another center or long-term care facility within the same city. Written permission for a transfer of information is required. This is a particular problem in the care of older adults when the complexity of comorbidity often requires communication between providers to avoid iatrogenic complications.

For these reasons, care for older adults and people at the end of life is approaching a moment of crisis. Psychiatrists need to have a more significant role in improving end-of-life care; however, few psychiatrists show interest in palliative and geriatric psychiatry, possibly due to fears of marginalization and lower compensation. They also may perceive a less prestigious professional identity in a medical system designed to reward those who treat disease and prolong life over those who reduce suffering (Eden et al. 2012).

Nonetheless, psychiatrists with appropriate training and support can bridge these gaps, meeting the crisis as a moment of opportunity. Psychiatrists can make major contributions to patient-centered care and systems integration. They can also influence public and policy makers' recognition of the needed shift in priorities through advocacy and education. What follows is a perspective on the delicate balance of cost and quality in psychiatric care of older adults and those at the end of their lives.

Perspectives on Advanced Age and End-of-Life Care

Within academic disability studies, the Social Disability Model (Nisker 2019) makes a distinction between *impairment* and *disability*. An impairment causes a functional limitation, whereas a disability is a disadvantage faced by those with impairments due to norms, systems, or structures in the environment. For example, a wheelchair-bound office worker is impaired, but is not disabled if the office is wheelchair accessible.

Typical medical models have conflated impairment with disability and attempt to cure the impairment rather than reduce the disability. This does not mean that medical interventions have nothing to offer, or that impairments do not cause physical limitations and psychological pain. Rather the consequences of an impairment should be accommodated if possible, to reduce the associated disability—as in the example of the wheelchair-bound office worker.

For older adults, the effects of impairment may extend beyond the patient to caretakers and the community that make up the social environ-

ment. Stakeholders must include family, caregivers, and community. For aging adults, particularly those living with chronic conditions or approaching the end of life, encounters with providers who can address both immediate and extended effects of impairments can optimize their independence by reducing their “disability.” Multiple avenues of intervention exist when multiple stakeholders are involved, and collaborative approaches will often be much more satisfying for clinicians. These approaches will influence cost, quality, and accessibility of care (Nisker 2019).

Because the current model of care is based on a compensation system that rewards action-based interventions above those that are based on relationships and emotional well-being, it frequently leads to inappropriate, avoidable interventions. Stakeholders have difficulty establishing significant relationships with physicians to communicate patients’ preferences and experiences. This deprives patients and their families of opportunities for important end-of-life interactions.

Even if payment models were to shift to favor the formation of these relationships, the prejudices of physicians would still need to be addressed. The notion that fulfillment and meaning cannot exist with aging, dying, and death still exists and needs to be challenged. Providers, including psychiatrists, for older adults receive minimal, if any, training in palliative care. As a result, they are often reluctant to discuss plans for death, even when doing so will ultimately provide comfort for both patients and family members. For those who are aging or at end of life, investment in home-based, person-centered care rather than disease-centered institutional care supports the well-being of individuals and communities far better than the current system. Incorporation of these models of care into medical education and residency training is a way to begin to overcome existing biases. Proposed comfort care guidelines (in place of curative care), which would facilitate this evolution in practice (Brown 2019), are discussed later in this chapter.

Determining Appropriate Care

As the aging population grows, expanding programs specifically designed to serve geriatric health needs and creating additional jobs in the field are necessary investments. An intervention studied by Foldes and colleagues (2017) is one example of such a program. It provided group support and 24-hour telephone access to coaches for family members caring for patients with Alzheimer’s dementia. Compared with care as usual, the intervention significantly delayed nursing home admissions and reduced caregiver burden. Savings of approximately \$40 million per year were estimated if the pro-

gram were to be implemented throughout New York State. Programs such as this reduce spending in the long run, but payers are reluctant to implement them due to high up-front costs related to infrastructure and personnel. Unfortunately, long-term investments that improve public health have no immediate gain for payers who insure populations at the end of their purchasing life. This is especially so when private for-profit insurers must maximize short-term profits for shareholders.

Consequently, programs such as the one just described are not in widespread use. Commitment and planning will be required for their adoption by health care systems. Successful integration of mental health, geriatrics, and end-of-life care will need to include appropriate funding sources, easily accessible communication methods, and strategies to facilitate cultural change. Simply colocating a psychiatrist in a primary care site by providing office space, phone, and Internet access is not likely to be as effective as the process of full integration, in which the psychiatrist works directly with a team of providers including primary care, nursing, and social work. This team care facilitates screening, initiation of treatment, and treatment planning. It includes direct psychiatric consultation when mental health, substance use, or treatment resistance conditions are encountered. The integration of the psychiatric perspective is essential to the provision of "appropriate care" for older adults (Callahan et al. 2018). The demand for this innovative kind of care, involving psychiatrists with knowledge of geriatrics and palliative care, will grow as the population ages. Providing an adequate workforce to meet these needs will be challenging.

Several measures can be applied to define *appropriate care*, meaning care that is individualized but also beneficial to the population at large. Cost per quality-adjusted life years (QALY) gained and cost per disability-adjusted life years (DALY) reduced are two examples. To clarify, dialysis can restore the quality of life as well as extend the lifespan of persons with kidney failure. The expense of dialysis can be used to calculate cost per QALY gained. *Quality* is variably defined along five dimensions: mobility, self-care, usual activities, freedom from pain or discomfort, and levels of anxiety and depression (Coast et al. 2018). Similarly, dialysis can reduce the duration of disability to yield the DALY reduced measure. This calculation can be stated as a question: "For every dollar spent on dialysis, how much is the disabled time associated with chronic renal failure reduced compared with no dialysis?"

Another measure is the cost-effectiveness ratio, which represents the incremental costs divided by the incremental benefits of a treatment compared to either care as usual or another intervention. This ratio also can be exemplified with a question: "Compared with life with chronic renal failure without dialysis, how many additional years would be lived if dialysis were

given?” As shown above, therapy for family members caring for a patient with dementia saved costs compared to care as usual. The caregiver intervention for persons with dementia was calculated as a net savings because nursing home admissions were delayed and the subsequent expense forestalled. Potential savings realized over 15 years in Minnesota alone would approach \$1 trillion (Long et al. 2014).

These measures give some indication of what kinds of interventions provide the most quality per dollar spent, or the best value (see Chapter 1, “Defining and Measuring Value”). When outcomes are measured by metrics such as reduction in years of life lost to disability rather than cure rates or survival time, the intervention is more appropriate for both the individual and the population as a whole. This broader perspective provides a different view of what constitutes success. Considering the example of dialysis for chronic kidney disease again, treatment is palliative rather than curative, reducing disability but not eliminating the disease. Similarly, current approaches to the dementias are palliative, with quantifiable population-based benefits (Foldes et al. 2017).

Integrated Care for Older Adults

The value of integrating behavioral health personnel into primary care is well established, showing benefits in the management of comorbid diabetes, heart failure, and depression (Bruce and Sirey 2018). There are several examples of successful integrated approaches to enhancing the value of end-of-life services. One such approach is the integration of a depression care management program into Medicare home care services. This intervention conducted across seven states achieved a reduction in 30- and 60-day hospital readmission rates (Bruce et al. 2016). Nevertheless, integrating psychiatric care for Medicaid and Medicare beneficiaries was challenging in a disadvantaged community such as this.

The Montefiore Medical System’s Certified Home Health Agency serves a majority of African American and Latino patients. The agency works with primary care and managed long-term care providers. It integrated a geriatric psychiatrist into the weekly team triage meeting and home visits to evaluate patients with emotional health needs. This integration has been self-sustaining in two ways: 1) by becoming incorporated as an educational component of the adult and geriatric residency training programs, and 2) by providing a fee-for-service reimbursement to the attending psychiatrist. Thus, the geriatric psychiatrist is supported as both a faculty member and a service provider. Of the patients seen, 52% received a new mental health diagnosis, with most new diagnoses being neurocognitive disorders. Of the 62% of patients who were offered psychotropic medications by the visiting

psychiatrist, 90% accepted. It was suggested that this may have been due to the provision of care in a nonstigmatized home setting for older, minority adults (Ceide et al. 2016).

In New York State, Medicare will pay for in-home mental health care if provided by a psychiatrist or psychiatric nurse practitioner. Staff of a Certified Home Health Agency, including nurses and special workers, cannot bill for mental health services. The article by Ceide and colleagues (2016) describes one example of how a health care system can enhance value by expanding funding arrangements, which would not have supported the addition of behavioral health services in the past. The alliance of an academic medical center with a community-based agency to better train psychiatrists and provide better care for older adults is promising.

Interventions used in subacute care and rehabilitation facilities have been adapted for use with depressed patients who have advanced chronic obstructive pulmonary disease (COPD) or the sequelae of stroke (Avari and Alexopoulos 2015). A simplified psychotherapeutic approach used with depressed patients in rehabilitation for advanced COPD reduced depression as well as dyspnea, by promoting behavioral activation through physical activity and social interactions (Jackson et al. 2019). The reduction in dyspnea was unexpected, in that the initial goal was a reduction in depression. These improvements suggest a critical change in priorities for the care of older adults (Kennedy 2018). The addition of a behavioral health component to primary care may produce unexpected improvements in health overall. As argued by Applegate and colleagues (2018), the priorities for older adults with multiple comorbidities are the maintenance and optimization of the person's independence and self-direction. Rather than a disease-centered perspective, this approach is patient centered, and emotional health is a key component.

When curing a disease is no longer possible, as with a chronic illness, the goals of care should change. Moving from cure to palliation, from disease-centered to patient-centered care, is especially relevant when mental and physical illnesses are comorbid and disabling. Recent studies (e.g., Brink et al. 2019) have shown that persons with psychotic disorders have shortened lifespans relative to the general population. Although suicide is partly responsible for this phenomenon, difficulty accessing primary care and preventive services is also a significant contributor, even more so for individuals of advanced age. Experience with the integration of primary care into mental health clinics demonstrates a significant reduction of physical morbidity associated with serious and persistent mental disorders. Demonstrated benefits include reductions in obesity, improved patient self-management, and reduced risk of hospitalizations for both general medical and psychiatric issues (Bartels et al. 2018a, 2018b).

Emotional Care at Life's End

Progress in medical technology and public health has prolonged life expectancy, as well as the "active" lifespan, meaning those years of life in which the person is independent or minimally reliant on others. It has become apparent that health care providers need to focus on more than decreasing disability. A more holistic perspective takes into consideration the physical, social, cultural, and spiritual needs of older adults. This approach is necessary to promote a sense of meaning and purpose for older adults and to prevent or minimize despair and hopelessness. Respect for the patient's understanding of the aging process, in both personal and cultural contexts, is an essential aspect of patient- and community-centered care.

The use of a narrative, life-review approach in geriatric care has been a helpful way to bridge different aspects of the patient's experience (Clark 2015). This narrative technique is one of the hidden treasures of geriatric care. The patient is asked to give a brief synopsis of one or more important life events to illuminate their values and preferences. For example, one might ask older veterans to talk about their combat experience, or to describe how they felt about returning to racial segregation after fighting for one's country. More general questions, such as how they met their spouse or how they lost their parents, begin to clarify their world view and emotional life.

The integration of psychologists, social workers, psychiatrists, and spiritual counselors in palliative care and hospice teams has proven invaluable to patients and families. Terminally ill patients frequently experience depression and hopelessness, which are associated with a desire for hastened death in many cases. These desires can be mitigated by interventions to lessen depression or increase spiritual well-being (Breitbart et al. 2000; McClain et al. 2003). Meaning-centered group psychotherapy, which explores values learned and purposes achieved, was studied in a randomized controlled trial with advanced cancer patients. Results demonstrated a positive impact on patients' emotional suffering (Breitbart et al. 2010). This type of intervention may also be used for survivors of advanced cancer who live with increased disability and shortened life expectancy (van der Spek et al. 2018).

There is ample evidence to suggest that older adults suffering with depression have higher levels of physical disability, poorer overall health indicators and outcomes, and higher levels of utilization of health care services. A study conducted across Europe found an association between the loss of a sense of meaning in life and depression in older community residents, particularly older males (Volkert et al. 2017). Therefore, strategies aimed at reducing depression, hopelessness, loneliness, and social iso-

lation will likely improve most health indicators and reduce cost of care by enhancing self-care, such as adherence to diet, exercise, and medication regimens. Some cognitive or behavioral strategies typically used to address these issues may not be as effective in older adults. Impaired cognition, particularly executive dysfunction, may require a simplified form of therapy, but age by itself is not an obstacle to most established interventions. Case reports suggest that a psychotherapeutic approach focusing on life's meaning and purpose, and the reappraisal of values and identity, is helpful for older adults facing loss and grief (Yang et al. 2018). A protocol for assessing the effectiveness of meaning-centered psychotherapy in cancer patients showed that the most successful interventions were administered in group format at the oncology clinic where patients went for follow-up. The therapy was time limited (8–12 sessions) and task focused, aiming to reengage patients with creative activities and the people who have been part of their support systems in the past (Breitbart et al. 2010). A randomized controlled trial examining a similar set of interventions for older adults would be welcome and could demonstrate a reduction in the existential despair at the end of their lives.

End-of-Life Planning and Family Counseling

It is also essential for providers to help older adults and patients at the end of life to maintain a sense of control and agency. Advanced care planning can provide the opportunity for patients and their loved ones to have a thoughtful conversation with a skilled provider about available options. A compassionate clinician can absorb the family's hopes and fears and provide realistic information without shying away from the truth or falling into euphemistic expressions. Such an encounter allows the patient and family to express preferences, mourn losses, come to terms with what is no longer possible, and attain a measure of peace. Patients and their families may approach the end of life in the context of their past experiences with health, illness, and loss, but also with love and accomplishment.

The health and well-being of older patients hinge on continuity of care and the provision of supports that allow the optimal level of independence in old age as well as comfort and security. With these in place, older adults can be a resource to their families and their communities, rather than the burden they are sometimes considered to be. Grandparents as babysitters, retired professors as tutors, and community volunteers at polling places are only some of the examples. The indirect societal costs related to the disrupt-

tion of family members' roles in work and childcare are enormous and must be considered as an offset to the cost of service provision (Mittelman et al. 1996).

Family members are partners in care. They provide support for the older adults in the community. They bear witness to the history of the patient's values and preferences when the patient is no longer able to do so. Family can reinforce the message and the plan on which the team and patient have agreed. The provider's ability to engage family and caregivers in a strong collaboration can make the difference between success and failure in any plan of care. Caregivers are also subjected to high levels of stress and have an increased prevalence of anxiety and depression. Proactive interventions allowing the caregiver to maintain connections to the community include education, peer support groups, and direct care. These can have a positive impact on the health and independence of patient and caregiver alike (Mittelman et al. 1996; Teri 1999; Teri and Logsdon 2000). Envisioning caregivers as service recipients themselves is essential for good patient outcomes.

Mental health professionals possess an awareness of interpersonal and social dynamics to address families in distress, and to help other team members negotiate family conflicts that are more likely to emerge in times of crisis or loss. Successful mediation of conflicts over care choices (e.g., to undergo dialysis or not) can avoid prolonged power struggles and animosity. It can guide appropriate end-of-life care choices, avoiding expensive and inappropriate care and litigation.

The palliative care and hospice movement was born out of a concern about the excessive medicalization of patients near the end of life, which has too often left patients and family members feeling dehumanized and alone. For everyone—the patient facing the end of life, the family member facing the loss of a loved one, and even the health care provider confronted with the limit of science and technology—death represents an anxiety-provoking challenge that forces one to come to terms with one's limitations. The focus on how and where one dies often displaces the anxiety related to the confrontation of the simple reality that everyone does indeed die. Much has been written about “a good death.” The fear of dying alone is often mentioned as a distressing possibility by both patients and family members, and this is even more haunting for older adults living alone in the community or living in a long-term setting (Thompson et al. 2019). Not much consensus can be found on the concept of “successful dying,” according to a review published in the *American Journal of Geriatric Psychiatry* (Meier et al. 2016). Perhaps the most disturbing concern that arises is the prevalence of discordant views between patient and family as to what “success” in death might

mean. This finding suggests that improvement in communication, education, and advanced planning could go a long way in facilitating the implementation of patients' wishes, and hopefully allowing for a narrowing of the gap in expectations.

Extending the Palliative Care Paradigm

The lack of geriatric mental health personnel is exacerbated by the concentration of geriatric specialists around academic medical centers, and their lack of linkage to community-based socially supportive services and home health care agencies. Transportation and physical limitations make attending those centers problematic for older adults. As the population continues to become older, the insufficient numbers and knowledge of existing providers will be even more obvious. This situation will only be ameliorated by expanding the workforce and restructuring health care systems to facilitate access to mental health care for older adults (Eden et al. 2012). A greater emphasis on palliative care will be a key element in meeting these emerging needs.

The impact of the aging population on society and the health care system is profound, and the number of older adults who will require end-of-life care is growing globally. In recent years, a shift has taken place such that more deaths are occurring in the community than in the hospital. Patients and their families are more often expressing preferences for a patient- and family-centered approach to end-of-life care and opting for the older adults to spend the last of their lives in familiar surroundings. Frequent visits to the emergency room and crisis hospitalizations deprive the patient of the opportunity to die as the patient and family desired and planned. Because communication between patients and health providers around end-of-life directives and preferences is often inadequate, potentially avoidable trips to the emergency department when older adults have difficulties continue to occur. These occurrences not only reduce the quality of the end-of-life experience but also increase expenses and burdens to the health system. Unless the deficits in communication and services are addressed, this state of affairs will only increase as the aged population grows (Bone et al. 2018a, 2018b; Jha 2019).

Hospice care has emerged in recent years as one way to avoid the overuse of hospitalization and emergency room visits, and to reduce suffering at the end of life. Part 418 of the Electronic Code of Federal Regulations (www.ecfr.gov) defines criteria for a patient to become eligible for admission to in-home hospice services: the patient must 1) be entitled to Medicare Part A and 2) have a prognosis of 6 months or less to live. Services provided include a physician assessment and certification, ongoing care by a nurse

practitioner, availability of a social worker and pastoral counselor, and 4 hours daily of a hospice aide for personal care and homemaking. These services provided in the home need to be recertified after 90 days. Inpatient hospice services in long-term care facilities are also available. To facilitate the determination of when an individual may appropriately receive hospice care, online prognosis calculators (e.g., see <https://eprognosis.ucsf.edu>) can be used by patients, family members, and practitioners to estimate survival probabilities based on comorbidity data (Gagne et al. 2011).

Substantial evidence also supports a population-based shift from tertiary interventions to palliative primary care (Kocher and Chigurupati 2016). Although still scarce, examples of successful community-based primary and preventive mental health care are found involving urban and rural populations, different economic and racial groups, and different payers. Most of these models have benefited from public funding. Olazarán and colleagues (2010), after completing a systematic review of the literature, developed a set of recommendations related to primary care for people with Alzheimer's dementia. One of the highest rated recommendations of that review was multicomponent caregiver interventions for delay in institutionalization. Abundant nonpharmacological interventions were given the next highest rating; these included cognitive, behavioral, affective, and functional training for both the person living with dementia and the caregiver. Overall, Olazarán and colleagues (2010) found substantial evidence for beneficial outcomes and quality-of-life improvements for older adults with dementia and their caregivers, as well as potential cost savings related to the provision of primary care.

Opting to accept an impending end of life with palliative care in the home, rather than continuing to accept procedures and hospitalization, not only would improve the quality of an individual's remaining time, but also would generate enough savings to offset the costs of in-home interventions. However, the number of palliative care practitioners is low and will continue to be inadequate. As a result, more "palliative care champions" (Kamal et al. 2019) schooled in the palliative approach will need to emerge. These champions, who are not palliative care specialists, include providers from various disciplines who have additional exposure to the palliative perspective. Increased opportunities for experience with a palliative care model during training in primary care, geriatrics, or psychiatry would expand this supportive segment of the workforce.

Another model to expand the capacity for palliative care is home-based primary care, which is especially promising for frail older adults who do not meet the 6-month mortality prediction required for in-home hospice. Still, their needs are essentially palliative (Temkin-Greener et al. 2019). Brown (2019) calls for the formulation of formal guidelines with indicators of "com-

fort care," to clarify for physicians when to pivot from curative to palliative care and how to address the change with patients and families. Brown suggested three markers to initiate this change: 1) terminal illness which has become treatment resistant or for which treatment would be associated with high risk, 2) complications associated with the first illness or the occurrence of a second condition, and 3) frailty of a high degree. Brown's recommended guidelines would be broader than the more narrowly defined criteria for the receipt of hospice care services. These efforts to expand the availability of palliative care will provide greater comfort at the end of life and help eliminate needless expense.

The Psychiatrist's Role and Existential Angst

Facing mortality represents a unique existential challenge for both the patients and their clinicians. Working as consultants or team members, psychiatrists are able to facilitate more open communication that can assist older adults to face the existential issues that naturally arise as one faces death. These interactions between patient and psychiatrist may take place in a range of circumstances, from outpatient mental health visits to house calls for patients in palliative care. The opportunity for the patient to speak openly to a nonjudgmental third party may alleviate emotional suffering, and it enables the psychiatrist to assess the emotional status of the elder person and their natural supports.

According to Erik Erikson's psychosocial stages, the developmental task of old age is "ego integrity versus despair," or stated differently, wisdom versus dissolution (Erikson 1950). Having accomplished the more generative tasks, such as achieving financial security and building a family, a person faces a new developmental challenge. At the end of life, the task becomes acceptance of the finite quality of one's existence, the recognition of all that has been achieved and all that has not, and the realization that some hopes and dreams will remain unfulfilled. The capacity to look back at one's life with satisfaction, finding in it a sense of meaning and purpose, can help in approaching the unavoidable losses and vulnerabilities of the final years. Facing the ultimate separation from life itself is particularly salient. Confronting this task is challenging not only for the patients and their loved ones, but also for their physicians. Traditionally, physicians have drawn professional meaning by trying to avoid loss and vulnerability, through efforts to save, restore, and extend their patients' lives. This existential angst among the many stakeholders involved in late-life care is the type of question

geriatric psychiatrists are trained to address (Jeste 2018). Alleviation of this type of discomfort is a quality measure that is hard to capture, but it is intuitively more valuable than extraordinary measures to prolong life, and it is significantly less costly.

Ethical Issues at End-of-Life Decisions

The U.S. health care system, focused on extending life as long as possible, has emphasized the individual rather than the family and other social supports. Ironically, these priorities increase both direct and indirect costs. Apart from the actual dollar amounts spent to prolong life, there are the emotional costs of dying painfully and being removed from familiar surroundings. Direct costs can be lowered by achievement of fewer inpatient admissions to or duration of stays in acute or long-term care facilities. Indirect costs include disruptions of family members' ability to maintain normal work schedules and to attain child care. Some of these indirect costs are reduced if patients are able to have more independence and comprehensive care. Decisions must be made regarding who bears responsibility for the costs of newer models of care, as we discuss in this section.

Health care for older adults in the United States has focused on medical treatments that are typically aggressive and cure oriented, which in too many instances only prolong suffering (Hayes et al. 2015). An example of this type of treatment is the placement of a feeding tube in a patient with advanced dementia who is losing weight despite spoon feeding. The evidence is clear that although the feeding tube may prolong life for a short time, it will not prevent other common geriatric problems such as bed ulcers or aspiration pneumonia. The gastrostomy necessary for tube insertion is an invasive procedure, and the tube can be uncomfortable once in place. Despite these considerations, some families insist on placement of the gastrostomy tube and feel that failure to do so is tantamount to killing their loved one. Choosing to continue dialysis in the context of advanced dementia is yet another example of opting for an aggressive medical treatment. These types of short-term, cure-oriented decisions have traditionally been supported by physicians and other medical staff who are biased toward keeping people alive without regard to cost or quality of life. Part of this bias involves a lack of training for how to discuss, and an inability to take time to discuss, other less aggressive and more palliative options with patients and family members.

In recent years, some attitudes about end-of-life treatments have started to change, and the medical team is much more likely to discuss options and realistic outcomes in an emotionally adept manner (Bell et al. 2019). They

often advocate for alternative, more appropriate choices with regard to quality of life. These include protecting patients from burdensome or painful interventions, helping families find ways to reduce the burden of caregiving, and obtaining resources to maintain the older patient in the community. For example, instead of recommending placement of a gastrostomy tube in a patient with advanced dementia, providers should suggest continued spoon feeding, provision of comfort, and development of advanced directives about resuscitation and other interventions. Avoiding emergency department visits and putting in-home hospice care in place should also be part of the discussion. When these alternative systems are in place, families do not feel abandoned to burdensome care with a dearth of resources. Still, even with these resources available, many families insist on extraordinary measures to prolong life, and providers are often uncomfortable discussing the cost of care as a consideration for decision making.

Encouraging decisions that promote quality of life, and that direct resources to support public health, is not practical unless adequate community supports can be provided. This is especially important when mental health issues further complicate end-of-life decisions. When supports are not available, or when families choose to use hospital-based care and extraordinary measures to prolong life, who pays? Simply put, everyone bears the cost, but some people will bear more depending on their circumstances (Joynt-Maddox 2018). Insurance often influences this decision. Decisions about how and what treatment should be covered present ethical dilemmas for both public and for-profit insurers, as well as family members. Unlimited coverage will encourage families to choose more expensive options. High deductibles or arbitrary endpoints of coverage discriminate against those with few resources. Some families can afford costly interventions that have minimal benefit even if their insurance will not cover them. Other families might want these interventions but cannot afford them. When families must pay a substantial amount of the cost of prolonging the life of a loved one, how will that influence their decision? Cost-related questions are not easily answered but must be considered by those who make health care policy, as well as individuals and family members making end-of-life decisions.

When patients are covered by traditional financing arrangements, physicians and medical team members, including clergy, can help guide the most appropriate end-of-life decisions. They may agree to family members' requests for interventions that have a low probability of benefit, but this should only be the case when families are fully informed of costs and likely outcomes. Emerging models of universal coverage will need to establish parameters for end-of-life care that will influence public expenditures. The extent of coverage will in turn influence individual choices. If health care is to be considered a right, society must designate responsibility. Con-

flicts over where responsibilities lie are inevitable and will be part of public debate when new models for financing are considered. Health care providers, including psychiatrists, will need to assist individuals to make decisions that are best for all concerned in the context of the resources that are available to them. Training in ethics and resolution of personal conflict must be part of curricula in psychiatry and other behavioral health professions. Although the focus of this chapter is on older adults, these questions arise whenever the possibility of extending threatened life presents itself. Palliative care and family support in decision making are essential aspects of a value-oriented system of care for all ages (Kharrat et al. 2018).

There are cases in which people with a poor prognosis may wish to hasten their death to reduce their suffering. Several states have legalized procedures for physicians to assist in that process. Some European countries have even allowed euthanasia to be practiced by physicians in certain circumstances (Roest et al. 2019). These practices have generated a great deal of controversy, which are beyond the scope of this chapter. It is important to recognize, however, that these practices will generate much debate in the future and may be among the most challenging ethical issues facing end-of-life care and the pursuit of value.

Conclusion

This chapter has considered issues faced by people at the end of their lives, and the need to address them. Part of the process involves examining questions related to existence and the meaning of a life's experience, as well as being allowed to die in familiar surroundings with loved ones present. The traditional medical bias toward prolonging life regardless of cost is often inconsistent with people's wishes. Hospital-based care, trips to the emergency room, and invasive procedures are very costly and do little to extend a life of value. Quality in this arena must be defined by measures that account for the emotional well-being of individuals approaching death, rather than additional days alive alone.

Psychiatric care should be integral to services designed to facilitate a satisfying transition to death. Psychiatrists have both biomedical and psychosocial training, which allows them to be both generalists, able to integrate all aspects of treatment planning, and specialists, providing direct care for mental illnesses encountered during this period. These dual perspectives are particularly helpful when working with older adults and persons at the end of life, when multiple comorbidities and polypharmacy may be prevalent. Their training should allow them to competently prioritize interventions and maximize patient well-being, which is a critical aspect of high-value health care at the end of life. Training programs in geriatrics

and palliative care emphasize this approach across systems of care from clinic, to nursing homes, to the community.

The collaborative care model for depression in primary care offers a compelling and well-established basis for integration of behavioral health care into primary care services. A growing body of evidence demonstrates both cost- and quality-related benefits of this integrated approach to dementia care. Unfortunately, deficiencies in the behavioral health care workforce, identified by the Institute of Medicine's Mental Health and Substance Use Workforce for Older Adults, may limit the availability of these arrangements (Blazer et al. 2012). The older adult health care system's transition may require better public funding (Medicaid or Medicare enhancement and expansion) to support primary and preventive mental health care for aging and dying patients. Any expansion, however, must be prioritized along with workforce expansion (Spetz and Perivakoil 2019).

The provision of palliative care and community supports will better allow older adults to bring their lives to a satisfying end. The formation of relationships with individuals at the end of their lives to make their transition more comfortable and peaceful will give providers a greater sense of accomplishment and satisfaction than that provided by the disconnected and mechanical role taken in preserving life beyond its capacity for meaning. Those relationships allow providers to continue to grow in the context of the health care team and confront their own existential issues.

The approaches described in this chapter aim to achieve the delicate balance of cost and quality in psychiatric care of older adults and those at the end of their lives; however, much remains to be done before the balance is attained.

References

- Applegate WB, Ouslander JG, Kuchel GA: Implementing "patient-centered care": a revolutionary change in health care delivery. *J Am Geriatr Soc* 66(10):1863–1865, 2018
- Avari JN, Alexopoulos GS: Models of care for late-life depression of the medically ill: examples from chronic obstructive pulmonary disease and stroke. *Am J Geriatr Psychiatry* 23(5):477–487, 2015
- Bartels SJ, Aschbrenner KA, Pratt SI, et al: Implementation of a lifestyle intervention for people with serious mental illness in state-funded mental health centers. *Psychiatr Serv* 69(6):664–670, 2018a
- Bartels SJ, DiMilia PR, Fortuna KL, et al: Integrated care for older adults with serious mental illness and medical comorbidity: evidence-based models and future research directions. *Psychiatr Clin North Am* 41(1):153–164, 2018b

- Bell J, Whitney RL, Young HM: Family caregiving in serious illness in the United States: recommendations to support an invisible workforce. *J Am Geriatr Soc* 67(S2):S451–S456, 2019
- Blazer D, Le M, Maslow K, et al (eds): *The Mental Health and Substance Use Workforce for Older Adults: In Whose Hands?* Washington, DC, National Academies Press, 2012
- Bone AE, Evans CJ, Higginson IJ: The future of end-of-life care. *Lancet* 392(10151): 915–916, 2018a
- Bone AE, Gomes B, Etkind SN, et al: What is the impact of population ageing on the future provision of end-of-life-care? Population-based projections of place of death. *Palliat Med* 32(2):329–336, 2018b
- Breitbart W, Rosenfeld B, Pessin H, et al: Depression, hopelessness, and desire for hastened death in terminally ill patients with cancer. *JAMA* 284(22):2907–2911, 2000
- Breitbart W, Rosenfeld B, Gibson C, et al: Meaning-centered group psychotherapy for patients with advanced cancer: a pilot randomized controlled trial. *Psychology* 19(1):21–28, 2010
- Brink M, Green A, Bojesen AB, et al: Excess medical comorbidity and mortality across the lifespan in schizophrenia: a nationwide Danish register study. *Schizophr Res* 206:347–354, 2019
- Brown T: How to make doctors think about death. *New York Times*, April 27, 2019. Available at: www.nytimes.com/2019/04/27/opinion/sunday/health-death.html. Accessed March 29, 2020.
- Bruce ML, Sirey JA: Integrated care for depression in older primary care patients. *Can J Psychiatry* 63(7):439–446, 2018
- Bruce ML, Lohman MC, Greenberg RL, et al: Integrating depression care management into Medicare home health reduces risk of 30- and 60-day hospitalization: the Depression Care for PATients at Home cluster-randomized trial. *J Am Geriatr Soc* 64(11):2196–2203, 2016
- Callahan CM, Bateman DR, Wang S, et al: State of science: bridging the science-practice gap in aging, dementia and mental health. *J Am Geriatr Soc* 66 (suppl 1):S28–S35, 2018
- Ceide ME, Nguyen SA, Korenblatt A, et al: Beyond primary care: integrating psychiatry into a certified home health agency to identify and treat homebound older adults with mental disorders. *J Community Med Health Educ* 479(6), 2016
- Clark PG: Emerging themes in using narrative in geriatric care: implications for patient-centered practice and interprofessional teamwork. *J Aging Stud* 34:177–182, 2015
- Coast J, Bailey C, Kinghorn P: Patient centered outcome measurement in health economics: beyond EQ-5D and the Quality-Adjusted Life-Year—where are we now? *Ann Palliat Med* 7(Suppl 3):S249–S252, 2018
- Eden J, Maslow K, Le M, et al (eds): *The Mental Health and Substance Use Workforce for Older Adults: In Whose Hands?* Washington, DC, National Academies Press, 2012

- Erikson EH: *Childhood and Society*. New York, WW Norton, 1950
- Foldes SS, Moriarty JP, Farseth PH, et al: Medicaid savings from the New York University Caregiver intervention for families with dementia. *Gerontologist* 58(2):e97–e106, 2017
- Gagne JJ, Glynn RJ, Avorn J, et al: A combined comorbidity score predicted mortality in elderly patients better than existing scores. *J Clin Epidemiol* 64(7):749–759, 2011
- Hayes MM, Turnbull AE, Zaeh S, et al: Responding to requests for potentially inappropriate treatments in intensive care units. *Ann Am Thorac Soc* 2(11):1697–1699, 2015
- Jackson DS, Banerjee S, Sirey JA, et al: Two interventions for patients with major depression and severe COPD: impact on quality of life. *Am J Geriatr Psychiatry* 27(5):502–511, 2019
- Jeste DV: Positive psychiatry comes of age. *Int Psychogeriatr* 30(12):1735–1738, 2018
- Jha AK: End-of-life care, not end-of-life spending. *JAMA* 320(7):631–632, 2019
- Joynt-Maddox KE: Financial incentives and vulnerable populations—will alternative payment models help or hurt? *N Engl J Med* 378(11):977–979, 2018
- Kamal AH, Bowman B, Ritchie CS: Identifying palliative care champions to promote high-quality care to those with serious illness. *J Am Geriatr Soc* 67(S2):S461–S467, 2019
- Kennedy GJ: Added value of the personalized intervention for depressed patients with COPD. *Am J Geriatr Psychiatry* 26(2):172–173, 2018
- Kharrat A, Moore GP, Beckett S, et al: Antenatal consultations at extreme prematurity: a systematic review of parent communication needs. *J Pediatr* 196:109.e7–115.e7, 2018
- Kocher R, Chigurupati A: The coming battle over shared savings—primary care physicians versus specialists. *N Engl J Med* 375(2):104, 2016
- Long KH, Moriarty JP, Mittelman MS, et al: Estimating the potential cost savings with the New York University caregiver intervention in Minnesota. *Health Affairs (Millwood)* 33(4):596–604, 2014
- McClain CS, Rosenfeld B, Breitbart W: Effect of spiritual well-being on end-of-life despair in terminally ill cancer patients. *Lancet* 1603(9369):1603–1607, 2003
- Meier EA, Gallegos JV, Thomas LPM, et al: Defining a good death (successful dying): literature review and a call for research and public dialogue. *Am J Geriatr Psychiatry* 24(4):261–271, 2016
- Mittelman MS, Ferris SH, Shulman E, et al: A family intervention to delay nursing home placement of patients with Alzheimer disease. A randomized controlled trial. *JAMA* 276(21):1725–1731, 1996
- Nisker J: Social model of disability must be a core competency in medical education. *CMAJ* 191(16):E454, 2019
- Olazarán J, Reisberg B, Clare L, et al: Nonpharmacological therapies in Alzheimer's disease: a systematic review of efficacy. *Dement Geriatr Cogn Disord* 30(2):161–178, 2010

- Roest B, Trappenburg M, Leget C: The involvement of family in the Dutch practice of euthanasia and physician assisted suicide: a systematic mixed studies review. *BMC Medical Ethics* 20(1):23, 2019
- Spetz J, Perivakoil VS: Introduction to the special issue on the workforce for seriously ill older adults in the community. *J Am Geriatr Soc* 67(S2):S390, 2019
- Temkin-Greener H, Szydowski J, Intrator O, et al: Perceived effectiveness of home-based primary care teams in Veterans Health Administration. *Gerontologist* January 18, 2019 [Epub ahead of print]
- Teri L: Training families to provide care: effects on people with dementia. *Int J Geriatr Psychiatry* 14(2):110-116, 1999
- Teri L, Logsdon RG: Assessment and management of behavioral disturbances in Alzheimer disease. *Compr Ther* 26(3):169-175, 2000
- Thompson G, Shindruk C, Wickson-Griffiths A, et al: "Who would want to die like that?" Perspectives on dying alone in a long-term care setting. *Death Stud* 43(8):509-520, 2019
- van der Spek N, Jansen F, Holtmaat K, et al: Cost-utility analysis of meaning-centered group psychotherapy for cancer survivors. *Psychooncology* 27(7):1772-1779, 2018
- Volkert J, Harter M, Dehoust M, et al: The role of meaning in life in community-dwelling older adults with depression and relationship with other risk factors. *Aging Ment Health* 22(10):100-106, 2017
- Yang JA, Wilhelmi BL, McGlynn K: Enhancing meaning when facing later life losses. *Clin Gerontol* 41(5):498-507, 2018