VIEWPOINT

Reliable and Sustainable Comprehensive Care for Frail Elderly People

Joanne Lynn, MD, MA, MS
Center for Elder Care and Advanced Illness, Altarum Institute, Washington, DC.

For most of history, people died young. Just a century ago, the median life expectancy was less than 50 years of age. Growing old was rare, and even more rarely did Surgeons and physicians see much benefit in treating elderly people, except to relieve symptoms. Even half a century ago, when Medicare started providing coverage for older individuals, the median age at death was only slightly above the eligibility threshold of 65 years.

Today, most people in the United States who survive infancy and avoid serious injury live into their 80s and beyond. Better nutrition, occupational and obstetrical safety, prevention strategies, and improved medical treatments have yielded more years of good health, and it is likely that science will continue to make progress in delaying the effects of aging.

Nevertheless, death is inevitable. As the incidence of sudden and premature deaths has declined in the United States, the last part of most individuals’ lives has come to be marked by progressive chronic illnesses and diminishing physical reserves that engender self-care disabilities and frailty. Those who live past age 65 years now average 3 years of self-care disability at the end of life, needing long-term services and supports (LTSS). For those living past 85 years old, nearly half will have serious cognitive decline.

The Situation
The health care interventions and capabilities that rescue people from acute threats like myocardial infarctions and major trauma serve the last phase of life poorly. Although the elderly person with self-care disability and numerous diagnoses would usually prefer comfort, function, meaningfulness, and living at home, the current “care system” provides disjointed specialty services, ignores the challenges of living with disabilities, tolerates routine errors in medications and transitions, disdains individual preferences, and provides little support for paid or volunteer caregivers. This maladapted service delivery system now generates about half of the person’s lifetime costs for health care services, yet patients and families are left fearful and disoriented, with pain, discomfort, and distress. Medicare covers only about half of medical care costs and very little LTSS, so most costs of living with frailty are paid by elderly persons and their families and then by Medicaid when family resources are spent. Clearly, care during the last years of life for elderly individuals is difficult and costly.

Many believe that the challenges of the frail years should be a family responsibility, and families do provide more than half of the personal care and paid services. However, relying on family will be insufficient. The number of frail elderly individuals will double as the children born after World War II, the “boomers,” age into their years of frailty, starting in about 2025. Many simply have no family; almost half of women older than 75 years live alone. Those who have children will find that the younger generation has inadequate retirement savings and will be unable to leave work to help care for them. The ratio of working people to dependent and disabled older adults, which was 5:1 in 2011, is projected to decline to 3:1 by 2029.

In short, the United States needs arrangements that allow elderly people to live with confidence, comfort, and meaningfulness at a cost that families can afford and the nation can sustain. Failing to meet this predictable demographic change would force frail elderly people to live without critical services, effectively abandoned.

The Solutions
First, citizens and leaders must recognize that frail elderly people have different priorities and needs than they had earlier in life, and their care system must reflect those priorities. Understanding frailty requires that the public become more familiar with narratives concerning this part of life and the need for trustworthy supports. Discussions about living with frailty now are virtually absent from popular media, political discussion, and professional education. To counteract this shortcoming, reformers will need to generate discussion about the challenges of aging, disability, and death, along with the continuing opportunities to live meaningfully and comfortably. Medical professionals, political leaders, and popular culture must generate vigorous discussion about how people live well with frailty and how best to die.

Second, each frail elderly person has unique resources, priorities, fears, medical issues, and aspirations, and each should be given an opportunity to evaluate his or her potential futures and to have an individualized plan for services. A multidisciplinary team should conduct an appropriately comprehensive assessment and work with the patient and family to generate a care plan that documents the patient’s goals and the chosen service strategies. While special programs such as PACE (Program of All-Inclusive Care of the Elderly) have long made care planning a regular practice, most health care practitioners do not engender or follow care plans; there is no place for them in most electronic records; and their adequacy, implementation, and performance are not measured. Even emergency care plans such as POLST (Physician Orders for Life-Sustaining Treatment, now authorized in 43 states) are rarely used and have no established place in information systems. Frail elderly persons and their families should demand care plans, and health care teams must learn to generate assessments and care plans and imple-
ment them across settings and time. Care plan evaluation should measure achievement of personal goals for each individual and for the local frail population, which will require developing new metrics.

The health care delivery system requires substantial redesign. Many services should be brought to the elderly person’s residence, because moving frail elderly people to the physician’s office or hospital entails substantial risks, costs, and compromises in the quality of care. One strong probe into the adequacy of a complex system is the ability of a professional anywhere in the system to make important promises for system performance from now to the end of life (e.g., “you will never feel like you are struggling to breathe”). A high-performing care system for frail elders would ensure continuity of relationships and care plans, rather than fragmentation, and would provide both routine and urgent visits at home. PACE, Evercare, GRACE (Geriatric Resources for the Assessment and Care of Frail Elders), Guided Care, and hospice provide guidance as to how to start on improvement.

The service delivery system should encompass health care and LTSS as equal partners. A balanced system would give integrated multidisciplinary teams the tools and authority to match services with each frail person’s priority needs. Food, housing, transportation, and direct personal services are often more important than diabetes management or chemotherapy. Elderly people and their families often choose comfort, function, and familiar environments and relationships over small chances for cure or longer survival. Medicare’s open-ended entitlement to medical interventions contrasts with the limited and often inadequate safety-net programs to support personal needs, and this mismatch complicates development of a coherent and efficient service delivery system. Today, a physician can order any drug for any Medicare patient at any cost—but that physician cannot order a substitute caregiver or adequate housing, except perhaps by arranging nursing home admission. The mismatch of service availability with the priorities of frail elderly people engenders high costs as well as frustration and heightened fear of decline and death for frail elders.

Each community has resources, priorities, and gaps, but few communities have a locus where the performance and equity issues that are most relevant to frail elders can be identified, evaluated, debated, and decided. Health care reform has aimed to change financial incentives at the state and federal levels and to evaluate quality and value at the insurer, institution, agency, or practitioner level, but it has not attended to the allocation and monitoring of diverse systems of care that must come together at the local level to serve frail elderly people. Other countries have local entities authorized by, or part of, local government that investigate system performance and provide the forum for decision making.

These insights converge to create a remarkable opportunity for the United States. By allowing localities to take a role in monitoring and managing their arrangements for supporting frail elders, the services could become more reliable and appropriate, and most or all of the funding for supplementing social services for people who cannot afford them could come from sharing in the savings from better health care. The Department of Veterans Affairs’ Home-Based Primary Care is reducing hospitalization rates and nursing home utilization substantially. Reforms could use the emerging accountable care organization (ACO) model, modified to allow a “MediCaring” ACO to serve frail elderly people in a defined geographic area and to allow savings from more appropriate and efficient medical care to support housing, personal care, and other LTSS. For now, the governance of a MediCaring ACO could be part of local government, a voluntary local coalition, or a home care or social service agency serving as the hub of a network of contracted LTSS and health care service agencies and practitioners. The enterprise would monitor a dashboard of quality and efficiency metrics to ensure broad public support.

Without significant structural changes in service delivery, an aging nation faces a future of substantial costs and needless pain and distress among those who are old. Essential reforms include requiring development and use of comprehensive care plans; modifying medical care to ensure continuity, comprehensiveness, honesty about treatment goals, and comfort; bringing health care and LTSS together into stable funding and management arrangements; and enabling some degree of local monitoring and control. Meeting the challenges of long lives requires substantial changes, quickly, in how people in the United States envision health care, community obligations, and the lives of frail older adults.

ARTICLE INFORMATION
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REFERENCES