Costs at the End of Life: Perspectives for North Carolina

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Many elders require supportive services, with many costs covered by Medicaid. Once terminal illness sets in, palliative care and hospice may help control cost while ensuring quality. This commentary reviews trends in cost at the end of life and describes selected strategies to improve patient-centered care in North Carolina.

Life expectancy and medical innovation in the United States have increased dramatically over the last century [1]. The rise of antibiotics and critical care technologies (eg, ventilation, dialysis) allows people to live longer, with evidence indicating expansion rather than compression of morbidity between 1998 and 2008 [2]. This expansion of morbidity—as well as the increasing incidence of dementias at older ages and social trends around caregiving—challenges the ability of families to care for their aging elderly at home. The shift toward long-term care settings as elders approach the end of life is a driver of health care costs, making it an important societal conversation. While evidence indicates that hospitalizations decline with age [3], total costs remain high due to increasing incidence of chronic disease, declining functional status, and increasing use of long-term care services.

The historical roots of health care reform in the United States yielded a Medicare system that does not cover long-term care costs, leaving those costs primarily to individual private pay or Medicaid. At the patient level, Medicare beneficiaries in need of long-term care must spend down certain assets to qualify for Medicaid, which will then kick in to cover long-term care costs. Long-term care can take diverse forms, including home care, nursing homes, and long-term acute care hospitals. In 2016, 21% of Medicaid costs in North Carolina (ie, $2.6 billion out of a total of Medicaid spending of $12.4 billion) were attributed to long-term care costs covered by Medicaid. Once terminal illness sets in, palliative care and hospice may help control cost while ensuring quality. This commentary reviews trends in cost at the end of life and describes selected strategies to improve patient-centered care in North Carolina.

Compared to nursing home care, evidence suggests home- and community-based programs offer better quality of life, especially for patients with certain conditions, including dementia [5]. Various strategies target both costs and quality, including Home and Community-Based Service (HCBS) Waivers at the state level that act to support home-based care to keep people in their communities longer [6]. Innovations such as Continuing Care Retirement Communities (CCRCs) support independence and aging-in-place, but they are primarily an option for persons with higher incomes who can buy into the model early. Long-term acute care facilities that support the chronically ventilated, critically ill—a smaller proportion of long-term care patients—present a different set of barriers to both cost and quality of life for residents, including protracted stays dependent on technology (eg, chronic ventilator support) that cannot be readily transferred to a community setting or even a less-equipped nursing home [7].

Regardless of the location of long-term care, another important aspect of costs pertains to persons with serious illness near the end of life, when intensive treatments that may not be concordant with patient preferences may be used without consideration of value or palliative alternatives. These treatments are high contributors to Medicare spending that occurs in the last year of life [8]. A seminal study of the 5% of persons with highest health care expenditures in 2011 showed, however, that persons dying during that year only accounted for 11% of the 18.2 million high-cost users [9]. Forty-nine percent of high-cost users have a discrete high-cost event (eg, cardiac surgery) but a high likelihood of low costs the following year (see Figure 1); 40% of high-cost users had persistent high costs, reflected by a high likelihood of being a high-cost user in the years shortly before or after 2011. Furthermore, of the estimated 2.5 million people who died in 2011 (represented by the small, shaded circle in Figure 1), half a million (20%) were not among those with highest costs. Two important points emerge from this examination: (1) end-of-life care costs are not the primary driver of high health care expenditures; and (2) even so, persons at the end of life do account for significant costs, meaning attention to ensuring the value of dollars expended and provision of preference-sensitive care is important.

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rates of live discharge (patients discharged from hospice) serving patients as they approach the end of life. The changing current hospice models will need to be adapted to better benefit in the year in which they die, but the high prevalence of very short hospice enrollments and extremely long stays for approximately 10% of hospice users mean that half of Medicare beneficiaries use the Medicare hospice benefit. Originally oriented primarily toward cancer patients when implemented in 1982, Medicare hospice is now used by patients with a diverse set of diseases—including dementia, heart failure, and respiratory problems—that have less certain prognoses as well as waxing and waning symptoms that can be hard to manage. With some exceptions (e.g., dementia patients residing in nursing homes), use of hospice is associated with lower costs near the end of life by reducing hospitalizations and likely delivering care that is both more goal-concordant and cost-effective. Two Medicare requirements—that persons must (1) be identified by their physicians as having a life expectancy of less than 6 months and (2) forgo acute care services to receive hospice services—have long been perceived as reducing the willingness of both providers and patients to initiate or continue hospice care. Currently, over half of Medicare beneficiaries use the Medicare hospice benefit in the year in which they die, but the high prevalence of very short hospice enrollments and extremely long stays for approximately 10% of hospice users mean that current hospice models will need to be adapted to better serve patients as they approach the end of life. The changing disease landscape has also been accompanied by high rates of live discharge (patients discharged from hospice before death) and by high profit margins for some for-profit hospices, which may support further reimbursement and regulatory reform.

The Medicare Care Choices Model is an innovation being tested by the Centers for Medicare & Medicaid Services to enable Medicare beneficiaries to receive hospice-like support services from selected hospice providers while concurrently receiving curative care. Seven North Carolina hospices are among the 141 hospices participating in this 5-year demonstration and evaluation that began in 2015.

Alternative models for care, like the Medicare Care Choices Model, may be particularly applicable to dementia. Dementia prevalence is rising nationally with the aging population, and the disease trajectory can take many years, with some patients living with late-stage, care-dependent disease for up to 3 years. Dementia also has the highest out-of-pocket costs of any disease group, much of which can be attributed to long-term care and other care needs, including nursing home memory care units. As an example of successful reform driven by dementia care, feeding tubes were long associated with both poorer quality of life and higher costs among late-stage patients compared to assistance with feeding by mouth. Recent trends indicate a shift away from feeding tubes and a movement toward goal-concordant care for nursing home residents with dementia.

Innovative Approaches to Ensure Value from End-of-Life Care Costs in North Carolina

A number of investigators in North Carolina are taking innovative approaches to the cost-meets-quality problem for patients with complex chronic conditions, many of whom may be approaching the end of life. The approaches include timely initiation of palliative care in a variety of settings, including primary care. Broadly, the goals of palliative care include: (1) pain and symptom management, which can result in fewer hospital encounters due to acute symptom exacerbation; and (2) goal-setting and advance care planning, which may reduce intensive treatments near the end of life. The rest of this section briefly describes selected examples of some current projects in the state.

Tim Platts-Mills, MD, MSc, is conducting formative research to determine if starting advance care planning conversations with older or seriously-ill adults when they encounter the emergency department can help improve future goal-concordant care. Similar work led by Laura Hanson, MD, MPH, integrated a goals-of-care decision aid and care plan meetings in nursing homes; the study demonstrated more treatment planning and fewer hospital transfers for residents with advanced dementia.

In the setting of chronic critical illness, Christopher Cox, MD, MPH, is doing work to improve decision-making in intensive care units for patients at high risk of severe functional impairment that might limit them to long-term acute care hospitals. A decision aid designed to convey...
prognosis and support surrogate decision-making may help patients receive more goal-concordant care; data for 600 surrogate decision makers are currently being analyzed.

David Casarett, MD, MA, is interested in early palliative care for seriously-ill patients. His current work focuses on primary palliative care, which aims to integrate palliative elements (eg, goal-setting, symptom management) into care from non-specialty palliative care providers [20]. Such approaches may be particularly important in places where specialty palliative care is limited, including many rural areas in North Carolina.

Timothy Daaleman, DO, MPH, has established a community-based, serious-illness care program in the UNC Health Care System that focuses on providing care outside of traditional health care settings for vulnerable adults [21]. The Reaching out to Enhance the Health of Adults in their Communities and Homes (REACH) Program uses an inter-disciplinary approach that is based on a Veterans Affairs (VA) model and incorporates palliative care into home-based primary care for patients who are limited in getting to their physicians and other providers. The overall goal is to provide high quality, patient-centered care that allows patients to remain in their own communities with their own support systems.

Conclusions and Future Challenges
While the aforementioned North Carolina programs are certainly not exhaustive, programs like these—both nationally and in North Carolina—can reduce health care costs and enhance patient satisfaction, primarily by providing value-based alternatives to emergency departments and acute hospitalizations. Other important challenges that require attention and innovation for efficient provision of care include funding mechanisms, payment models, workforce training, and workforce/caregiver supply. Clearly, much work remains to be done to ensure quality and value of care for persons with chronic conditions and serious illness.

Long-term and serious illness care, including care near the end of life, will only draw more attention as the population ages. While budgetary pressures can challenge the ability of both public and private payers to provide quality care, the ultimate goal should be patient-centered approaches with attention to value per dollar expended and an emphasis on identifying cost-effective ways to provide quality care near the end of life. Thoughtful innovations are essential, and investigators are making strides toward improving care for those with serious illness. Such matters should remain at the forefront of the economic and social consciousness, as they will likely impact us all.

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