INVITED COMMENTARY

Meeting the Needs of Those with Serious Illness in Their Homes and Communities

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North Carolina’s providers and payers increasingly recognize the unique needs of people and their caregivers burdened from the pain, symptoms, and stress of serious illness. This article lays out five actions for expanding access to medical and social supports outside the hospital setting.

Mrs. H. was surprised when told her breast cancer had spread to her bones. Her oncologist recommended chemotherapy. She hated the side effects and had to go to the emergency room twice for nausea and dehydration, so she stopped her chemo. She is doing better now on hormone therapy, but her anxiety and pain seem worse. She lives on a farm in rural North Carolina where she and her husband care for her horses and cats, and she feels isolated from her medical care. She does not like the long commute to her oncologist. With all her stress and pain, she finds herself calling the office nurse almost daily.

Serious illness is “a health condition that carries a high risk of mortality AND either negatively impacts a person’s daily function or quality of life, OR excessively strains their caregivers” [1].

Most clinicians have experienced someone struggling with functional and physiological decline or the burden of diseases, such as stage IV cancer, end-stage pulmonary disease, and heart failure, which may limit the person’s ability to travel to an appointment, function independently in their home, talk on the phone, or discuss difficult decisions and symptoms with their loved ones or care team. People and families dealing with a serious illness face challenges that could often be prevented with stronger and more structured 24/7 medical and social supports where they live—in their home or community setting (Table 1).

North Carolina is seeing continued growth in those with, or at risk of having, a serious illness: the over-65 population of North Carolina is projected to increase 67% between 2016 and 2036, from 1.6 million to 2.6 million people [2]; from 2009 to 2019 there was a 35% increase in reported cancer cases in North Carolina [3]; and over 27% of adults in North Carolina have multiple chronic conditions [4].

Shifting current models of care and support and investing in new models outside the hospital will entail deeper partnerships and collaboration across settings, involving patients and family caregivers, interdisciplinary clinical teams, payer and provider organizations, and community systems. Patients and families increasingly expect to be fully informed about their condition and want their personal wishes considered in their care. North Carolina has already begun to acknowledge the unique needs of this population and has the opportunity to proactively build upon services already in place to change the paradigm of care for those with serious illness in all regions and counties.

Strategies for Expanding Access

Mrs. H. was pleased when her oncologist suggested that a palliative care specialist come visit her at the farm to help with her pain management. Krissy, the palliative care nurse practitioner, found her way to the farm, listened, and prescribed medications for Mrs. H.’s pain and stress. Amanda, the nurse for palliative care, came by for regular visits. Krissy or Amanda initially visited weekly to help with pain and anxiety and to listen to Mrs. H.’s fears about her health and future. When Mrs. H.’s symptoms became difficult to manage, Krissy was able to talk to her husband over the phone, adjusting medications and providing strategies to make Mrs. H. more comfortable.

Studies have demonstrated that increased access to clinical services and practical supports, such as home-based primary care, home-based palliative care, advance care planning in nursing homes and cancer centers, and transportation resources, can have a positive impact on total cost of care, use of health care resources, and patient and family caregiver experience.

Strategies for Supporting People with Serious Illness

Train all clinical providers in core communication skills and education of serious illness care. Enhancing the skills of all clinicians in every community in communication, advance care planning, and symptom management for serious illness care will exponentially expand access to quality care. Among

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in building capacity for needed services in the community [8].

Expand access to specialty-level serious illness/palliative care in all communities. North Carolina has a number of health systems and organizations that have invested in palliative care and serious illness programs to support patients as they are discharged from the hospital or are identified through home health. Hospice organizations have led the way in transforming their expertise in holistic interdisciplinary care and in the home and are using that expertise to start separate community palliative care programs for patients stressed with serious illness who do not qualify for the hospice benefit. Generous philanthropic organizations, such as The Duke Endowment, have funded some of the start-up costs for many community-based palliative care programs.

While North Carolina has several programs that train physicians in the specialty of palliative care, there is a state and national shortage of palliative care specialists [9-14]. Advance practice professionals, like nurse practitioners and physician assistants, are stepping in by obtaining training and education to provide care for people with serious illness. Even with this support, there are not enough specialists to attend to all the people stressed with serious illness, particularly as care is extended into settings outside of the hospital.

Regional workforce strategies, through partnerships with North Carolina’s academic medical centers, community colleges, and statewide programs such as North Carolina Area Health Education Centers, provide opportunities for developing the necessary interdisciplinary skills and workforce needed to support the growing need.

Integrate social determinants of health and medical care models. Social determinants of health, such as poverty, food insecurity, safety, and access to transportation, have a huge impact on health care. Currently, many payers will pay for a medical provider’s time but not for other supports, like transportation, caregiver time, or food. A strategy for addressing both social and medical determinants of health is needed.

North Carolina recently proposed the Healthy Opportunities Pilots, designed to provide this type of support to North Carolina’s Medicaid populations [15], an important component in North Carolina’s effort to rede-

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**Table 1. Serious Illness Challenges Amenable to Home and Community Supports**

| Unnecessary and often unwanted hospitalizations and emergency room visits due to uncontrolled pain or unpredictable timing of severe symptoms that occur in the evening or on weekends, when calling 911 is the only option |
| Unnecessary suffering, both physically and mentally, from the pain or emotional stress of a serious illness, which could be identified and addressed through telehealth or a home visit |
| Caregiver stress and burnout from working financially, physically, and emotionally for their loved one |
| Fragmented care with poor communication regarding the goals and wishes of the person with serious illness and their family |

Source. Gualtieri-Reed T, Morris J.

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**Table 2. Uncovered or Inadequately Covered Serious Illness Programs and Supports**

| Nurses and advanced practice professionals conducting visits for pain and symptom management and guidance for medical decisions in long-term care facilities |
| Social workers and chaplains—critical members of the interdisciplinary team—providing high-quality advance care planning, counseling support, and help in connecting families with needed community resources such as transportation |
| Cancer centers incorporating palliative care expertise into routine interdisciplinary cancer care |

Source. Gualtieri-Reed T, Morris J.
Sign its Medicaid programs. Though there have been several delays, state and regional Medicaid plans are actively working to complement or integrate these critical social and practical supports into their offerings, recognizing the important role they play in caring for vulnerable, often high-risk patients and family caregivers.

**Integrate caregiver support into medical models for serious illness care.** Often the most important factor allowing a person with serious illness to stay in their home is the presence of a caregiver. Unpaid caregivers spend countless hours each week supporting loved ones and often quit jobs and face financial stress to provide this care [16]. The physical work and psychological stress of caring are difficult enough that caregivers have higher rates of anxiety, depression, heart disease, and mortality, sometimes leading to health care crises for the caregivers themselves [17-20].

The current medical system does not support caregivers with adequate communication, education, counseling, and guidance for medical decisions. In addition, respite care is rarely covered, leaving family caregivers with limited opportunities to care for themselves. Some employers recognize the impact of caregiver burden and have enhanced their employee assistance programs and, in some cases, their health benefits, to include supports for family members of an employee with serious illness. More changes are needed to provide the full community engagement required to proactively address all needs of those with serious illness.

**Planning Forward**

Mrs. H. is living more comfortably with her cancer. She is happy caring for her animals and spending time with her husband. She knows she can call Amanda or Krissy any time, and this has kept her from going to the hospital on more than one occasion. She appreciates having time to socialize, reflect on life, and spend quality time with her husband.

Major national efforts have improved access to care for those with serious illness across all settings. Recent national
trends in home-based care models include the approval by the Centers for Medicare and Medicaid Services (CMS) of home care support through Medicare Advantage plans and the development of specialized home care programs to care for individuals with conditions such as heart failure, chronic obstructive pulmonary disorder, and dementia. CMS is also piloting a new Seriously Ill Population payment model. National clinical quality organizations such as the American Society of Clinical Oncology (ASCO) are recommending a referral to specialty palliative care within eight weeks of diagnosis. In October 2018, the National Consensus Project published updated Clinical Guidelines for Quality Palliative Care that include guidelines for primary and specialty palliative care across all settings [21].

The North Carolina Institute of Medicine's Task Force on Serious Illness Care has provided a roadmap of actions for North Carolina [22]. Health care organizations, community leaders, health plans, policymakers, employers, and accountable care organizations are encouraged to review those recommendations and partner to have a meaningful impact on the patients and family caregivers affected by a serious illness, providing them with the opportunity to have the highest quality of life through improved access to care and support wherever they call home.

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