

The Task Force on Serious Illness Care examined how serious illness care is operationalized—including where it is provided, who is part of the care team, and the impact of other factors on care delivery and the experience of care, including payment/financing, access to insurance coverage, and drivers of health. The task force made recommendations for improving the delivery of high-quality, person-centered serious illness care.

LONG-TERM SERVICES AND SUPPORTS

Among all adults aged 65 and over, it is estimated that around half will develop an illness serious enough to need long-term care or services. About one in seven adults over 65 will need these services for longer than five years. There are a broad range of long-term services and supports that provide varying levels of medical and non-medical care, including assistance with activities of daily living. Long-term services and supports can be provided in the home, in a community setting, or in a designated long-term care facility. Due to the range of types and locations of long-term services and supports, there are also a range of payment systems for these different types of care.

HOME AND COMMUNITY-BASED SUPPORTS

Home-based long-term supports and services from unpaid caregivers constitutes the vast majority of long-term care. Additional care needs, such as home health care following surgery or illness; physical, occupational, or speech therapy; or other temporary health needs, are usually provided by paid home health providers. Other paid home-based long-term care may include personal care and assistance with activities of daily living, tasks such as laundry and cooking, instrumental activities of daily living, and companion services.^{1,2}

ACTIVITIES OF DAILY LIVING

Activities of daily living (ADLs) are every day personal tasks such as bathing, dressing, eating, toileting, and moving around within the home. Other activities, called instrumental activities of daily living, include housework, financial management, medication management, meal preparation, shopping, and responding to emergency alerts.

In North Carolina (2019), there are 1,665 licensed home care agencies, including licensed home care, private duty, companion/sitter, home health, and hospice agencies. Of these, there are 208 Medicare-certified home health agencies (including corporate and branch offices). In FY 2016-17, these agencies served a total of 227,778 home health patients. Over 90% of home health users covered by Medicare had three or more chronic conditions.³ Recent trends in home health include the approval by the Centers for Medicare and Medicaid Services of home care support through Medicare Advantage plans and the development of specialized home care programs to care for individuals with specific conditions, such as heart failure, chronic obstructive pulmonary disorder, and dementia.³

Community-based long-term supports and services consist of services intended to delay or prevent placement in out-of-home care (such as a skilled nursing facility) and help people remain at home as long as possible. These services often include adult day care services, home-delivered meal services, transportation assistance services, in-home aide services, and respite care for unpaid caregivers. These services vary by community and are provided by government agencies such as social services or health and human services or private organizations.¹ Many of these services have long wait lists and are unable to meet service needs of everyone who may need them.

LONG-TERM CARE FACILITIES

Long-term supports and services are provided within residential facilities. There are a variety of levels of care provided in long-term care facilities, including assisted living facilities and skilled nursing facilities. Adult care homes provide minimal assistance with activities of daily living, but not as much care as is provided in a skilled nursing facility. Additional supplemental services may include meals, housekeeping, and social activities. A skilled nursing facility, also referred to as a nursing home, provides more intensive personal and health care, often including 24/7 nursing care, supervision, and rehabilitation services. Skilled nursing residents are those who need short-term care following an injury or illness, as well as those who require care for a longer period.⁴

CONTINUING CARE RETIREMENT COMMUNITIES

Continuing care retirement communities also provide long-term supports and services. The range of services needed by residents of these communities includes assisted living care, skilled nursing care, and other health care, along with social engagement, recreation, and often independent living arrangements within the same location. These types of living arrangements are private pay only, not supported by Medicaid or Medicare, and often have long waiting lists and/or substantial entry fees.⁴

PALLIATIVE CARE AND HOSPICE CARE

Throughout the work of the Task Force on Serious Illness Care, the task force discussed palliative care, hospice care, and the similarities and differences between the two, as well as misconceptions about when and how palliative and hospice care are delivered.

LONG-TERM SERVICES AND SUPPORTS

Long-term services and supports include a wide range of paid and unpaid medical and personal care assistance that people may need—over many weeks, months, or years—when they have difficulty completing self-care tasks as a result of aging, chronic illness, or disability. These services can be provided at home, in a community setting, or in an institutional setting such as a nursing home.

a As an alternative to enrolling in Original Medicare, individuals have the option of enrolling in Part C, called the Medicare Advantage program (following the enactment of the Medicare Prescription Drug, Improvement, and Modernization Act of 2003). Individuals who choose to have Medicare Advantage enroll in private plans, approved by Medicare, which provide coverage for all services covered by Original Medicare. Medicare Advantage plans also can include coverage for additional services (such as vision and hearing) and often include prescription drug coverage. http://nciom.org/wp-content/uploads/2018/06/NC_Medicare_Primer_FINAL-copy-1.pdf

WHAT IS PALLIATIVE CARE?

Palliative care is a type of specialty care provided to individuals living with serious illness. Palliative care focuses on providing relief from symptoms, increasing comfort, and improving quality of life for individuals and their families. Palliative care includes clinical care such as symptom management, expert communication about disease trajectory and what to expect, and coordination of care across health care providers and settings.⁵

Many of the components of palliative care can and should be provided by primary care providers and palliative care specialists focused on more complex needs. In practice, however, most health care providers have not received adequate training in palliative care.⁷

Palliative care is most commonly provided in acute care hospitals. Between 2005 and 2015, hospital palliative care programs increased by more than 150%.⁷ As of 2019, 94% of hospitals with more than 300 beds and 72% of hospitals with more than 50 beds had palliative care programs nationally.⁸ In North Carolina, 94.1% of hospitals with more than 300 beds and two-thirds (67.6%) of hospitals with more than 50 beds have palliative care programs.⁸

Within a hospital setting, palliative care is generally provided by an interdisciplinary consultation team. Some large hospitals may also have dedicated inpatient palliative care units.

Palliative care can also be provided in home and community settings. Historically, community-based palliative care was provided only through hospice programs, limiting the number and type of patients to whom it was available (typically patients with a prognosis of under six months' survival who had chosen not to receive additional curative treatment).⁷ While hospice providers continue to provide the majority of home-based palliative care, new community-based palliative care models have emerged to provide palliative care to non-hospice-eligible individuals.^b Community-based models include many of the same interdisciplinary providers and focus on symptom management, communication on goals of care, as well as care coordination and caregiver support in the home setting.⁷

Palliative care is also increasingly provided within long-term care facilities such as skilled nursing facilities. Palliative care models in long-term care facilities include: provision through external/contracted hospice services; palliative care consultation, in which an external palliative care provider recommends care to facility clinicians; or internal palliative care teams, often for residents with dementia.⁷

FIGURE 3.1 Components of Palliative Care

1. **Appropriate at any stage in a serious illness; beneficial when provided concurrently with curative treatment**
2. **Provided over time based on patients' needs, rather than prognosis**
3. **Offered in all care settings and by various organizations, including physician practices, health systems, cancer centers, dialysis units, home health agencies, hospices, and long-term care facilities**
4. **Focused on patient and family goals of care and care preferences**
5. **Interdisciplinary**

Source: Adapted from: National Consensus Project for Quality Palliative Care. *Clinical Practice Guidelines for Quality Palliative Care*, 4th edition. Richmond, VA: National Coalition for Hospice and Palliative Care; 2018. <https://www.nationalcoalitionhpc.org/ncp>.

In recent years, the use of palliative care for people with serious illness has been rapidly growing and clinical trial research has shown its benefits, including increased patient and provider satisfaction, improved symptom management, fewer hospital admissions in the last month of life, and lower anxiety and depression. Palliative care has also been shown to lessen caregiver distress and to improve if and how individuals' goals and values for their care and end of life are honored. In addition, palliative care has shown to lower costs of care.⁶

HOW IS PALLIATIVE CARE DELIVERED?

Palliative care is interdisciplinary and provided across care settings by a broad variety of health care providers. These providers may include physicians, nurses, physician assistants, nurse practitioners, social workers, chaplains, front line staff, home health workers, and others.

FIGURE 3.2 Palliative Care Programs in Hospitals: Regional and National Comparisons to North Carolina

GEOGRAPHIC AREA	TOTAL PROGRAMS/ HOSPITALS, 2015 (%)	TOTAL PROGRAMS/ HOSPITALS, 2019 (%)	>300 BEDS, 2019 (%)	<50 BEDS, 2019 (%)
North Carolina	47/72 (65.3)	50/74 (67.6)	16/17 (94.1)	11/22 (50.0)
South Atlantic Region	270/420 (64.3)	313/344 (70.5)	124/133 (93.2)	44/128 (34.3)
United States	1,591/2,393 (66.5)	1723/2409 (71.5)	671/716 (93.7)	557/1535 (36.3)

Sources: Center to Advance Palliative Care (CAPC). *State by State Report Card on Access to Palliative Care in our Nation's Hospitals*. Table 1: Prevalence and Distribution of Palliative Care Programs in U.S. Hospitals by State and U.S. Census Region. (2019 and 2015) <https://reportcard.capc.org/>; Center to Advance Palliative Care (CAPC). *America's Care of Serious Illness*. Table 1: Prevalence and Distribution of Palliative Care Programs in U.S. Hospitals by State and U.S. Census Region. (2015) <https://reportcard.capc.org/tables-charts/>

^b Please see page 32 for more on hospice eligibility

FIGURE 3.3 Barriers to Palliative Care

1. Lack of palliative care resources
2. Not knowing that resources exist
3. Not understanding what palliative care is for
4. Reluctance (by providers) to refer individuals to palliative care services
5. Reluctance by individuals to receive referrals to palliative care services
6. Restrictive specialist palliative care eligibility criteria

Source: Hawley P. Barriers to Access to Palliative Care. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5398324/>

HOW IS PALLIATIVE CARE FINANCED?

Private and public insurers (including Medicare and Medicaid) pay for all or part of palliative care services, in much the same way that they pay for other medical services.⁹ However, traditional fee-for-service payment models can prove inadequate for palliative care, as palliative care consists of time-intensive tasks such as care coordination, medical management, and counseling that do not align with the ways fee-for-service payment incentivizes volume.

Since the passage of the Patient Protection and Affordable Care Act (ACA) in 2010, payers have applied new payment models in ways that better align with the goals and logistics of palliative care. Alternative payment models for palliative care may include per-member-per-month payments, shared savings, and bundled payments for episodes of care, often combined with care management services to improve communication with patients and families, improve transitions of care, and reduce spending.^{9,10}

BARRIERS TO PALLIATIVE CARE

Despite an increasing understanding of the value of palliative care through all stages of serious illness, many individuals face barriers to receiving it. Access to palliative care services remains challenging; while there was nearly a three-fold increase between 2000 and 2012 in the number of 50+ bed US hospitals providing palliative care services,¹¹ nearly one-third of these hospitals still do not provide palliative care services.¹²

Community palliative care settings serve to alleviate some of the barriers regarding access/availability of services. A recent study by the Center to Advance Palliative Care attempted to map available community palliative care services. Researchers found that two-thirds of community palliative care programs are operated by hospitals or hospice care facilities, with the remainder operated by home health agencies, long-term care facilities, and office practices or clinics; nearly two-thirds of community palliative care programs provide care in patients' homes, about half provide care in an office or clinic setting, and nearly one-third provide care in long-term care settings.¹³ One noticeable barrier to access to community palliative care is for children: only 6% of programs serve children only, and less than one-quarter (24%) treat children in addition to adults.¹³

Other barriers to palliative care services may include lack of knowledge about available services or a misunderstanding of what palliative care is and when or in what care setting palliative care is appropriate. Research has shown that both patients and providers often think of palliative care as equivalent to end-

of-life care; this misperception can be a major barrier in integrating palliative care into care throughout the course of disease.¹¹ Health care providers may also worry about their patients' understanding of palliative care; in a survey of 155 physicians caring for people with lung cancer, nearly half of respondents referred fewer than 25% of their patients for palliative care consultations, many citing concern that this type of referral would alarm patients and families. Other provider-cited barriers to palliative care include patients' and families' misunderstandings of disease prognosis and the perception that palliative care means stopping all other treatment.¹¹

Additional barriers to palliative care include those related to workforce. Recent national estimates put current hospice and palliative medicine specialists at 4,400 nationally, the equivalent of 1 for every 20,000 older adults with serious illness. To meet the growing need for specialty palliative care, an additional 6,000-10,000 specialty palliative care physicians and an equal number of advanced practice nurses would be needed.¹⁴ In addition, only 25% of hospital-based palliative care programs meet national staffing recommendations (include at least one physician, one advanced practice or other registered nurse, one social worker, and one chaplain). In community palliative care services, training, demand, and turnover were cited as workforce-related barriers to access.¹⁴

WHAT IS HOSPICE CARE?

Hospice care, like palliative care, also focuses on providing comfort, relieving symptoms, coordinating care, and improving quality of living for people with serious illness. Unlike with palliative care, however, in hospice care curative treatments are stopped. Hospice care is for individuals nearing the end of life, usually for those expected to live for less than six months, though hospice can be provided for any individual with a life-limiting illness.¹⁵

HOW IS HOSPICE CARE DELIVERED?

"Hospice" does not refer to a specific place or location; hospice can be offered at home, or in a facility such as a hospital, skilled nursing facility, or a separate hospice care facility.¹⁵ Hospice care is provided by specially trained teams, including physicians, nurses, social workers, chaplains or spiritual advisors, and volunteers.¹⁵

WHO IS ELIGIBLE AND HOW IS HOSPICE CARE FINANCED?

For individuals covered by Medicare Part A (hospital insurance), hospice care is paid for by Medicare under the following conditions:¹⁶

- Health care provider certifies that the individual has a life expectancy of six months or less.
- Individual accepts palliative care for comfort, instead of curative care.
- Individual signs a statement choosing hospice care instead of other Medicare benefits to treat illness and related conditions. Individuals can still receive covered services for conditions not related to the illness and related conditions.

FIGURE 3.4 Elements of Hospice Care:

- Hospice helps improve comfort for people with serious or terminal illness.
- Hospice focuses on comfort, not on curing an illness.
- Hospice care is provided by a specially trained team of professionals and caregivers and emphasizes care for the “whole person,” including physical, emotional, social, and spiritual care.
- Services may include physical care, counseling, spiritual care, prescription drugs, equipment, and supplies.
- Care is provided in the home, in a hospital, or in another health care facility (such as a nursing home)
- Family caregivers can get support.

Source: Adapted from: <https://www.medicare.gov/pubs/pdf/11361-Medicare-Hospice-Getting-Started.pdf>

Under Medicare Part A, individuals can receive hospice care for two 90-day benefit periods, followed by an unlimited number of 60-day benefit periods. The conditions outlined above must be met (and forms signed/completed) before hospice care can continue.¹⁶ Under these requirements, individuals may stop hospice care at any time for any reason, and may return to hospice care at any time, if eligible.

Medicare pays the hospice provider directly, with no deductible for individuals. There are applicable copays for outpatient prescription drugs, and individuals also pay 5% of the Medicare-approved amount for inpatient respite care.¹⁶

In 2017, Medicare paid hospice providers a total of \$18.99 billion, an increase of 6.3% from 2016. Average spending per patient was \$12,722. Nearly all of the Medicare spending on hospice care (98.2%) was for the last seven days of hospice care.¹⁷

In North Carolina, Medicaid and NC Health Choice beneficiaries are also eligible for covered hospice services. Services are identified and coordinated by a hospice interdisciplinary group (IDG), which aims to develop and manage comprehensive hospice care plans for eligible beneficiaries. Under NC Division of Health Services Regulation requirements, only Medicare-certified and North Carolina-licensed hospice agencies are eligible to provide hospice services to Medicaid beneficiaries. Each site providing hospice services must be separately licensed, and hospice providers must have contracts with a skilled nursing facility or hospital if hospice services are provided in those facilities (most services are provided at home).¹⁸

The Veterans Health Administration (VA) also provides hospice care. Hospice services provided by the VA are very similar to those provided under Medicare. Many commercial/private insurers also provide coverage of some hospice services.¹⁹

FIGURE 3.6 Who Pays for Hospice Care?

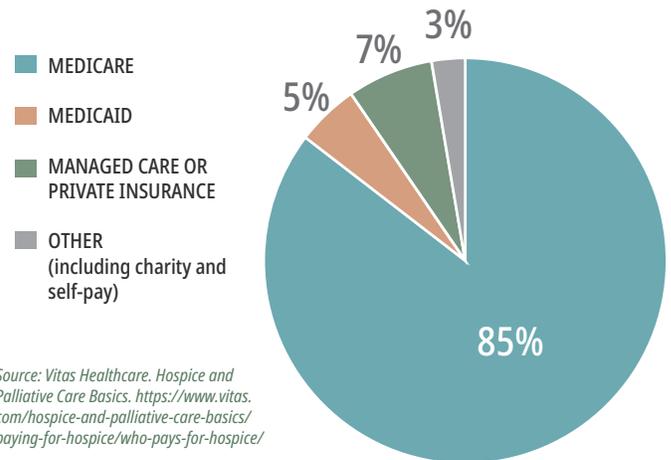


FIGURE 3.5 What is Covered Under Medicare and NC Medicaid Hospice Benefits?

MEDICARE HOSPICE BENEFIT:

- Physician services
- Nursing services
- Social services
- Counseling services (grief/loss, dietary, spiritual)
- Medical equipment (like wheelchairs or walkers)
- Medical supplies (like bandages and catheters)
- Short-term inpatient care (for pain and symptom management)
- Hospice aide and homemaker services
- Physical therapy, occupational therapy, speech-language pathology services

OTHER:

- Prescription drugs
- Short-term respite care
- Other Medicare-covered services needed to manage pain and other symptoms

MEDICAID HOSPICE BENEFIT:

- Physician services
- Nursing services
- Social services
- Counseling services (bereavement, dietary, spiritual)
- Medical equipment (like wheelchairs or walkers)
- Medical supplies (like bandages or catheters)
- Short-term inpatient care (for pain and symptom management)
- Hospice aide and homemaker services
- Physical therapy, occupational therapy, speech-language pathology services

OTHER:

- Interdisciplinary group, care planning, coordination of services
- Volunteer services
- Any other service that is specified in the beneficiary’s plan of care as reasonable and necessary for the palliation and management of the patient’s terminal illness and related conditions and for which payment may otherwise be made under Medicaid
- Ambulance transport services (when related to management of terminal illness)

Source: Centers for Medicare and Medicaid Services. 2020 <https://www.medicare.gov/pubs/pdf/11361-Medicare-Hospice-Getting-Started.pdf>

Source: North Carolina Department of Health and Human Services, Division of Medical Assistance. https://files.nc.gov/ncdema/documents/files/3D_5.pdf

IMPROVING SERIOUS ILLNESS CARE IN NORTH CAROLINA

WHO RECEIVES HOSPICE CARE?

In 2017, among Medicare hospice patients nationally, nearly half (47.5%) were aged 85 or older. Another 16.7% were aged 80-84. Nearly one-third (31.1%) of Medicare hospice patients had cancer as their primary diagnosis, followed by circulatory/heart disease (17.6%) and dementia (15.4%).¹⁷

There are large racial/ethnic disparities in the receipt of hospice care. A large majority of Medicare hospice patients (82.5%) were white, 8.2% were African American, and 6.4% were Hispanic/Latino.¹⁷ (Please see Chapter 2 for additional discussion of disparities)

While most individuals who receive hospice care in the course of a serious illness are older adults, hospice is also provided to younger adults and children who are eligible. However, reliable statistics for children who receive hospice care are difficult to identify. There are different prognostic criteria for children, and different levels of accessibility to services. In addition, epidemiological data generally focuses on numbers of children who die, have complex chronic conditions, or have special health care needs, while palliative and hospice care programs use definitions such as life-limiting conditions or life-threatening conditions, so the data is not consistent across categories. Pediatric populations are also defined differently by different sources in terms of the age groups included.²⁰

BARRIERS TO RECEIVING HOSPICE CARE

Many of the barriers to receipt of hospice care have to do with misunderstandings of what hospice care is or the conditions/timing for when it is appropriate. One common misunderstanding is that hospice care is only appropriate when an individual is in the final stages of illness and very close to dying. However, hospice can be most beneficial at the time an individual’s goals of care change from curative care, and when the

individual in hospice care and their caregivers can develop a relationship with the hospice care team and focus on improving quality of living. Earlier discussion and referral to hospice services may prevent costly care delivered for patients often against their wishes at the end of life.

TEAM-BASED CARE FOR SERIOUS ILLNESS

The Task Force on Serious Illness Care examined the importance of a team-based model of care in providing high-quality serious illness care. Both palliative care and hospice care utilize a team-based model of care in which medical staff, including physicians, nurses, certified nursing assistants (CNAs), and non-medical staff such as social workers, chaplains/faith leaders, therapists, and volunteers, work to meet individuals’ and families’ needs. Of particular importance in team-based care for individuals with serious illness is the recognition of the individual and their family as integral members of the care team. Teams focus on understanding the relationships between the individual with serious illness, their family, their medical providers, and their community.²¹ Teams also focus on caring for other members of the care team and emphasize the different skills and disciplines that work to provide the best care possible.

The interprofessional collaborative practice model maintains focus on communication and understanding between individuals, families, and providers to maintain the highest quality of care.⁴ This model is often seen as the gold standard for providing serious illness care, with shared decision-making, common goals, and blending skills and knowledge to improve care.²²

FIGURE 3.7 Distinctions Between Hospice and Palliative Care

	PALLIATIVE CARE	HOSPICE
MODEL OF CARE	Interdisciplinary team, including physicians, nurses, social workers, chaplains, care managers; primary goal is improved quality of life	Interdisciplinary team, including physicians, nurses, social workers, chaplains, care managers, and volunteers; primary goal is improved quality of life and relief of suffering
ELIGIBILITY	Any age and with any diagnosis or stage of illness; can be delivered concurrently with life-prolonging and disease-directed treatments	All ages with prognosis of less than six months to live; must forgo Medicare coverage for curative and other treatments
PLACE	Hospitals, clinics, group practices, home settings, skilled nursing facilities	Home, long-term care facilities including nursing homes and assisted living, residential hospice facilities or inpatient hospice units
PAYMENT	Physician, physician assistant, and nurse practitioner fees covered by Medicare part B for inpatient or outpatient care; hospital care covered by Medicare part A or commercial insurance; flexible bundled payments under Medicare Advantage, managed Medicaid, ACOs, other commercial payers	Medicare hospice benefit; commercial insurance usually modeled after Medicare; Medicaid. Medication costs included for drugs related to primary illness

Source: Kelley AS, Morrison RS. Palliative care for the seriously ill, *N Engl J Med* 2015; 373:747-755. <https://www.nejm.org/doi/full/10.1056/NEJMra1404684>

In North Carolina, Four Seasons Compassion for Life, a state leader in serious illness care, uses an interprofessional collaborative practice model to develop competency in care teams across four domains: team member roles and responsibilities, communication, collaboration, and values and ethics. Primary elements of the model include continuous assessment of team performance and learning, training on team-based care, and relationship building across team members.²¹

FIGURE 3.8 Principles of Team-based Health Care

SHARED GOALS: The team—including the patient and, where appropriate, family members or other support persons—works to establish shared goals that reflect patient and family priorities, and can be clearly articulated, understood, and supported by all team members.

CLEAR ROLES: There are clear expectations for each team member’s functions, responsibilities, and accountabilities, which optimize the team’s efficiency and often make it possible for the team to take advantage of division of labor, thereby accomplishing more than the sum of its parts.

MUTUAL TRUST: Team members earn each other’s trust, creating strong norms of reciprocity and greater opportunities for shared achievement.

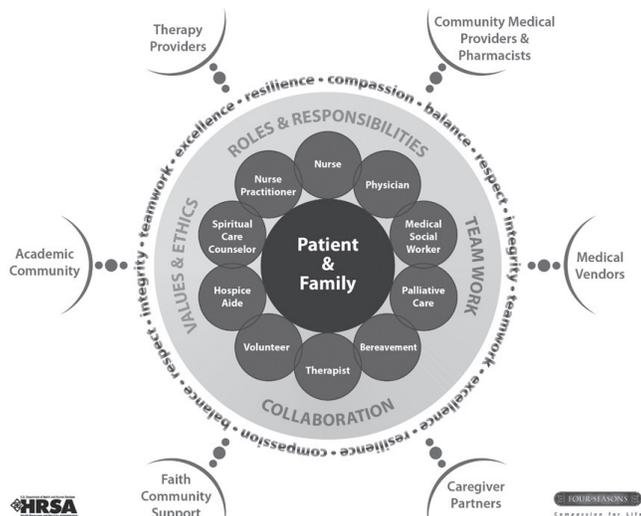
EFFECTIVE COMMUNICATION: The team prioritizes and continuously refines its communication skills. It has consistent channels for candid and complete communication, which are accessed and used by all team members across all settings.

MEASURABLE PROCESSES AND OUTCOMES: The team agrees on and implements reliable and timely feedback on successes and failures in both the functioning of the team and achievement of the team’s goals. These are used to track and improve performance immediately and over time.

Source: <https://nam.edu/wp-content/uploads/2015/06/VSRT-Team-Based-Care-Principles-Values.pdf>

FIGURE 3.9 Interprofessional Collaborative Practice Model

The Four Seasons Interprofessional Collaborative Practice (IPCP) model in end-of-life care guides the development of IPCP competency in 4 domains: roles and responsibilities of each team member; communication, collaboration, and values and ethics.



Source: HRSA and Four Seasons. Reprinted from NCMJ 79:4. Available online at: <https://www.ncmedicaljournal.com/content/ncmj/79/4/256.full.pdf>

The Task Force on Serious Illness Care recognized the strengths of this model and recommended that health providers and systems identify and implement similar team-based models of care that will improve quality of living and care delivery for individuals with serious illness.

RECOMMENDATION 3.1:

Deliver goal-concordant, coordinated, team-based care for individuals with serious illness (PRIORITY)

In order to improve access to care and quality of care for individuals with serious illness, health care providers and systems should identify and implement effective team-based models of care that seek to optimize meeting patient goals of care and care coordination for individuals with serious illnesses. These models should aim to improve care delivery by:

1. Identifying and ensuring the incorporation of patient’s self-identified goals of care across all care settings
2. Incorporating a broad array of providers into care team, including physicians, nurses, chaplains, social workers, community health workers, community paramedicine providers, patient navigators, care managers, home health workers, patients, family (and support system) caregivers, volunteers, and others, including those with specific palliative and hospice care expertise
3. Increasing use of family advocates and patient/community navigators to help patients and families receive appropriate services, to ease transitions of care, to identify the health care proxy, and discuss goals of care, with specific attention to ensuring that patients who may be unable to advocate for themselves are receiving needed care and services
4. Recognizing the role of unpaid/family caregivers as members of the health care team, including documenting family caregivers, promoting training options for caregivers to learn necessary skills, and identifying support resources
5. Identifying and connecting to resources for non-clinical health needs (also see Recommendation 3.3)

As included in Recommendation 3.1, the task force also emphasized the importance of providing “goal-concordant care” for individuals with serious illness. Goal-concordant care is care that “promotes (a) patient’s goals, regarding such matters as aggressiveness of curative treatment, hoped-for functional outcomes, and ability to participate in future events.” Goals of care are hard to assess, may not be documented, change over time, and goal concordance is hard to assess retrospectively.²³

The task force also identified the challenges that providers and health systems have in identifying which individual patients will have higher clinical needs, and how to appropriately anticipate and treat these needs in a goal-concordant way. Cone Health System in Greensboro has utilized predictive analytics to apply a one-year mortality risk score. Individuals above a designated threshold are triaged for clinical needs, scheduled for a visit to discuss advance care planning, and during acute care or emergency department patients receive a consultation with the inpatient palliative care team.²⁴

While acknowledging potential benefits of such predictive analytics approaches, the task force also cautions about unintended consequences. Research has shown that some algorithms may underestimate health needs of black patients in particular, running the risk of worsening racial disparities in care and outcomes. Longstanding cultural biases that influence access and utilization of care impact algorithm inputs and results: one studied showed that since black patients generally use less health care, an algorithm was less likely to predict their use of more care in the future, despite many health conditions that might indicate otherwise.²⁵

In addition to health system/provider tools for identifying goals of care and clinical needs, providers and systems can also encourage the use of consumer-driven assessment tools. These tools, also known as patient experience measurement tools, are key in the health care framework known as the Triple Aim, used to measure patients' satisfaction and engagement with their care, inform payment and reimbursement models, and improve quality of care. When used with individuals with serious illness, however, they often have shortcomings: they are not always designed to address the unique care needs of people with serious illness and they may be administered too late in the disease trajectory to provide meaningful information to the care team. In addition, many of these tools do not include assessment of goals of care (medical or non-medical), relationships with members of the care team, or whether the patient felt their providers aimed to understand the whole person beyond certain clinical needs.²⁶ Systems and providers should aim to utilize consumer-driven assessment tools that include measurement of relationships/communication and understanding of goals of care, and these tools should be used earlier and more frequently across the illness trajectory.

In order to improve the delivery of timely, goal-concordant care, and assure that care plans are reassessed and revised as appropriate, the task force recommends:

RECOMMENDATION 3.2:

Incorporate regular and timely assessment processes to identify and develop effective and goal-concordant plans of care for individuals with higher health needs

In order to more effectively identify patients with serious illness who may be in need of additional/enhanced/targeted clinical services, and connect them earlier to needed services, health care providers and systems should:

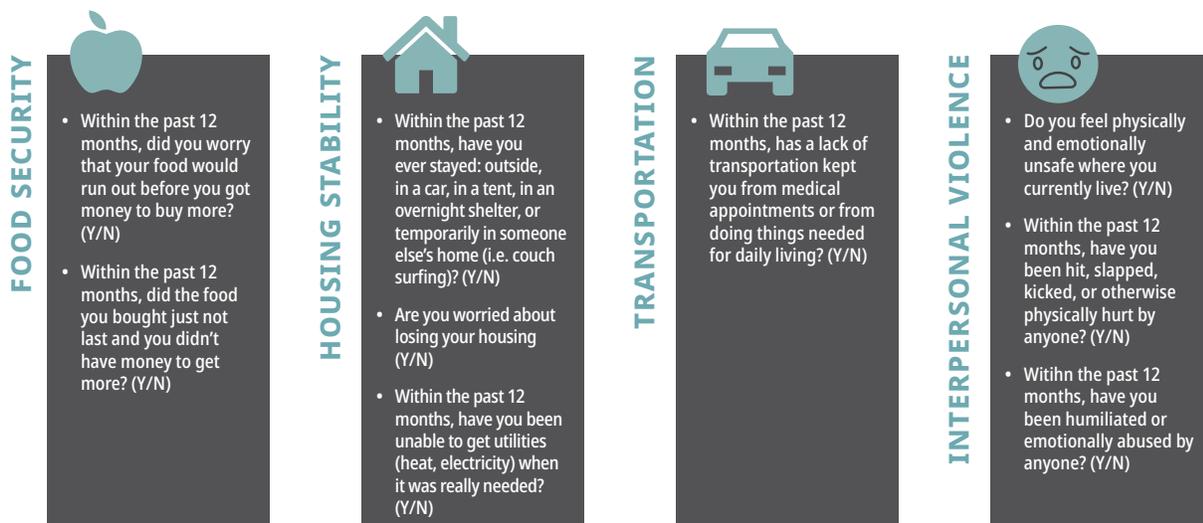
1. Utilize best practices in clinical assessment to identify individuals' clinical health needs and goals of care
2. Explore feasibility of incorporating best practices in predictive analytics and ways to connect results with improving care
3. Connect patients and caregivers with consumer-driven assessment tools (including those that are designed for individuals with serious illness) and encourage self-assessment (and/or family assessment) of needs and goals of care at regular intervals

ADDRESSING OTHER FACTORS THAT IMPACT DELIVERY OF SERIOUS ILLNESS CARE

DRIVERS OF HEALTH

Increasingly, health care providers and policymakers recognize the ways that factors outside of the medical system influence health status and health outcomes. These factors, known as drivers of health, have been shown to determine up to 80% of an individual's overall health. Social and environmental factors such as education, income, geographic location, food insecurity, housing instability, transportation, and violence can significantly impact overall health. The task force examined the way these factors impact the experience of receiving care.²⁷

FIGURE 3.10 Screening for Unmet Social Needs



Source: NC DHHS. Updated Standardized Screening Questions for Health-Related Resource Needs. Accessed January 30, 2020. <https://www.ncdhhs.gov/about/departments-initiatives/healthy-opportunities/screening-questions>

Alex is a 69-year-old man with end stage kidney disease. At the time of his diagnosis, he was working as a plumber, but is no longer able to work. Alex lives in a small town, and must travel 45 minutes to visit his doctor and receive dialysis. Since he is no longer able to drive, his wife Susan must take off work to take him to his appointments. Although Alex and Susan own their home, they have struggled financially since losing Alex's income and often have difficulty paying bills on time. Alex worries that as his illness progresses, Susan may not be able to afford to keep their house.

Caring for caregivers can also improve the well-being of the care recipient. Individuals with serious illnesses, particularly Alzheimer's disease or related dementias, are more likely to have high emergency department and hospital utilization if their caregivers are under psychological and physical distress.¹¹ Therefore, caregiver burden assessment tools provide a means by which providers can gain insight into the caregiver-recipient relationship and identify areas where support would be beneficial.

To begin to address the unmet needs related to drivers of health, health systems must identify these unmet needs, generally through a systematic approach to screening.²⁸ The North Carolina Department of Health and Human Services (NC DHHS) has developed a standardized screening tool. The tool, developed by a group of stakeholders representing public health, health care, and sectors related to health-related social needs, incorporates tested and standardized items from existing screening tools (e.g., PREPARE, Health Leads, and items standardized for use in multiple tools). Through 2018, the draft tool was field tested through the Community Health Grants at 18 clinical sites, as well as through telephonic care management settings through Community Care of North Carolina.²⁹ The screening tool contains nine questions across four priority domains: food, housing/utilities, transportation, and interpersonal safety. There are also three optional questions about the nature of the needs and whether help is wanted to address those needs. Upon transition to Medicaid managed care, prepaid health plans will be required to screen beneficiaries for unmet needs upon enrollment.

Last year, Kimberly's 9-year-old son Christopher was diagnosed with an aggressive leukemia after breaking his leg in a soccer game. While chemotherapy has been effective in reducing the size of his tumors, Christopher has spent many weeks in the hospital with recurring infections. After Christopher's diagnosis, Kimberly and her husband decided that she would quit her job to be Christopher's primary caregiver. Although her husband and daughter help out when they are able to, Kimberly attends every appointment with her son, and sleeps on a mattress on the floor in his bedroom at home to assist him if he needs help in the night. Kimberly is exhausted, and feels like she doesn't have the energy for fun things that the family can do together on Christopher's good days.

CAREGIVER BURDEN ASSESSMENT TOOLS

Many long-term supports and services are provided by nonprofessional caregivers—generally a close friend or family member of the care recipient.³⁰ Family caregivers play a critical role in the treatment and support of persons with serious illnesses, supplementing any medical and paid caregiving that an individual might be receiving. However, many caregivers lack training and support to manage their caregiving responsibilities. Caregivers may also have unmet social, physical, and mental needs that impact their ability to provide care for a loved one or to ensure they are taking care of themselves. Screening can be used to identify strengths that caregivers have and areas in which supports could improve their health and well-being and that of the care recipient. Specific tools^e are designed to assess aspects of the caregiving situation, such as the caregiver's psychological well-being, financial circumstances, social isolation, employment status, ability to provide necessary care, and the anticipated duration of caregiving.^{30,31} Assessment results can then be used to connect caregivers to support groups, therapy programs, financial support programs, and educational opportunities that can help caregivers develop coping mechanisms and alleviate stress.³² These interventions can be directed at both the caregiver individually and at the care dyad (the caregiver and the care recipient) and can be incorporated into care management plans.³³

CONNECTING TO SERVICES

The North Carolina Department of Health and Human Services is currently rolling out NCCARE360, a statewide coordinated care network connecting individuals to local services and resources. NCCARE360 is a partnership between Unite Us, NC 2-1-1, Benefits Data Trust, and Expound. A public-private partnership led by the Foundation for Health Leadership and Innovation oversees and funds development of NCCARE360, which consists of a call center run by NC 2-1-1 and a shared technology platform powered by Unite Us. Through NCCARE360, health and human service providers can send and receive secure electronic referrals, communicate in real time, share client information, and collect outcome and cost data. NCCARE360 integrates the NC DHHS standardized screening tool, a community resource identification and referral system, and referral status tracking. In its first phase, the focus areas for available resources will be the NC DHHS priority domains of food security, housing stability, transportation, interpersonal violence, and employment.³⁴ Currently, NCCARE360 has the capacity for weekly analysis of number of organizations included in the system, organizations' response to referrals, open/closed referrals, number of users, and number of referrals. There is not currently capacity for state or system-wide analysis of receipt of services.^f

STATE-COUNTY SPECIAL ASSISTANCE

Cost of residential or home care can be a barrier for individuals with serious illness. The state has designed a financial assistance program that helps individuals afford the cost of room and board in a residential facility, or alternatively, helps offset some of the costs associated with arranging supportive services to remain at home.^{35,36} The core State-County Special

^e The Zarit Burden Interview is perhaps the most well-known of these tools, although many have been developed to assist providers in assessing their patients' caregivers. (https://journals.lww.com/jbisirir/fulltext/2007/05101/a_comparison_of_tools_used_to_screen_for_caregiver.12.aspx)

^f Bridges, J. NC Department of Health and Human Services, Division of Aging and Adult Services. Written (email) communication. Feb. 28, 2020.

Assistance program provides low-income individuals with financial support to live in a residential adult care home, family care home, or group home approved by the state. To be eligible for the program, applicants must be over the age of 65,⁹ must require residential care services, and must meet income requirements.^{36,37} The General Assembly sets an annual maximum rate that residential facilities can charge individuals within the Special Assistance program. If an individual qualifies for the program, he or she will receive the maximum rate, plus a small personal needs allowance, less any individual financial contribution (i.e., social security income or retirement income).³⁶

The State-County Special Assistance In Home Program for Adults (SA/IH) provides support to those who are eligible for residential care but can safely remain in their homes with assistance. To qualify for the SA/IH program, an individual must meet the general Special Assistance program eligibility requirements but must also be eligible for Medicaid. Applicants for the program are assessed on their ability to afford safe housing, care and support needs, community and family caregiver resources, and any barriers they may face in accessing the services they need. If a case manager determines that an individual can remain safely in his or her home, a care plan and payment structure is developed to ensure applicant needs are met.^{35,38}

The task force recognized the importance of assessing and providing non-clinical services to individuals with serious illness as an integral part of improving care and well-being.

RECOMMENDATION 3.3:

Assess drivers of health and connect individuals with serious illness and caregivers with appropriate non-clinical services

1. Health care providers working with individuals with serious illness and their caregivers should use the North Carolina Standardized Screening Tool (as developed for NC Medicaid) and/or other applicable screening tools, including caregiver burden assessment tools, to identify and address drivers of health and unmet needs. Tools should be used on an ongoing/regular basis.
2. The North Carolina Department of Health and Human Services should develop a communication plan to engage with providers of serious illness care to increase awareness of and capacity to implement screening tools listed above.
3. NCCARE360 should develop a plan to integrate specific resources for individuals with serious illness and family caregivers (such as referrals to respite care and advance care planning assistance) into resource platforms including No Wrong Door, NC 2-1-1, and NCCARE360, with particular attention to promoting equity of access to services.
4. NCCARE360 should enhance capacity to evaluate appropriate connection to and receipt of services on a statewide level.
5. The North Carolina General Assembly and/or County Commissioners should increase appropriations to the State-County Special Assistance Program in order to increase capacity to meet non-clinical needs of individuals with serious illness.

PAYMENT AND FINANCING FOR SERIOUS ILLNESS CARE

The Task Force on Serious Illness Care also examined models of and challenges to paying for specific types of care for individuals with serious illness. As described above, both Medicare and Medicaid have specific payment models to cover hospice care with similar covered services. Researchers and advocates have developed proposed payment models that seek to provide similar comprehensive coverage for palliative care.

One innovative model examined by the task force was the Advanced Illness Management model (AIM) currently under proposal to the Center for Medicare and Medicaid Innovation (CMMI). Sutter Health developed AIM in 2003 as a model of providing home-based palliative care services to individuals with serious illness as they transition from intensive curative services to end-of-life-care. The model aimed to address the confusion many patients and families face during this transition, as well as the challenges faced as they make choices about curative treatments and those focused on providing comfort and improving quality of life.³⁹ AIM staff emphasize coordinating care and services across providers, starting or continuing advance care planning conversations, pain management, and hospice enrollment when appropriate. Patients can receive concurrent curative treatment (unlike in hospice); however, patients eligible for AIM services must have a high disease burden, meet criteria for hospice services but decline them, have nutritional and/or functional decline, have recurrent and unplanned hospitalizations, or their providers would not be surprised if they were to die within the next 12 months.⁴⁰ Patients spend an average of 190 days in the AIM program; about 50% of patients move to hospice, 15% die, and 10% stabilize and can be supported by a Sutter disease management program.^{h,39}

At Sutter, a retrospective cohort study showed that participation in the AIM program resulted in a 28% increase in hospice referrals compared to patients receiving usual care within the same branch of the Sutter home health program, including a 60% increase among African American patients.⁴⁰ The AIM model has shown financial benefits to Sutter Health: for a cost of between \$2,400 and \$2,500 per patient per year, it has produced annual savings of approximately \$8,000 to \$9,000 per patient, primarily from reduced emergency department visits and hospitalizations at the end of life. Based on these results, the Center to Transform Advanced Care (CTAC) has proposed the use of an AIM delivery and payment model to CMMI.

The Patient and Caregiver Support for Serious Illness model (PACSSI), developed by the American Academy of Hospice and Palliative Medicine, aims to move palliative care services from a fee-for-service to a value-based payment model. Under the PACSSI model, providers would receive tiered monthly payments to support interdisciplinary palliative care teams who provide care for individuals with diagnosis of a serious illness, multiple chronic conditions, functional limitations, and/or high health care utilization.⁴¹ The goal of the PACSSI model is to allow payers (Medicare first, with others as interested) to provide goal-concordant palliative

g There is also funding available to individuals between the ages of 18 and 65 who have SSD-qualifying disabilities and children who are legally blind and living in residential centers (Special Assistance Program, 2016).

h The remainder of patients leave the program for other reasons, including moving from service area.

care services of higher quality and with reductions in unnecessary and unwanted spending. Providers such as social workers, spiritual advisors, and others not currently reimbursed by Medicare for palliative care services could be reimbursed as part of the care team under this model.

CMMI has also developed a Medicare payment model to encourage primary care practices to manage care for individuals with serious illness in high need of care. CMMI will attribute what it identifies as Seriously Ill Population patients to Primary Care Firstⁱ practices participating in this payment model option. Practices must show relevant capabilities, care coordination experience, and a network of relationships with other care organizations in the community in order to receive payment under the Primary Care First model for caring for these patients.⁴² There are several cautions of this model, including that some palliative care providers have reported concerns that payments may be less than what they receive from commercial payers, and that differences between expertise/care delivery of specialty palliative care physicians and primary care providers may not be appropriately accounted for in this model. In addition, small practices may be at a disadvantage, as they must have at least 125 Medicare beneficiaries, have relevant experience with value-based payment models and coding models used to identify higher-risk patients, and use certified electronic health record technology with the capability of connecting to other providers and to a state health information exchange.⁴²

Currently, North Carolina is not eligible to participate in the Primary Care First model, or in the model allowing Primary Care First practices to care for the seriously ill population, as the state is a control in the federal Primary Care First pilot experiment.⁴²

Some private payers are also implementing payment structures designed to improve care for individuals with serious illness. Blue Cross and Blue Shield of North Carolina has designed Care 360, a comprehensive payment system for palliative care, with the intent of meeting challenges inherent in providing palliative care services under a fee-for-service payment model.^j Care 360 uses per-member-per-month reimbursement to pay for all palliative care services provided by an interdisciplinary palliative care team. Goals of the payment system include improved quality of living for patients and caregivers, supported family and caregivers, and reduced stress, anxiety, and unwanted care. The model also aims to decrease unplanned care, especially utilization of the emergency department, intensive care, and ambulance transportation, and to decrease preventable hospitalization and readmission rates. Under the Care 360 model, Blue Cross and Blue Shield of North Carolina has provided care for 201 enrolled members as of June 2019. With this new model, Blue Cross and Blue Shield of North Carolina cautions that payment systems may not be enough to incentivize referrals to some palliative care providers, that misperceptions about palliative care must continue to be addressed among both providers and patients, and that access and provider capacity remain a challenge. Blue Cross and Blue Shield of North Carolina is currently evaluating the pilot.

The task force acknowledged the limitations of fee-for-service models to deliver quality palliative care and identified models for consideration for payers.

RECOMMENDATION 3.4: Develop and apply new payment models to support palliative care delivery (PRIORITY)

Payers, including Medicaid, should apply payment models that support the use of high-quality palliative care for individuals with serious illness, including community-based palliative care. Models may include the “advanced illness management” model proposed by the Coalition to Transform Advanced Care, and/or the “Patient and Caregiver Support for Serious Illness” model developed by the American Academy of Hospice and Palliative Medicine. Payment models should:

1. Ensure the delivery of palliative care services, to include comprehensive assessment and care planning services delivered by an interdisciplinary team of health care providers (comprised of physicians, nurses, spiritual leaders, social workers, and advanced practice practitioners)
2. Ensure that all payment models allow concurrent palliative care and disease treatment; evaluate benefits of concurrent hospice care
3. Work toward establishing payment tiered by patient complexity, functional status, and intensity of interdisciplinary services
4. Be subject to quality metrics and models of quality improvement, aligned across payers
5. Utilize screening for non-clinical health needs and connection with community services (also see [Recommendation 3.3](#))
6. Apply across the spectrum of institutional and home-based care

QUALITY MEASUREMENT FOR SERIOUS ILLNESS CARE

As part of addressing payment for serious illness care, the task force discussed existing metrics that aim to assess quality of serious illness care and cost impacts. The Centers for Medicare and Medicaid Services (CMS) develops quality measures at the federal level for use in quality improvement and related reporting programs for health care providers. Data on these measures is reported through a variety of sources, including claims, patient and provider-reported data, provider chart data (including electronic medical records), and population-level registries.

The Hospice Quality Reporting Program at CMS requires reporting on the Hospice Item Set and the Hospice Consumer Assessment of Healthcare Providers and Systems survey. In addition, hospital-based metrics such as length of stay or mortality rates are often used to assess outcomes of palliative care. Other metrics, such as those addressing clinical care or patient satisfaction, are also used to assess quality of palliative care.⁴³

ⁱ Primary Care First is a CMS-developed payment model that aims to improve quality, improve patient experience of care, and reduce costs. The model aims to increase patient access to primary care, with elements designed to support care for patients with serious illness or complex needs. Participating practices will be incentivized to reduce hospitalization, improve access and continuity, improve care management, increase care coordination, emphasize patient and caregiver engagement, and improve population health.

^j Fee-for-service has traditionally been the dominant payment structure in American health care. Under a traditional fee-for-service health care payment model, health care providers and health systems receive compensation for each clinical encounter or service provided during discrete episodes of care. While this model has some advantages, namely that it is a familiar model to many patients and health care providers, it also tends to disproportionately reward volume of care rather than quality of care, and also does not reward important elements of high-quality care such as care coordination or care management.

FIGURE 3.11 Hospice Quality Reporting Program Quality Measures (CMS)

Patients Treated with an Opioid who are Given a Bowel Regimen

Pain Screening

Pain Assessment

Dyspnea Screening

Dyspnea Treatment

Treatment Preferences

Beliefs/Values Addressed (if desired by patient)

Hospice Visits when Death is Imminent

Hospice and Palliative Care Composite Process Measure: Comprehensive Assessment at Admission

Source: Centers for Medicare and Medicaid Services <https://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/Hospice-Quality-Reporting/Current-Measures> Accessed February 9, 2020.

FIGURE 3.12 Palliative Care Outcome Metrics

Length of stay

Mortality rate

30-day readmission

Consultation volume

Consultation rate

Symptom measures

Live discharges

Inpatient deaths

Hospice discharges

Source: Grodwohl R, Brant JM. Hospital-Based Palliative Care: Quality Metrics that Matter. *J Adv Pract Oncol* 2015;6:597–610 <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5017551/pdf/jadp-06-606.pdf>

Recent collaborative efforts have addressed ways in which CMS or other standardized quality measures may not be specific enough to effectively measure the quality of serious illness care. A team of experts from the American Academy of Hospice and Palliative Medicine and the Hospice and Palliative Nurses Association convened a process called Measuring What Matters that aimed to identify and prioritize measures to benchmark best practices in palliative care.

The Task Force on Serious Illness Care recognized the many ways that quality measures for serious illness care may be revised to more effectively assess the experience of care specific to serious illness and end of life, and recommends additional study to develop a concise list of metrics.

RECOMMENDATION 3.5:

Convene a work group tasked with assessing and developing appropriate quality metrics for serious illness care (PRIORITY)

The North Carolina Serious Illness Coalition (as named in [Recommendation 2.1](#)) should convene a serious illness quality metrics work group. Work group membership should include experts in quality improvement, data collection, and serious illness care. It should also have inclusive representation of patients, family members, or other support system members/caregivers, as well as members of underserved communities.

This group should be tasked with:

1. Reviewing existing palliative, hospice, and serious illness care metrics, including Centers for Medicaid and Medicare Services standard measures, American Academy of Hospice and Palliative Medicine recommended measures, and/or additional evidence-based measures, including those under development

2. Developing a concise list of recommended process and outcome metrics to assess quality serious illness care, compile current performance data (as available) on these metrics, identify best practices for frequency of data collection, and identify recommended performance targets/benchmarks for improvement on the list of metrics
3. Studying data collection, reporting, risk adjustment, disaggregation of data, and implementation of quality improvement strategies to meet performance targets specific to serious illness care; developing educational materials for professional associations on results of study
4. Determining and recommending metrics specific to pediatric care

ACCESS TO HEALTH INSURANCE COVERAGE FOR SERIOUS ILLNESS CARE

Access to comprehensive, quality health care services is critical to achieve and maintain health, prevent and manage disease, and achieve health equity. For most people, access to affordable health care services is dependent upon whether they have health insurance coverage. For those without health insurance, care may be inaccessible and unaffordable, resulting in poor health outcomes. Lack of health insurance coverage can also lead to financial burdens that further negatively impact one's health. For North Carolinians with serious illness, lack of health insurance can be a significant barrier to receiving needed health care services. While much of the population discussed by the task force is eligible for Medicare coverage, younger adults with serious illness are often vulnerable to being uninsured, particularly once their illness has progressed to impact employment. Although uninsured rates in North Carolina decreased between 2013 and 2016, they have started to rise again. Policy options available to state lawmakers have the potential to greatly reduce the number of people who are uninsured in North Carolina.

FIGURE 3.13 Measuring What Matters Project Metrics

Comprehensive assessment
Screening for physical symptoms
Pain treatment
Dyspnea screening and management
Discussion of emotional or psychological needs
Discussion of spiritual/religious concerns
Documentation of surrogate for decision-making
Treatment preferences
Care consistency with documented care preferences
Patient and family quality perceptions

Source: Grodwohl R, Brant JM. Hospital-Based Palliative Care: Quality Metrics that Matter. *J Adv Pract Oncol* 2015;6:597–610 <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5017551/pdf/jadp-06-606.pdf>

As serious illness progresses, individuals may also be in need of behavioral health services to address the psychological impact of long-term illness or end of life. People with serious illness are at higher risk of depression, for instance. Some risk factors are directly related to the other illness, such as changes in the brain from stroke or Parkinson's disease. For some people, anxiety and stress related to their diagnosis and illness may trigger symptoms of depression.⁴⁴ Under North Carolina Medicaid's move to managed care plans, there is opportunity to ensure improved integration of behavioral health services with physical health services.

REFERENCES

1. National Institute on Aging. What Is Long-Term Care? U.S. Department of Health and Human Services. <https://www.nia.nih.gov/health/what-long-term-care>. Accessed February 6, 2020.
2. Mlinac ME, Feng MC. Assessment of Activities of Daily Living, Self-Care, and Independence. *Arch Clin Neuropsychol*. 2016;31(6):506-516. doi:10.1093/arclin/acw049
3. Rogers T. Presentation to NCIOM Task Force on Serious Illness Care. May 2019. Home Health & Home Care Trends and Serious Illness.
4. National Institute on Aging. Long-Term Care. U.S. Department of Health and Human Services. <https://www.nia.nih.gov/health/caregiving/long-term-care>. Accessed February 6, 2020.
5. Palliative Care Definition: What is Palliative Care. Center to Advance Palliative Care. <https://www.capc.org/about/palliative-care/>. Accessed October 18, 2019.
6. Hughes MT, Smith TJ. The Growth of Palliative Care in the United States. *Annu Rev Public Heal*. 2014;35:459-475. doi:10.1146/annurev-publhealth-032013-182406
7. Kelley AS, Morrison RS. Palliative care for the seriously ill. *N Engl J Med*. 2015;373(8):747-755. doi:10.1056/NEJMr1404684
8. America's Care of Serious Illness. Center to Advance Palliative Care. 2019. <https://reportcard.capc.org/> Accessed February 10, 2020.
9. Palliative Care Report Card : FAQ. Center to Advance Palliative Care. <https://reportcard.capc.org/frequently-asked-questions/>. Accessed October 29, 2019.
10. Siderow S, Silvers A. Alternative Payment Supports Palliative Care Across the Continuum. Center to Advance Palliative Care. https://media.capc.org/posters/2016/Cen-ter_to_Advance_Palliative_Care_1_Allison_Silvers_Alternative_Payment_Supports_PC_Across_the_COntinuum.pdf Accessed February 9, 2020.
11. Aldridge MD, Hasselaar J, Garralda E, et al. Education, implementation, and policy barriers to greater integration of palliative care: A literature review. *Palliat Med*. 2016;30(3):224-239. doi:10.1177/0269216315606645
12. Hawley P. Barriers to Access to Palliative Care. *Palliat Care*. 2017;10. doi:10.1177/1178224216688887
13. Mapping Community Palliative Care: A Snapshot | Center to Advance Palliative Care. https://www.capc.org/documents/700/?utm_source=Mapping+Community+Palliative+Care+report&utm_campaign=Mapping+report&utm_medium=email. Accessed January 2, 2020.
14. Palliative Care Research. National Palliative Care Registry. <https://registry.capc.org/metrics-resources/research-in-the-field/>. Accessed January 2, 2020.

As discussed throughout this chapter, there are various services for individuals with serious illness that can be covered through Medicaid, including long-term supports and services, hospice benefits, and non-clinical services such as Special Assistance programs. These services have different eligibility requirements, application processes, and administrative homes. The task force acknowledged the need for ensuring that these processes are examined and revised to improve efficiency of eligibility determination and delivery of services.

RECOMMENDATION 3.6:

Expand access to coverage for health care services

In order to ensure access to health care services for individuals with serious illness:

1. The North Carolina General Assembly should support legislation to:
 - a. Close the health insurance coverage gap
 - b. Ensure integration of behavioral and physical health services for Medicaid beneficiaries under Medicaid managed care
2. The North Carolina Department of Health and Human Services should revise processes for determining eligibility for services covered by Medicaid, including long-term care and Special Assistance programs (including Special Assistance for Assisted Living and Special Assistance In-Home programs). Processes should ensure timely and efficient eligibility determination.

15. National Institute of Aging. What Are Palliative Care and Hospice Care? U.S. Department of Health and Human Services. <https://www.nia.nih.gov/health/what-are-palliative-care-and-hospice-care>. Accessed January 3, 2020.
16. Centers for Medicare and Medicaid Services. Medicare and Hospice Benefits. U.S. Department of Health and Human Services. February 2019.
17. NHPCO Facts and Figures: 2018 Edition. National Hospice and Palliative Care Organization.
18. NC Medicaid: Hospice Services. North Carolina Department of Health and Human Services. 2019.
19. FAQ: How is Hospice Care Paid For? American Hospice Foundation. <https://americanhospice.org/learning-about-hospice/how-is-hospice-care-paid-for/>. Accessed January 9, 2020.
20. Friebert S, Williams C. 2015 Edition.; 2015. www.ssa.gov/OP_Home/ssact/title18/1861.htm. Accessed March 17, 2020.
21. Albers A, Bonsignore L, Webb M. A team-based approach to providing person-centered care at the end of life. *N C Med J*. 2018;79(4):256-258. <http://www.ncmedicaljournal.com/content/79/4/256.full.pdf>. Accessed February 3, 2020.
22. Bridges DR, Davidson RA, Odegard PS, Maki I V., Tomkowiak J. Interprofessional collaboration: Three best practice models of interprofessional education. *Med Educ Online*. 2011;16(1). doi:10.3402/meo.v16i0.6035
23. Halpern SD. Goal-Concordant Care — Searching for the Holy Grail. *N Engl J Med*. 2019;381(17):1603-1606. doi:10.1056/NEJMp1908153
24. Golding, E. All's Well That Ends Well: A Comprehensive Advance Care Planning Strategy. Presentation to NCIOM Taskforce on Serious Illness; 2019.
25. Johnson CY. Scientists detected racial bias in a product sold by Optum, but the problem likely extends to algorithms used by major health systems and insurers . *The Washington Post*. Oct. 24, 2019. https://www.washingtonpost.com/health/2019/10/24/racial-bias-medical-algorithm-favors-white-patients-over-sicker-black-patients/?fbclid=IwAR1Ski2dDr_zPhVxdLnlCjNAbvjwLl7Wockzp4t0hb5KAosDM_hHDSjL06w. Accessed February 3, 2020.
26. Fernstrom KM, Shippee ND, Jones AL, Britt HR. Development and validation of a new patient experience tool in patients with serious illness. *BMC Palliat Care*. 2016;15(1):99. doi:10.1186/s12904-016-0172-x
27. North Carolina Department of Health and Human Services. Healthy Opportunities Pilots. <https://www.ncdhhs.gov/about/departments-initiatives/healthy-opportunities/healthy-opportunities-pilots>. Accessed December 16, 2019.
28. How to improve screening for social determinants of health . American Medical Association. <https://www.ama-assn.org/delivering-care/patient-support-advocacy/how-improve-screening-social-determinants-health>. Accessed March 17, 2020.
29. North Carolina Department of Health and Human Services. Field Test Report: Standardized Screening for Health-Related Resource Needs in North Carolina. <https://files.nc.gov/ncdhhs/NC-Screening-Questions-Report-Final-73019.pdf>. Accessed January 30, 2020.
30. Kepic M, Randolph A, Hermann-Turner KM. Care for Caregivers: Understanding the Need for Caregiver Support. *Adultspan J*. 2019;18(1):40-51. doi:10.1002/adsp.12068
31. Darlak, L. Selected Caregiver Assessment Measures: A Resource Inventory for Practitioners 2nd Edition. Margaret Blenkner Research Institute. 2012.
32. Reinhard SC, Given B, Petlick NH, Bemis A. Supporting Family Caregivers in Providing Care. Agency for Healthcare Research and Quality (US); 2008. <http://www.ncbi.nlm.nih.gov/pubmed/21328765>. Accessed February 14, 2020.
33. Slaboda J, Fail R, Norman G, Meier DE. A study of family caregiver burden and the imperative of practice change to address family caregivers' unmet needs. *Health Affairs Blog*. January 11, 2018. <https://www.healthaffairs.org/doi/10.1377/hblog20180105.914873/full/>. Accessed February 14, 2020.
34. NCCARE360. Now Live in 50 North Carolina Counties. <https://nccare360.org/nccare360-now-live-in-50-north-carolina-counties/>. Accessed January 30, 2020.
35. North Carolina Department of Health and Human Services. State-County Special Assistance, In Home. <https://www.ncdhhs.gov/assistance/adult-services/state-county-special-assistance-in-home>. Accessed February 14, 2020.
36. North Carolina Department of Health and Human Services. State-County Special Assistance. <https://www.ncdhhs.gov/assistance/adult-services/state-county-special-assistance>. Accessed February 14, 2020.
37. North Carolina Department of Health and Human Services. How and Where Can I Apply? <http://www.ncdhhs.gov/dss/local/index.htm>. Accessed February 14, 2020.
38. North Carolina Department of Health and Human Services. Am I Eligible?
39. Hostetter M, Klein S, McCarthy D. Sutter Health's AIM Model and Patients at End of Life. *The Commonwealth Fund*. <https://www.commonwealthfund.org/publications/case-study/2018/jan/supporting-patients-through-serious-illness-and-end-life-sutter>. Accessed February 7, 2020.
40. Stuart B, Mahler E, Koomson P. A Large-Scale Advanced Illness Intervention Informs Medicare's New Serious Illness Payment Model. *Health Aff (Millwood)*. 2019;38(6):950-956. doi:10.1377/hlthaff.2018.05517
41. Smith SR. Physician-Focused Payment Model Technical Advisory Committee. U.S. DHHS Asst. Secretary for Planning and Evaluation Office of Health Policy. 2017.
42. Primary Care First Model Options. Center for Medicare & Medicaid Innovation. <https://innovation.cms.gov/initiatives/primary-care-first-model-options/>. Accessed February 9, 2020.
43. Current Measures. CMS. <https://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/Hospice-Quality-Reporting/Current-Measures>. Accessed February 14, 2020.
44. Chronic Illness & Mental Health. National Institutes for Mental Health. <https://www.nimh.nih.gov/health/publications/chronic-illness-mental-health/index.shtml>. Accessed March 17, 2020