



# Understanding the Impact of Community-Based Palliative Care

Phyllis Whitehead, Senaida Keating,  
Shereen Gamaluddin, Carolyn White,  
Christi Stewart, and Kye Y. Kim

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P. Whitehead  
Carilion Roanoke Memorial Hospital Palliative Care  
Service, Roanoke, VA, USA

Virginia Tech Carilion School of Medicine,  
Roanoke, VA, USA  
e-mail: [pbwhitehead@carilionclinic.org](mailto:pbwhitehead@carilionclinic.org)

S. Keating  
Virginia Tech Carilion School of Medicine,  
Roanoke, VA, USA

Veterans Affairs Medical Center, Salem, VA, USA

S. Gamaluddin · C. White  
Centra Health Palliative Care Service,  
Lynchburg, VA, USA

C. Stewart  
Carilion Roanoke Memorial Hospital Palliative Care  
Service, Roanoke, VA, USA

Virginia Tech Carilion School of Medicine,  
Roanoke, VA, USA

Carilion Center for Healthy Aging,  
Roanoke, VA, USA  
e-mail: [castewart1@carilionclinic.org](mailto:castewart1@carilionclinic.org)

K. Y. Kim (✉)  
Carilion Roanoke Memorial Hospital Palliative Care  
Service, Roanoke, VA, USA

Carilion Center for Healthy Aging,  
Roanoke, VA, USA

Department of Psychiatry and Behavioral Medicine,  
Virginia Tech Carilion School of Medicine, Roanoke,  
VA, USA  
e-mail: [kykim@carilionclinic.org](mailto:kykim@carilionclinic.org)

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## Introduction

In the past century, medicine has changed and advanced more than at any other point in history. Innovative treatments, earlier diagnostic capabilities, and improvements in clinical and surgical techniques have changed previously terminal diseases, such as certain cancers, coronary artery disease, and HIV care from “death sentences” to chronic disease states. The population is living longer than ever before, and the average life expectancy has increased from 53.5 years in 1919 to 78.3 years in 2019 [1]. With the advancements in treatments for previously terminal conditions, more Americans are now living with chronic serious illnesses for longer periods of time. Not only are there often associated symptoms of the disease itself, but often treatments for these chronic disease states have significant and debilitating side effects. These serious illnesses often impact quality of life (QOL), comfort, and function. Dealing with serious illness for prolonged periods of time can threaten an individual’s and family’s financial stability, dignity, comfort, and even rob a person of their identity.

Palliative medicine was formally approved by the American Board of Medical Specialties as a subspecialty in 2006, but the practice of palliative medicine can be dated back far earlier. Palliative medicine as a subspecialty focuses on the management of pain, symptoms, and stress for those living with a serious chronic disease. It provides

an interdisciplinary focus and layer of support for patients and their families. Palliative medicine as an adjunct to standard medical care has been shown to improve quality of life and reduce emergency department and hospital utilization, and in some cases even prolong life expectancy. Palliative medicine, unlike hospice medicine, is appropriate at all points in chronic disease states, from the time of diagnosis, throughout the course of treatment, through end-of-life care, and even for families in bereavement support. The type of services and support that palliative medicine can provide may change and increase with disease progression over time, but unlike hospice care, palliative medicine can and should be provided concurrently with disease treatment through all points of management for chronic serious illness.

Palliative medicine provides a team-based approach to patient care to allow comprehensive assessment of patient needs and address care across a variety of domains. These include: (a) control of pain, symptoms, and side effects of treatments; (b) caregiver support; (c) social support; and (d) spiritual support. Addressing these domains can lead to improvement in pain and symptom management and relief of psychological, emotional, and spiritual suffering. Family and caregiver support is also paramount in the field of palliative medicine, including referrals to local community resources as indicated to allow better, more individualized care for patients in their preferred environment, whether that be home, long-term care, or group home settings. Palliative care provides communication about goal setting in the face of chronic disease management and can help to align patient and provider expectations with the reality of living with a serious illness. Team-based care is usually provided by physicians/providers, nurses, social workers, and chaplains, but also possibly including dietitians, counselors/psychologists, pharmacists, therapists (physical, occupational, or speech), and volunteers [2].

Due to the extensive needs and volume of patients and the lack of sufficient numbers of trained palliative specialists, it is imperative that aspects of palliative care be addressed by all providers. Primary palliative care can be provided by

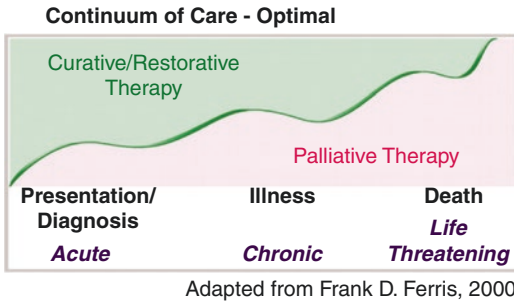
primary care providers and specialists without formal training in palliative medicine. Primary palliative care involves identification and basic management of symptoms of pain and suffering. It may also involve basic management of depression and anxiety often associated with chronic disease states. Providers can also engage patients and families in basic discussions of prognosis, code status, and goals of treatment. Specialized palliative medicine, also known as secondary palliative medicine, would be delivered by providers with specialty level training in palliative care, such as specialty certification or fellowship. These specialized practitioners can provide focus and management on refractory symptoms and/or complex depression, anxiety, grief, and existential suffering. They can also assist in conflict resolution regarding treatment plans and goals of care within families, between medical staff and families, and between treatment teams. Tertiary palliative medicine is indicated for patients with the most complex supportive care needs and is usually provided in an inpatient or academic center [3].

Throughout this chapter, the field of palliative medicine will be further explored at the community level—at national, state, and local levels—including barriers, resources, and opportunities for growth within the field.

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## Defining Hospice and Palliative Care

The terms palliative care and hospice care are often used interchangeably for one another, yet there is a significant difference between the two patient services. The National Hospice and Palliative Care Organization (NHPCO) clearly states that “palliative care is not hospice care: it does not replace the patient’s primary treatment being received (See Fig. 1). It focuses on the pain, symptoms and stress of serious illness most often as an adjunct to curative care modalities.” [4] The National Cancer Institute’s definition of palliative care is defined as care given to improve the quality of life of patients who have a serious or life-threatening diseases, such as cancer. Palliative care is an approach to care that addresses the person as a whole, not just their dis-



**Fig. 1** Continuum of care—optimal. (Center to Advance Palliative Care 2019)

ease. The goal is to prevent or treat, as early as possible, the symptoms and side effects of the disease and its treatment, in addition to any related psychological, social, and spiritual problems [5]. Hospice care, on the other hand, is defined by NHPCO as care focusing on the pain, symptoms, and stress of serious illness during the terminal phase. The terminal phase is defined by Medicare as an individual with a life expectancy of 6 months or less if the illness, disease, or condition runs its typical course [4]. The critical differences between palliative care and hospice care are the time limitation and not pursuing aggressive interventions in hospice. Whereas hospice care is provided when life expectancy is 6 months or less, palliative care has no time limitation and may be elected to manage secondary symptoms resulting from treatments of an illness from which recovery is a possible, but not guaranteed, prognosis.

### Hospice Challenges

A goal of hospice has been to utilize a multi-disciplinary team approach to patient care and needs. Addressing a patient’s emotional and psychosocial needs is as important as their physical needs. For this to be successful, hospice requires a group of providers, healthcare professionals, and caregivers to coordinate care. Until recently, any measure and reporting of the quality or success of that care was not required. The Affordable Care Act of 2010 mandated the initiation of a quality reporting program for hospices (HQRP)

[4]. Mandated reporting creates a necessary initiative to develop quality standards within hospice, which in turn can translate into improved patient care [6].

The Department of Health and Human Services (HHS) utilized the Measure Applications Partnership (MAP) to help initiate this strategy. MAP consists of 60 organizations representing diverse interests and was convened in 2011 by the National Quality Forum (NQF) to provide guidance on measures for use in performance-based payment, public reporting, and other quality improvement programs [6].

The areas of focus for assessment for hospice coincide with essential needs for successful hospice implementation and care.

- Access and Availability of Services
- The average hospice length of stay continues to be less than 6 weeks. Measures would focus on when patients and family initially become aware of hospice services, the timeliness of care initiation once a patient has opted to utilize hospice services, as well as the accessibility to the healthcare team on a 24-hour basis.
- Patient- and Family-Centered Care
- Educating and providing support to patients and caregivers so they understand the scope of services provided, including spiritual, physical, and psychological care.
- Goals and Care Planning
- Establishing patient and family goals with regard to the care of the patient and assessing if these are being met.
- Care Coordination
- Hospice care is now often given across multiple settings. Measures help track potential breakdowns in care or communication concerns that occur in transitions. The average Medicare hospice enrollee is in the home for 56% of the time, an assisted living facility for 11% of the time, and a nursing home for 17% of the time [7].
- Provider Competency
- Ensures that the patient is cared for by a qualified healthcare team appropriately trained to provide hospice care. Physical aspects of care including management of pain, dyspnea, and

constipation are assessed using a standardized scale. Psychological and psychiatric aspects of care such as anxiety, depression, delirium, and behavioral disturbances are evaluated as well.

- Appropriateness/Affordable Care
- Assesses if patients are successful in avoiding unwanted trips to the hospital and/or unwanted medical procedures.

Utilizing these quality measures can create an opportunity to continually evaluate if care is appropriate, high-quality, patient-centered, and coordinated across providers. Though the primary goal of hospice has remained the same, hospice has undergone changes in the last decade. The use of hospice services has increased by 50% over the past decade [2]. The primary hospice diagnosis has also changed, moving from a primarily cancer as an admitting diagnosis to a variety of diseases including dementia, respiratory, and Parkinson's disease. As the demographics of hospice continue to change, care implementation will also need to be adapted to meet patient and family needs [8].

While having a reporting standard of quality is important, assessing and translating those measures to a personal, community level is also imperative. Communities now often include hospice needs as part of their community health need assessments. This specifically takes into account information such as the demographics of the population. Age, race, cultural preferences, as well as socioeconomic factors are important to understanding your specific population and their needs. The health status of the community, including the number of individuals using tobacco products, certain environmental exposures, or stress level is also important to take into consideration. Understanding care resources including hospital centers, physician and provider availability, and specialty services can impact how you coordinate or deliver care.

As hospice grows and its utilization increases, where and how to care for these patients also come into question. Many patients are not living out their days at home, either because they do not have caregiver support or because they do not meet requirements of a hospital or inpatient unit. This is where residential hospices can come into

play. Since residential hospices do not need to meet many of the code requirements or regulations of long-term care facilities or hospitals, they often have a much more comfortable, serene, homelike atmosphere, which is appealing to many patients and families [9].

While hospice covers the medications, equipment, and nursing services, the room and board costs are typically not covered. Those expenses are often covered by the patient or family paying a daily room-and-board rate out of pocket. This can sometimes be subsidized by an endowment fund or other donations.

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## Palliative Care Challenges

Access to palliative care options in the United States, and the care itself, has made significant gains in the last two decades. According to 2018 Palliative Care Growth Snapshot issued by the Center to Advance Palliative Care (CPAC), the prevalence of hospitals (50 or more beds) with a palliative care team increased from 658 to 1831—a 178% increase from 2000 to 2016. The rise in prevalence of palliative care in US hospitals has been steady over the last 16 years. In 2000, less than one-quarter of US hospitals (658) had a palliative care program, compared to three quarters (1831) in 2016. The unremarkable increase, however, has occurred at centralized medical facilities in urban areas that serve a community so long as the members of that or nearby communities can access the hospital to receive palliative care. Rural areas are less likely to have access to palliative care services where populations are disproportionately older, poorer, and more likely to have a range of chronic illnesses than their urban counterparts [10].

A survey conducted in California in 2011 found that while the majority (53%) of California's acute hospitals offered inpatient palliative care services, only about 18% offered outpatient palliative care [6]. A 2018 analysis by Kathleen Kerr of data collected in California indicates that statewide, there is only a 52% inpatient palliative care (IPPC) sufficiency and only a 40% community-based palliative care (CBPC) [11]. The significance of sufficiency data

from California is that as of 2014, the California Department of Health Care Services (DHCS) is required to expand community-based palliative care services to Medi-Cal beneficiaries [11].

The costs, the relative newness of the formal recognition of palliative care, and misunderstanding of palliative care by those who could benefit from it serve as roadblocks for the expansion of community-based palliative care outpatient programs. Costs affect both providers and patients and/or their insurance providers. Although studies have shown the benefits gained through the use of community-based palliative care, including statistically significant 20% reduction in total medical costs, 38% reduction in ICU admissions, 33% reduction in hospital admissions, and 12% reduction in hospital days [2], the fee-for-service does not adequately support the significant amount of time spent by an interdisciplinary team with patients and families [9].

To date, there are only a few models or examples of how a palliative care service can break even in a fee-for-service billing context, regardless of setting, and persuasive arguments are required for hospital or health plan subsidies. For patients, not all palliative care options are covered by Medicare or Medicaid, resulting in them paying out of pocket or simply forgoing the care. Many insurance plans cover some palliative care services, such as pain management. Many Medicare, Medicaid, and private insurance plans offer scant or no coverage of home visits, coordination of care, wound care, social and spiritual counseling, 24-hour hotlines, advanced care planning, or family support. Most of the insurance coverage is for patients who are hospitalized or in hospice care [12]. Most often, palliative care is provided to the geriatric group who are typically on fixed incomes.

Formalized and Board-recognized palliative medicine is relatively new to healthcare. It was only as recent as 2006 when the American Board of Medical Specialties (ABMS) approved the creation of Hospice and Palliative Medicine (HPM) as a subspecialty of 10 participating boards [13]. Although it has been shown that the expansion of palliative care providers is on the rise and the number of Accreditation Council for

Graduate Medical Education (ACGME)-approved Hospice and Palliative Care Fellowship Program slots has jumped from 283 in 2013–2014 to 413 for 2018–2019, only 87% of the slots are filled. Only in 2016 did the Joint Commission establish a community-based palliative care (CBPC) certification that recognizes home health and hospice organizations that provide top caliber community-based palliative care to patients and families in their home (primary place of residence) [14]. Compounding the issue of the requirements resulting from the rapid expansion of palliative care is the misunderstanding and poor messaging of palliative care in general. Overall, 9 of 10 adults in the United States have little or no knowledge of palliative care and still more physicians are unaware that their own institutions offer it [15]. Berry Medical institutions themselves often combine palliative care medicine with geriatric care medicine, as is the case with the University of Texas, the University of Chicago, and The George Washington University, to name a few, which can lead patients to associate palliative care with geriatric care. Further compounding the difficulty of correctly branding palliative care is the frequent association of palliative medicine as hospice or end-of-life care, and studies of patients with cancer suggest that many initially associate palliative care with hospice and death and/or dying [15].

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## Financial Issues

There are many challenges to community based palliative care programs. These programs are often “stand alone,” providing care for the most complicated, ill patients who live at home. They are doing so without the support of a facility or programs such as hospice. As most community-based programs are not affiliated with or part of an integrated health system, their services cannot be subsidized [16]. The traditional form of Medicare fee-for-service is not sustainable when trying to support the services of a multidisciplinary team, which is the hospice care model. Reimbursement for physicians and advance practice registered nurses is inadequate considering the time required to effectively

manage these complex patients. Additionally, the Medicare system does not financially reimburse healthcare providers such as registered nurses, social workers, bereavement counselors, and the administrative staff needed for an effective advanced illness management program [16].

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## Staffing Issues

Access to healthcare services is critical to achieving or maintaining health, yet those who live in rural areas face a variety of access barriers. There is no single definition of a rural area. One general definition is a geographical area not neighboring a city or town with insufficient healthcare resources, not greatly populated, with predominance of medically underserved patient populations [21]. It is especially important for those residents in rural areas to have access to hospice and palliative services as it can improve the quality of life for those of all ages who are dealing with serious, life-limiting illnesses. Unfortunately, the less populated a county or area, the higher the degree of poverty and less likelihood of a hospice agency to provide those services [1].

Residents in rural areas often encounter general barriers to healthcare that limit their ability to obtain the care they need. These residents must have sufficient access to appropriate health services, and those services must be available, affordable, and obtainable in a timely manner. Even if services are available in the community, there can be many other factors that could limit a resident's ability to access these services [17]. This section will look at these barriers that rural residents often face today.

In order for rural residents to utilize appropriate healthcare services, they must have the following:

- Financial means to pay for services
- Means to reach and use those services
- Confidence in their ability to communicate with providers
- Trust that they can use those services without compromising their privacy
- Belief that they will receive quality care [17].

Those individuals without health insurance have less access to healthcare services, especially in rural areas. A US Census Bureau Report found that the proportion of populations living outside a metropolitan area without any type of health insurance coverage was 9.2% in 2017, compared to 8.8% in metropolitan areas [18].

According to the National Advisory Committee on Rural Health and Human Services, even rural residents who have Medicare may have limited access to hospice care [19]. This is very problematic since rural people tend to be older, sicker, and have lower incomes than their urban counterparts. The use of hospice services by Medicare beneficiaries has increased overall since 2000 in all locations, but hospice is still more available and used more often in urban areas. According to the Hospice Services chapter in the 2019 Report to Congress, Medicare Payment Policy, as of 2017, there were a total 878 rural hospices, down from a peak of 945 in 2007, with a decline of 2.6% from 2016 to 2017 alone. Therefore, in 2017, only 20% of all hospices in the United States were located in rural areas. The Report also notes that although the number of rural hospices has decreased, the percentage of rural Medicare decedents using hospice services has increased over this same period. [20]

Providing hospice and palliative care in rural areas can involve many challenges. In a 2013 phone survey of 53 rural hospice directors and key staff members from 47 states, the most important issues identified included the following:

- Financial issues, such as reimbursement and operating costs
- Rural factors, such as population changes, economics, culture, and geography
- Federal regulations and policies, such as requirement for face-to-face visits for recertification of hospice patients
- Workforce issues, such as challenges in recruiting and retaining staff, and staff burnout
- Relationships with other healthcare providers and competition for resources and patients
- Technology issues, such as limited access to Internet and connectivity problems [21].

Not just the elderly and poor have difficulty in getting appropriate care in rural areas. Another subset of patients that has great difficulty in accessing hospice and palliative care in the rural communities are those in the (lesbian, gay, bisexual and transgender) LGBT community. Lack of healthcare provider training/education in lesbian, gay, bisexual, and transgender cultural competence may greatly diminish access to providers. Even those culturally competent providers may exhibit microaggressions when providing care to the LGBT patient, especially in socio-politically conservative areas. Microaggressions are those everyday verbal, nonverbal, and environmental slights, snubs, or insults, whether intentional or unintentional, which communicate hostile, derogatory, or negative messages to target persons based solely on their marginalized group membership [10]. In a study of healthcare providers in rural Tennessee, many of the interviewed providers felt they were competent to provide LGBT patient care, but they did describe behaviors and attitudes that likely contributed to inequities of care in those communities [22].

Palliative care has its own set of challenges. Although hospice is covered by Medicare and many other insurance plans as a benefit, palliative care typically is not [22]. Palliative care can be utilized at any time in the course of a chronic life-limiting illness. Optimally, it should be offered at the time of diagnosis, once clinical decline from the illness begins, and when the patient begins to experience treatment failures. This is especially difficult in rural populations due to the multiple issues outlined in this section. It can be generally stated that living in rural communities is negatively associated with hospice and palliative services as these patients often exhibit poorer health status and greater need for care [1].

One answer to the difficulty in accessing palliative care could potentially be the use of telemedicine. While this can often be easily utilized in urban areas, it is frequently difficult to access in rural areas. Some of the difficulties encountered can include the following:

- Limited access to high-speed internet
- Limited access to smartphones

- Credentialing and licensing of telehealth providers
- Reimbursement issues
- Sustainability
- Malpractice concerns as some policies do not cover telehealth
- Transportation, as some telehealth services still require patients to travel to participate in live video consultations
- Interoperability, in which some telehealth programs may have issues with secure methods to access and share medical information
- Mistrust of technology and healthcare in general
- Lack of provider utilization if they lack interest or ability to effectively interact by video [22].

### **Clinician Self Care and Staff Challenges in Rural Areas**

Some of the many challenges faced by the rural hospice and palliative care workforce are outlined in the report of Perspectives of Rural Hospice Directors [17]. The challenges include the following:

- Heavy workloads and provider shortages
- Wearing multiple hats
- Limited options for training
- Coping with fear and anger among patients and families who are having difficulty accepting their loved ones' illness or injury
- Emotional stress of caring for dying patients with whom they may have close relationships
- Safety concerns related to traveling to remote areas
- Low retention rates
- Physical stress
- Lower salaries in rural areas
- Potentially only part-time hours available due to financial constraints of rural agencies
- Scheduling concerns where staff may work alone and without adequate support
- Fewer options of medications and medical equipment in rural pharmacies
- Ongoing opioid crisis in rural areas may limit opioid use or choice.

Provider shortages are fairly typical in rural areas and encompass primary care and all specialties. Nurse practitioners (NPs), clinical nurse specialists (CNSs), and physician assistants (PAs) often fill the provider role in rural communities due to physician shortages [23]. Although these advanced practice providers partially fill the gap, rural communities continue to struggle. Additionally, shortages of trained hospice and palliative providers are a common theme in rural areas. All of these provider roles are often inadequately prepared for the care of terminally ill patients [24]. These providers can often be uncomfortable with talking to their patients and families about palliative and hospice referrals due to the lack of specialized training opportunities. Another issue is the limited scope of practice for NPs, CNSs, and PAs in certain states. Statutory laws often hinder NPs, CNSs, or PA from referring or admitting a patient to hospice. This can delay or defer access to services if these providers must defer a hospice referral to a physician. At this time, only physicians can certify that a patient has a terminal illness with a prognosis of less than 6 months and admit that patient to hospice. This can severely limit hospice care in those rural areas with very limited numbers of physicians [1]. Another provider issue can be overconfidence in their ability to manage a patient's symptoms and disease trajectory, which again delays or defers utilization of hospice or palliative services.

Another challenge is the limited options for education. End-of-life care is often not comprehensively taught in most undergraduate, graduate, or medical schools. Though this is slowly changing, it is still a major issue in the rural areas as opposed to urban areas where the majority of new medical school graduates tend to work. As chronic and terminal diseases progress, acute deterioration and symptom management can be more complex than providers are initially prepared to manage independently [25]. When providers are not adequately prepared to manage these conditions, patients suffer. This is especially true in rural communities.

The emotional stress of caring for patients at end of life can be especially difficult for provid-

ers and employees of hospice and palliative care agencies in rural communities. Many of those caring for patients are local to their communities and often know them personally. The boundary between professional and personal can become blurred and emotional. The fear of losing a loved one or personal friend can create a sense of urgency, a desire to continue curative treatments even when they are no longer effective, and result in discounting a patient's wish to focus on quality of life instead of quantity [1]. This situation becomes more difficult when providers and caregivers cannot accept reality and prognosis, either based on close relationship, fear, lack of education, or difficulty in communication of facts.

Often providers are uncomfortable or unable to have frank conversations with their patients about the specific disease process and prognosis, as well as all those services potentially available and provided by hospice or palliative care [26]. These hospice and palliative referrals can sometimes be perceived as negative options and can be seen as giving up, both by providers and families. Though these perceived negative options are seen in both urban and rural areas, they are more prevalent in rural areas. Rural patients and families tend to be less trusting of the medical establishment due to their limited education and increased poverty [23]. They can also be "more likely to think they are not getting equal treatment and that providers who discuss treatment withholding or withdrawal are doing so to save money." [23]. This can be especially true in the African American communities.

Safety concerns in rural areas are different from those in urban areas. Those providers and caregivers traveling to remote areas have their own set of concerns. Providers and staff often have to travel great distances alone as they have to cover large service areas. This can be especially difficult or dangerous in bad weather. It can be a financial burden due to lower salaries, rising gas costs, and wear and tear on personal vehicles. It is also an emotional stress to be alone without support from colleagues in dealing with those patients at end of life and those with difficult symptom management needs. Cell phone service is often sporadic and unreliable in remote areas,



leaving hospice and palliative staff without the ability to call for assistance if needed.

The ongoing opioid crisis can affect care in rural areas. Recent opioid legislation and increasing scrutiny from federal and state agencies have created multiple barriers for providers and patients to obtain adequate pain relief. These challenges can include prescription limitations, practitioner fear of litigation, and need for frequent face-to-face provider visits for refills and monitoring [27]. Rural communities suffer disproportionately from lack of opioid prescribers, shortages of opioid medications, and reluctance of providers to prescribe in those areas most affected. There is often a stigma associated with the use of opioids from providers, patients, family members, and caregivers.

Even at end of life, there is continuing stigma and fear surrounding the use of opioids. It is imperative that providers and nurses caring for patients at end of life in rural communities stay up-to-date on current regulations, opioid availability in their area, and education needs of their patients with respect to opioid use.

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## Ethical Issues Considerations

Ethical challenges exist in the community setting as in inpatient settings. Clinicians may experience ethical dilemmas such as the lack of surrogate decision makers, advance care planning for serious ill patients who lose capacity to make their own medical decisions, and palliative sedation. When these ethical issues arise, it is important to have access to a bioethicist and/or bioethics committee to assist in determining the most appropriate ethical course of action.

It is important to understand the following ethical principles. Autonomy is acknowledging the moral right of every capable individual to choose and follow his or her own plan of life and actions. Palliative care clinicians should always integrate shared decision-making with patients and their families/loved ones. Self-determination is crucial when appropriate, evidence-based medical interventions are clearly presented to patients and their loved ones.

Clinicians should consider the following questions when determining the ethically appropriate course of action [28]:

- Has the patient been informed of benefits and risks?
- Informed consent: does documentation matter ... Legally?
- Is the patient mentally capable and legally competent?
- If mentally capable, what are the patient's preferences?
- If lacking capacity, has the patient expressed prior preferences?
- Who is the appropriate surrogate?
- Is the patient unwilling or unable to cooperate with medical treatment?

Medical decision-making capacity is determined by evaluating the following items [28]:

- Comprehension and understanding of one's medical conditions
- Evaluation of the benefits and risks of the intervention and the consequences of refusing the intervention
- Selection of realistic alternative options of interventions
- Ability to communicate one's thoughts, questions, and concerns
- Psychiatry may be needed to verify if clinicians do not feel patients have medical decision-making capacity. It is important to know your agency or facility's policy for determining medical decision-making capacity.

Additionally, clinicians should be familiar with the legal hierarchy of designated decision makers. The process varies from locality to locality. If an advance directive or guardianship documentation does not exist, then the next of kin is spouse, majority of adult children (includes adopted children), both parents, majority of siblings, and so forth.

Benevolence is to do the right thing. It is the act of charity, mercy, and kindness with a strong connotation of doing good to others including

moral obligation. Nonmaleficence is defined as doing no harm. Medical futility is a common problem that occurs many times at end of life. It is defined as medically unnecessary, nonbeneficial healthcare interventions usually related to end-of-life care. Restricted quality of life (QOL, severely compromised QOL and/or profoundly diminished QOL) are factors associated with futility. The following questions should be considered [28]:

- Are the interventions in question recommended and indicated?
- What are the medical teams recommending?
- Is there consensus among the medical teams?
- What is the prognosis with and without treatment?
- What has been communicated to the patient and/or family?
- How do we determine QOL for our patients?
- Are there biases in determining QOL?
- Is this suicide if someone chooses to die?

Moral distress occurs when an individual's moral integrity is seriously compromised, either because one feels unable to act in accordance with core values and obligations, or attempted actions fail to achieve the desired outcome [29]. Moral injury is a new way of looking at burnout. It is the inability to provide high-quality care and healing related to complexities of healthcare. Moral injury focuses on system issues, whereas burnout implies poor individual resiliency and coping skills. Moral injury may lead to clinicians feeling wounded, disengaged, and learned helplessness. Moral residue is an aspect of moral distress. It is the residue that remains that can be damaging to the self and one's career, particularly when morally distressing episodes repeat over time.

Palliative sedation is defined as "when terminally ill, conscious patients experience intolerable symptoms that cannot be relieved by expert palliative care, palliative sedation involves administering sedatives and non-opioid medications to relieve suffering in doses that may induce unconsciousness, but not death." [30]. Palliative sedation is used more commonly to relieve severe

physical symptoms such as dyspnea, pain, nausea, and delirium and more rarely in patients with existential suffering [30]. Ethicists, numerous healthcare professional organizations, and the US Supreme Court has sanctioned palliative sedation therapy as an acceptable means of relieving suffering in the last days of life [30]. Palliative sedation is not euthanasia or assisted suicide.

A concern has emerged regarding whether it is ethically appropriate to sedate dying patients in such a way to intentionally make them unconscious to alleviate symptoms when all possible treatments have failed until they die [31]. Clinicians may struggle with potentially eliminating the patient's opportunity to live their last days with their children and family and secondly with accelerating their death. Despite frequent reports of palliative sedation, there have not been any studies to find a correlation between palliative sedation and the hastening of death [31]. Of particular debate is the use of palliative sedation to treat existential suffering. For example, if a patient has a prognosis of greater than two weeks, requires sedation that prevents oral intake, and refuses artificial hydration and nutrition, many experts feel palliative sedation may become a contributing cause of death. Mental health and spiritual care experts should be consulted to treat existential suffering prior to initiating total palliative sedation and to foster closure activities. It is imperative to incorporate the interdisciplinary team in assessing the patients' suffering and communicating with the patient, family, and other healthcare clinicians. [31]

Justifying ethical principles for palliative sedation include dignity, respect for autonomy, beneficence, nonmaleficence, and double effect. Having access to bioethicists and bioethics committees is essential in providing medically and ethically appropriate care.

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## Mental Health Challenges

Palliative care, designed to improve patients' QOL, often plays an important role in end-of-life care for those with advanced illnesses and their families [32]. In view of its care practices, the

World Health Organization further clarifies the core features: “Palliative care—integrates the psychological and spiritual aspects of patient care.” [33]. Most palliative care practitioners are keenly aware that the psychological distress of patients and their families can be a challenging clinical aspect, but the presence of psychiatric clinicians in this field previously has been limited. Various barriers that interfere with proper recognition and treatment of psychiatric problems at end-of-life care have been addressed in recent years. Some of them are related to professional factors, such as the belief among palliative care clinicians that they themselves could adequately address psychological distress, or lack of confidence among psychiatrists about their ability to be of value in caring for patients near the end of life.

Practice patterns with the field of psychiatry may have hindered the field’s involvement as well, because the emergence of palliative care coincided with the movement of psychiatry toward increasing reliance on psychopharmacology and away from psychotherapeutic modes of care. System-level factors, including funding structures that have been unfamiliar or inadequate to compensate psychiatry providers, may have been barriers [34, 35]. Although some of the barriers mentioned above still exist, the concept of palliative care psychiatry has been steadily evolving and maturing over the years. Several academic centers currently include psychiatrists on their palliative care services [36]. The American Psychiatric Association reports on formally integrating mental health services into hospice settings in one major community-based hospice care program [37].

Potential roles of the psychiatrist in caring for patients at the end of life are multiple. They can be (1) diagnosis and treatment of psychiatric disorders, (2) understanding psychodynamics and dysfunctional coping, (3) consultation on psychopharmacology, (4) assessment of decision-making capacity, (5) recognizing and treating staff stress, (6) facilitating effective team work and identifying team dysfunction, (7) bereavement care, (8) integrating developmental considerations into treatment plans, (9) psychiatric

education for palliative care staff, and (10) research [8]. In view of psychopharmacological contributions to the patient care, psychiatrists may review the appropriateness of medications, especially various psychotropic agents [38]. In an ideal model, mental health professionals such as psychiatrists, psychologists, and social workers should be included in a palliative care team. Each team member can make contributions to psychopharmacological intervention, cognitive-behavioral therapy, grief intervention, and mindfulness, etc.

As mental health professionals continue to evolve into an expert discipline in palliative care, there should be also more efforts to promote research in challenging areas, such as palliative care for patients with serious mental disorders, substance abuse disorders, personality disorders, delirium, dementia with neuropsychiatric symptoms, depression, anxiety, and desire to hasten death. In particular, it would be clinically valuable to know more about the relationship of mental health issues with pain.

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## Opportunities for Growth

Palliative care services are beginning to be successfully integrated into ambulatory clinics and home health agencies [39]. Another opportunity is partnering with managed care plans and local Area on Agency Aging offices and other elder service agencies. It is critical to target the most vulnerable individuals such as low-income ethnic and racial minorities. Experts continue to call for innovative models to deliver community-based palliative care to address these and other gaps in care. Because service agencies serve over 90% of elders with multiple chronic conditions including cancer, many have functionality deficits and report poorer health compared to older adults who do not receive these services [39–41].

Other studies provide further evidence to encourage adoption of community based palliative care specialists across multiple serious illnesses/conditions [42]. These findings should encourage policy makers and service providers to target delivery of palliative care services to all

people who could benefit, not just those with cancer [42, 43].

Furthermore, chronically ill patients in rural areas face challenges in accessing palliative care due to poverty, lack of insurance, and transportation [44]. Rural communities would greatly benefit from community-based palliative care programs. Culturally informed community-based palliative care services including patient navigators should be developed for Latinos, Asian, and African descendants [45].

Another vulnerable population is that of individuals with mental health disorders. People with schizophrenia were half as likely to enroll in community-based specialist palliative care and were half as likely to be admitted to hospital in the last year of life compared to people without schizophrenia who had a similar sociodemographic profile [42]. This presents an excellent opportunity to design community based palliative care programs that can address the unique challenges of people with mental illnesses.

Community-based palliative care services are associated with reduced use of costly hospital care, health system cost savings, reduced EOL care costs, increased hospice utilization with improved care patient satisfaction, and increased likelihood of death occurring out of the hospital [2, 40, 46–49]. As based upon the WHO's concept of palliative care, CBPC should be accessible to the entire community [47].

Future research should examine which aspects of the specialist palliative care teams contribute most to reducing health system costs using multi-level regression models and should assess the impact of these teams on informal caregiver costs [50].

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## Conclusion

Patients with serious illnesses prefer to receive care and die at home, yet the end-of-life period is characterized by high levels of acute care utilization, in-hospital deaths, and healthcare costs [10, 51, 52].

More intensive training, including didactic classes, shadowing of clinicians, case studies,

and continuing education, would help to improve EOL skills in some key areas. These include understanding the concept of community-based palliative care and need for greater focus on emotional issues at the end of life and distinguishing between what constitutes an emergency versus the natural dying process and conveying this information to patients and families [44, 53–55].

As the healthcare entities move to a more patient-centric healthcare delivery system tied across the community, community based palliative care programs are well positioned to bridge across the continuum of care settings and deliver a person-centered interprofessional approach to people dealing with serious illnesses and conditions [48, 51, 52, 56].

Care that is primarily driven by values, goals, and preferences of seriously ill individuals and their family members may result in more compassionate, affordable, sustainable, and high-quality care [2].

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## Palliative Care Resources

### Local Resources

- Palliative Medicine services through Carilion Clinic. <https://www.carilionclinic.org/specialties/palliative-medicine-and-supportive-care>
- Palliative Medicine services through Lewis-Gale. <https://lewisgale.com/health-education/palliative-care-information-for-patients-and-families.dot>
- Palliative Medicine services through the Salem VA Medical Center. [https://www.salem.va.gov/services/hospice\\_palliativecare.asp](https://www.salem.va.gov/services/hospice_palliativecare.asp)
- Palliative Care Partnership of the Roanoke Valley <http://www.pcpvr.org/>.
- Roanoke County Local Office on Aging <https://www.loaa.org/>.
- Local chapter of the Alzheimers Association, including lists of support groups – <https://alz.org/cwva>.

### State Resources

- Virginia Dept of Health – palliative care <http://www.vdh.virginia.gov/palliative-care/>
- Virginia Association for Hospices and Palliative Care <https://www.virginiahospices.org/>.

Virginia Advance Directive for Healthcare <https://www.wcch.org/Content/Uploads/Wythe%20County/files/Advance-Directive-Simple.pdf>.

Virginia Academy of Elder Law Attorneys <https://www.vaela.org/>.

## National Resources

National Hospice and Palliative Care Organization [www.nhpco.org](http://www.nhpco.org).

American Association of Hospice and Palliative Medicine [www.aahpm.org](http://www.aahpm.org).

National Hospice Foundation. <https://www.nationalhospicefoundation.org/>

## Educational Resources for Patients and Providers

Get Palliative Care – information for patients on palliative care [www.getpalliativecare.org](http://www.getpalliativecare.org).

Vital Talk – structured conversations for providers on how to discuss prognosis and goals of care [www.vitaltalk.org](http://www.vitaltalk.org)

Center to Advance Palliative Care – educational courses for providers on palliative care and symptom management (requires institutional membership for some courses) [www.capc.org](http://www.capc.org)

End of Life Nursing Education Consortium – educational courses for nurses on end of life care. [www.aacnursing.org/ELNEC](http://www.aacnursing.org/ELNEC)

<https://www.the-hospitalist.org/hospitalist/article/121673/hospice-palliative-medicine/new-community-based-palliative-care>

<https://www.chcf.org/publication/up-close-a-field-guide-to-community-based-palliative-care-in-california/>

<https://www.chcf.org/wp-content/uploads/2017/12/PDF-UpCloseFieldGuidePalliative.pdf>

<https://www.capc.org/about/palliative-care/>

<https://www.chcf.org/wp-content/uploads/2017/12/PDF-InnovativeModelsPalliativeFactSheets.pdf>

[https://media.capc.org/filer\\_public/2d/09/2d092090-5d06-4107-b4c6-851a93139ae9/capc-nhpco\\_webinar\\_slides.pdf](https://media.capc.org/filer_public/2d/09/2d092090-5d06-4107-b4c6-851a93139ae9/capc-nhpco_webinar_slides.pdf)

[https://www.nhpco.org/wp-content/uploads/2019/04/PalliativeCare\\_VS\\_Hospice.pdf](https://www.nhpco.org/wp-content/uploads/2019/04/PalliativeCare_VS_Hospice.pdf)

<http://worh.org/rural-community-based-palliative-care>

<https://www.cancer.gov/about-cancer/advanced-cancer/care-choices/palliative-care-fact-sheet>

<https://www.pewtrusts.org/en/research-and-analysis/blogs/stateline/2017/07/10/why-some-patients-arent-getting-palliative-care>

<https://www.capc.org/seminar/poster-sessions/novel-approach-outpatient-palliative-care-clinic-flow/>

<https://www.nationalcoalitionhpc.org/last-call-outpatient-palliative-care-programs-become-a-testing-site/>

<http://aahpm.org/about/strategic-plan>

<https://www.nationalcoalitionhpc.org/wp-content/uploads/2019/04/MACRA-Field-Test-Recruitment-Flyer-updated.pdf>

[https://www.jointcommission.org/community-based\\_palliative\\_care\\_certification\\_option\\_july\\_1\\_2016/](https://www.jointcommission.org/community-based_palliative_care_certification_option_july_1_2016/)

<https://reportcard.capc.org/>

<https://www.chcf.org/publication/palliative-care-california-narrowing-gap/>

<https://www.capc.org/about/press-media/press-releases/2018-2-28/palliative-care-continues-its-annual-growth-trend-according-latest-center-advance-palliative-care-analysis/>

<https://www.sciencedirect.com/science/article/abs/pii/S0885392412004629>

<https://www.ruralhealthinfo.org/rural-monitor/palliative-care/>

<https://www.chcf.org/project/increasing-access-palliative-care-rural-california/>

<https://www.thoughtco.com/us-states-by-area-1435125>

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3214714/>

<http://aahpm.org/certification/subspecialty-certification>

<https://csupalliativecare.org/sb-1004/>

[http://aahpm.org/uploads/Program\\_Data\\_122718.pdf](http://aahpm.org/uploads/Program_Data_122718.pdf)

<https://www.acgme.org/>

<https://med.uth.edu/internalmedicine/geriatric-palliative-medicine/>

<https://www.uchicagomedicine.org/conditions-services/geriatrics>

<https://smhs.gwu.edu/medicine/divisions/geriatrics-palliative>

**Dr. Phyllis Whitehead** is a clinical nurse specialist with the Carilion Roanoke Memorial Hospital Palliative Care Service and Associate Professor at the Virginia Tech Carilion School of Medicine. She is a clinical ethicist and initiated the Moral Distress Consult Service at CRMH. She is certified in pain management and as an advanced practice hospice and palliative care nurse. Dr. Whitehead has done numerous presentations on pain and symptom management, opioid-induced sedation, moral distress, and patients' end-of-life preferences locally, regionally, nationally, and internationally. Her research interests include moral distress and improving communication with seriously ill patients. She has been a co-lead of the NACNS Pain Task Force and the Access to Care Workgroup and recently appointed as co-lead of the Virginia Action Coalition. She is a Distinguished Practitioner and Fellow to the Nursing Academy of the National Academy of Practice. She is a graduate of Radford University where she earned her BSN and MSN and earned her doctorate degree at Virginia Tech.

**Dr. Senaida Keating** is an Academic Hospitalist at the Salem VA Medical Center. She is an Associate Professor at the Virginia Tech Carilion School of Medicine and the Edward Via College of Osteopathic Medicine. She is a coauthor of the chapters "Palliative Care for Persons with Serious Mental Illness" in *Palliative Care, Perspectives, Practices, and Impact on Quality of Life*, a Global View published in 2017, and "End-of-Life in Persons with Severe and Persistent Mental Illness: A Review of the Research Outcomes" in *Palliative Care, The Role and*

Importance of Research in Promoting Palliative Care Practices published in 2019. She completed her Internal Medicine Residency Program at Virginia Tech Carilion School of Medicine/Roanoke Memorial Hospital as well as Fellowships in Geriatric, and Palliative and Hospice Medicine. She is board-certified in Internal, Geriatric, and Palliative Medicine.

**Dr. Shereen Gamaluddin** is a palliative attending with the Centra Health Palliative Care Service in Lynchburg, Virginia, and the Associate Medical Director for Good Samaritan Hospice. She earned her bachelor's degree in biology from Carnegie Mellon University. She completed her medical degree at University of Pittsburgh School of Medicine and subsequent Family Medicine training at Lancaster General Hospital. After nearly 10 years of private practice, she transitioned her focus to palliative and hospice medicine, completing a fellowship at Carilion Clinic. She is board-certified in Family Medicine and Hospice and Palliative Medicine.

**Ms. Carolyn White** is a nurse practitioner in the palliative medicine department at Centra Health in Lynchburg, Virginia. She has been a nurse practitioner since 2009, and

prior to that was a registered nurse in hospice. She received her BSN from Radford University and MSN from University of Alabama in Birmingham. Serving patients and their families during serious illness and/or end of life is her life's greatest calling and honor.

**Dr. Christi Stewart** is the Palliative Medicine Medical Director at Carilion Roanoke Memorial Hospital and the Hospice Medical Director at Carilion Hospice Services of Roanoke, Virginia. She completed her medical degree at the University of Pittsburgh School of Medicine and subsequent Family Medicine training at Lancaster General Hospital. She is board-certified in Family Medicine, Geriatrics, and Hospice and Palliative Medicine.

**Dr. Kye Y. Kim** is a Geriatric Psychiatrist at Carilion Clinic Center for Healthy Aging and is also a Professor at the Virginia Tech Carilion School of Medicine's Department of Psychiatry and Behavioral Medicine. He received his medical degree at Yonsei University College of Medicine, Seoul, South Korea. Subsequently, he finished his general psychiatry residency at the State University of New York at Buffalo and geriatric psychiatry fellowship at the University of South Florida affiliated hospitals.