



Models of Community-Based Palliative Care

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The Community Palliative Care Interdisciplinary Team

“Palliative care is a complex field including medical, ethical, psychological, social, existential, and emotional dimensions” [12, 13]. In Sweden, indications are that as interdisciplinary teams communicate their varied assessments, the outcome of patient care is greater due to the collaboration, expertise, and knowledge of the team members [13]. Staffing a community-based palliative care teams is based on the needs of the patients and families served, the resources available, and the future goals and growth of the program. There are several models of community palliative care in existence that can vary in staffing ratios, interdisciplinary team members, funding, legal structure and other factors. At the core of all the different models is the goal to improve the quality of life of the patients and their families by providing access to specialized professionals.

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In Canada, the Canadian Society of Palliative Care Physicians (CSPCP) recommends starting a program with a registered nurse who is overseen by a palliative care physician [11]. In the United States, community-based palliative care (CBPC) ideally consists of a physician, nurse, social worker, and chaplain. The focus is expert assessment and management of pain and other symptoms, assessment and support of the patient’s and caregiver’s needs, and the coordination of care with the primary care physician and oncologist caring for the patient. The care is based on the individual patient’s needs and not the prognosis associated with the disease.

The nurse-led model utilizes **registered nurses** or **nurse coordinators** empowered to practice at top-of-license. This leads to direct patient advocacy, care coordination, and education as the core responsibilities of the registered nurse on the interdisciplinary team. The nurse also provides immediate and ongoing assessment of patient and family needs. In this nurse-led model, the registered nurse is often the first to meet the patient and families. They assess the patients for physical symptoms and psychosocial needs and arrange family meetings. The registered nurse then brings this information back to the team and triages the services of other disciplines.

As the psychosocial expert on the team, the **social worker** focuses on the family interactions, assesses and supports coping mechanisms, and

evaluates the social determinants of health. In addition, the social worker on the team identifies and facilitates access to resources and mediates family and social conflicts. Many social workers who practice palliative care hold a master's degree in social work, and Licensed Community Social Workers (LCSW) can be an integral addition to the care of patients when issues of mental and emotional health are of concern. There are currently certification programs for palliative care social workers as well as registered nurses.

Chaplains are the professionals on the team who are tasked to provide spiritual care for patients and families enrolled in CBPC. In the hospital setting, professional chaplains may be required to hold a board certification or added qualifications. In the community palliative care environment, these qualifications may not be as strict and there is more variation in qualifications and formal training. Nevertheless, training is essential in order to provide quality palliative care and support a patient facing a serious and life-threatening illness, particularly if the patient is at end of life. The spiritual assessment includes active listening, using a set of questions to engage and assess the patient's spiritual needs, and meeting with family members in the patient's home or environment that they call home. Chaplains also educate patients and families on community resources and help facilitate continuity with the patient's faith community and other spiritual sources of support. The work of the chaplain is interfaith and does not have to focus on a particular faith-based practice or organized religion; the focus is on the spirituality of the patient. Many community programs are unable to fund the chaplain position due to current models of reimbursement, and so, often this is a missing component of many programs. There are innovative collaborations between community palliative care programs and local hospices to mutually fund a chaplain position, and hospital-supported community palliative care programs may cross train acute care chaplains to fill this role. In some community models, the chaplain and social worker often meet with the patient together; this is done since many patients are

debilitated and families are exhausted. The two disciplines find it synergistic to work closely together and jointly assess the psychosocial issues in the same initial visit so that the patient does not have to repeat their "story" more than once. Then the two disciplines decide how to best support the patient at their individual level of expertise.

Palliative medicine in the United States became a subspecialty designated in 2006 by the American Board of Medical Specialties (ABMS) as an advance level practice that focuses on the total care of patients with serious illness. **The community physician** component of the interdisciplinary practice of palliative care comprises physicians with specialized training in pain and symptom management. "The physician, as the director of the team, focuses on the illness trajectory, prognosis, and medical treatments" [3]. They provide direct patient care and provide oversight and collaboration with any nurse practitioners or physician assistants on the team. Due to the high volume of community patients who need this care and the limited availability of physicians who provide community-based palliative care, **Advanced Practice Providers** (nurse practitioners or physician assistants) increase the capacity and accessibility to provide this specialized care.

A study published in the *New England Journal of Medicine* suggested that early use of palliative care improved life expectancy by more than 2 months, improved quality of life, and reduced cost for people with metastatic lung cancer [2].

Transitions of Care from Acute Care to Community

The two primary acute care models in the United States are consultation services and palliative inpatient units. Hospital-based palliative care teams have grown and 63% of all US hospitals reported having a palliative care team in 2011 [1]. A consultation service in the hospital setting typically consists of a physician as the medical director and one or more of the interdisciplinary team members. A Palliative Care Unit (PCU) is a

specialty unit providing care to palliative care patients in a hospital setting. Patients are admitted to the PCU when they need inpatient management of intense personal or symptomatic distress or have family members who are in severe distress. Each inpatient unit has specific criteria for admission. In comparison to many similar units around the country, most models require distinct goals-of-care criteria for admission or transfer [14].

With data collection in the United States, the efficacy of the program over time demonstrated a large improvement in quality-of-care by identifying patients' goals and aligning them with the plan of care, which leads to improved clinical outcomes. Palliative care programs have shown a reduction in cost for both hospitals and payers with the identification of patient and family goals. This is due, in part, to identifying and providing healthcare resources and transitioning to the appropriate level of care that meets the needs of the patients [4]. With hospital-based palliative programs in place, a decrease in hospital resources and emergency room and ICU utilization is seen, resulting in cost reduction. In a large healthcare system in Texas, a palliative care program reduced the 30-day readmission rate of seriously ill patients by half (from 18% to 9%) with the use of an interdisciplinary palliative care team [15].

As the acute care palliative programs identified patients who benefited from palliative care in the hospital systems, the need for transitioning these patients back into the community grew. Palliative care patients discharged into the community have complex post-discharge needs. Community-based models of palliative care focus on guiding principles and core competencies of community-based programs. The core competencies are described as follows:

- Identification of the target population.
- Goal-based care plans.
- Team-based care.
- Caregiver training.
- Attention to social determinants of health.
- Symptom management.
- Medication management.

- Transitional care.
- Ability to measure value for accountability and improvement.

Adopting these competencies is the standard of a high-quality community-based palliative care program for all patients with serious illness [4].

Identification of the Target Population

To have a successful and sustainable program, care should be taken to initially focus limited resources on high areas of impact. One way this can be achieved is to properly identify patients in need of palliative services who would benefit from the interventions available. For example, an Accountable Care Organization (ACO) that data mines their patient population and identifies patients who could benefit cannot have an impact on a patient who is a resident of a nursing home if they do not have the ability to perform nursing home visits or collaborate with the nursing home. Proper patient identification can be performed in various ways. Examples of ways to identify patients can include, but are not limited to, screening tools that utilize diagnosis; functional status; emergency room readmission; hospital admissions; and lack of documented advance care planning (ACP) as some of the criteria. Data mining of high-risk populations for readmission and high mortality is becoming more available as data scientists help large health systems position themselves to be able to abstract this data and ACOs gain expertise as they study their population.

Having an interdisciplinary team that includes physical, emotional, and spiritual support experts is defined as **team-based care**. Family and caregivers are also important stakeholders in the care of the patient and thus are considered part of the team. This leads to a more comprehensive and holistic approach to care in the community. Team-based care has the added advantage that it not only focuses on the care of the patient but also if nurtured by the leadership of the program

can place a high level of importance on the well being of the team members themselves. Self-care and resilience are seen in programs that have active leaders championing teams' well-being, and this can lead to decreased turnover in staff members and less compassion fatigue and burn-out [16]. A particular challenge that community programs face is team member isolation. Hospital-based teams, by the nature of their location, are exposed to other medical professionals and healthcare givers on a daily basis. Community program team members, particularly those who are home-based, can often work without the daily physical interaction with other colleagues. This can add a different level of stress not experienced by palliative care teams working in the acute care setting, clinic, or long-term care. This should be taken into account when interviewing potential hires and in developing strategies to support current employees. One innovative way to help with this challenge is the utilization of current technologies to allow teams that may be geographically spread out to feel more connected by using video technology to hold team huddles and conferences. Program leaders can also identify specific areas to focus on to improve team well being and team connectivity, for example, by holding retreats or regularly scheduled meetings where team members can be brought into one venue to increase team cohesiveness. This addition of focus to include the well being of providers and adding a fourth dimension to the Triple Aim movement has been referred to as the Quadruple Aim [20].

Community-based palliative care is often provided at home and the day-to-day care is provided by family and or caregivers. Caregivers are defined as a family member or paid helper who provides support. It is important that they are provided **caregiver training** to ensure that the patient is receiving optimal support. The palliative care team often collaborates with home health agencies to ensure that patients, families, and caregivers receive training for tasks provided in the home. Some examples include proper medication administration, tube feeding, wound care, assistance with activities of daily living, and proper utilization of equipment in the home. One

of the most important parts of caregiver training is the ability to identify and convey any problems or concerns to the medical team and palliative care team. Identifying a change in the physical, emotional, or spiritual condition of the patient and explaining those needs to the team are core competencies.

Social determinants of health have been defined by the Centers for Disease Control and Prevention (CDC) as "conditions in the places where people live, learn, work, and play [that] affect a wide range of health risks and outcomes" (www.cdc.gov). Some examples include poverty, mental illness, unsafe living conditions, low literacy, limited or no access to food and water, and lack of transportation. Social determinants of health are identified as major influences on a patient's inability to remain in the community resulting in unwanted emergency room and hospital visits. They are a universal challenge to delivering healthcare in many parts of the world.

Palliative care team members receive specialized training in **communication skills** that help them educate patients and their **support system** regarding specific diseases and their progression. These skills allow team members to further help educate family members and caregivers on medication administration and risk versus benefit of treatment options. A growing field is community healthcare workers who are often non-medical trained personnel who reside in the community setting where the patient lives and can be trained to provide focused education. This new addition of labor force is being utilized by innovative palliative care teams to increase their work force. Any member of the palliative care team can be trained to facilitate family meetings where the patient's goals of medical care are clarified, and advance care planning is conducted. Proper training allows each individual to practice at top-of-license. In the meetings, the team ensures that the **goal-based care plan** is specific to patient and family wishes. The team ensures that proper documentation is completed and provided to the patient, caregiver, and their oncologist and primary care physician. These documents include a medical power of attorney, living wills, and out-of-hospital do-not-resuscitate (DNR) forms

where legally required. Some states have specific documents such as physician orders for life-sustaining treatment (POLST) or medical orders for life-sustaining treatment (MOLST) forms, which are medical orders signed by a licensed provider based on that state's legal requirement.

Emergency department visits and unwarranted hospital admission can often be a result of unfavorable **symptom management** related to the chronic disease exacerbation. Palliative care team members are trained to identify and address symptoms such as pain, difficulty breathing, agitation, constipation, nausea, and other symptoms that patients are unable to control alone in the community. This is done with specialized **medication management** that focuses on decreasing side effects, adherence to regimen, financial access, and education on medication uses. The success of these action plans partly depends on the 24/7 phone access patients and families get from community programs. A goal of palliative care in the community is to provide patients with a serious illness **access** to quality care in their home setting and, when that home setting changes, the team provides transitional care with thorough handoff to the care team in the setting that is now identified with providing the level of care needed [4].

The guided principles discussed in Cohn et al. derive from the National Consensus Project for Quality palliative care. These principles include patient/family-centered care; shared decision making of patient goals; comprehensive, coordinated care; accessibility; and to provide value [4]. **Patient/family-centered care** is defined as support of the patient and the family goals combined as a unit. The care should be centered around the values of the family as a unit. **Shared decision making of patient goals** is led by a plan of care that originates from patients' beliefs and preferences. A comprehensive initial assessment is completed to identify and clarify the goals and key players in the care of the patient. **Comprehensive, coordinated care** is necessary to accommodate the complex needs of patients with serious illnesses. The needs can vary from home health support, meal delivery services, medication assistance, caregivers, emotional sup-

port to respite care. Palliative care teams in the community are valuable in assisting patients and families in filling these gaps in care. In recent years, the value of the program has been observed by payers and has been included in value-based healthcare models. The programs must **provide value** and show cost saving through shared savings, bundled payments, risk saving, and readmission penalties [4].

Palliative Care in Ambulatory Settings

The Oncology Clinic

An article published in the Journal of Clinical Oncology recommends that cancer patients newly diagnosed or living with advanced cancer should have palliative care services offered concurrent with cancer treatment and as early as possible if not at time of diagnosis [5]. Models of providing palliative care in the oncology clinic may include providing access to a member of the interdisciplinary team such as a palliative physician or advance practice provider in the clinic. It is encouraged to introduce the palliative care team (PCT) to the patient as early in the disease process as possible, as encouraged by the literature. The focus of the PCT physician or advance practice provider in the oncology clinic is to provide expert level symptom management to minimize symptom burden of the disease. These symptoms, if not managed, have the potential to delay the treatment plan created by the patient's oncology team. In models where other members of the PCT such as nurses, social workers, or chaplains are available, the care can be more interdisciplinary. This team approach to provide care focuses on relationship building and to provide not only support for symptom burden but psychosocial and spiritual support. There are models where only a social worker with special training in palliative care is available. The social worker focuses on the psychosocial factors and can be the person tasked with initiating the advance care planning discussions that benefit most patients. Since advance care planning is not

the process of simply discussing code status but rather to identify patient's goals, expectations, and values, this is a conversation very well suited to this member of the team who is then practicing at top-of-license.

Goal setting begins by ensuring that patients and families understand the plan and options that were presented by their oncology team and have good lines of communication with all members of the healthcare team. The American Society of Clinical Oncology guidelines reports that integrating palliative care services into routine care of patients with advanced cancer improves patient satisfaction, reduces depression, and improves quality of life. It also reduces the use of chemotherapy at end of life for patients and increases enrollment and length of stay in hospice [5].

Primary Care Clinics

Core competencies and principles of high-quality community palliative care remain the same in every setting where palliative care services are provided. Each setting has a unique need that is the focus of their palliative care program. Community-based palliative care is beginning to emerge in the primary care setting but finding a comprehensive palliative care team in a primary care setting is still rare at the time of this publication. Hurdles include the limited time allotted for the office visit with primary care providers, reimbursement for social workers and chaplains in a primary care setting, and lack of understanding of how to utilize palliative care in a primary care practice. Most settings involve a primary care physician who has received palliative care training and sees patients with palliative care needs within his or her primary care patient panel. An area of opportunity is teaching primary care providers additional skills in pain and symptom management and communication skills. These are core competencies that primary care clinicians should have in order to better care for patients with a serious or chronic illness. Integrating a goals-of-care discussion in an office visit and identifying high symptom burden from

a serious illness are two examples of additional interventions that can help provide improved quality of life for patients in the primary care setting [17]. An even more focused area is advance care planning, which is now reimbursable by the Centers for Medicare & Medicaid Services (CMS) and many commercial insurance plans in the United States that pay for voluntary advance care planning (ACP) under the Medicare Physician Fee Schedule (PFS) and the Hospital Outpatient Prospective Payment System ([cms.gov](https://www.cms.gov)).

Palliative Care Outpatient Clinic

Interdisciplinary specialist palliative care in stand-alone clinics remains the gold standard for ambulatory palliative care [6]. Palliative care clinics have shown the greatest impact on multiple patient and caregiver outcomes as the program is not integrated into other specialty clinics. Fewer resources are required in other models; however, they may not be able to provide the same level of comprehensive palliative care [6]. Patients are referred to palliative care clinics by acute hospital palliative teams, oncology clinics, and other specialty providers. Most often, these clinics are managed and funded by hospital systems as they have found value in post-acute care follow-up. Patients seen in the hospital with palliative care needs that are not home-bound are candidates to be referred to the palliative care clinic, thus providing continuity of care. When patients are no longer physically able to receive services in the clinic, they can be transitioned to a home program when this is available.

Home Visits

As palliative care continues to prove its value in patient care, it is seen in more hospital settings and specialty clinics. A variety of specialty clinics such as oncology, congestive heart failure, left ventricular assisted device (LVAD), nephrology, and amyotrophic lateral sclerosis (ALS) clinics have invested in this service. When patients of

these specialty clinics are no longer capable of leaving their home as a result of disease progression, palliative care can be provided in their homes: private homes, personal care homes, or assisted living facilities. Qualifications to receive palliative care services in the home are set by the entity providing the care. An assessment is performed by a team member during the initial visit to identify the needs of the patient and families. The patient's need for symptom management, advance care planning, community resources, and spiritual or psychosocial support is assessed and discussed with the other members of the interdisciplinary team. Based on the assessment, one of the team members is assigned to the patient for follow-up [8]. Most importantly, the palliative care team ensures that patient's family and primary providers are updated on patients' plan of care.

Home Health and Hospice Models

Several Medicare-Certified home health agencies also operate Medicare-approved hospice programs. Likewise, Medicare-approved hospices operate community palliative care programs [7]. Both entities have developed innovative programs to meet gaps in care faced by seriously ill patients but both programs face problems in reimbursement for this care by traditional payment models. These models of community-based palliative care (CBPC) are attractive to patients since there is no need to end curative treatments and patients can continue to pursue aggressive and curative treatments. Most of the home health CBPC programs admit patients who meet the Medicare eligibility criteria for home health and have a prognosis of one year or less, or meet other screening criteria such as functional decline, high symptom burden, or have declined hospice services [18]. This allows the home health to recover some of the cost of their operations.

Hospice programs that house a CBPC do not admit those patients to hospice; these programs often fund their own operations, and a few have developed value-based contracts with payers or

other entities to fund the program cost. Hospice programs providing CBPC often refer to these programs as "bridge" programs, as they seek to meet the gap between hospice eligibility and lack of services for seriously ill patients. Once there is decline and the patient becomes hospice eligible with a prognosis of 6 months or less, if the disease follows its normal course and the patient chooses comfort care, the patient can be offered this service. Many agencies cross train staff so that the patient can be seen by the same team and not have to transition to different providers.

Palliative Care in Long-Term Acute Care (LTAC) and Skilled Nursing Facilities (SNF)

There are emerging models of palliative care in the LTAC and SNF setting. As with other CBPC programs that utilize physicians and advance practice providers, the consulting physician or non-facility employed advance practice provider are the only members of the palliative team whose time is usually reimbursable by traditional payment models. Innovative programs have been able to develop value-based agreements with payers to get reimbursement for the interdisciplinary members of the team. Composition of teams can vary but some of these programs cross train their nursing and social work staff to meet the needs of the program. Chaplains are becoming increasingly more available in these settings. Studies have shown that the palliative care teams in long-term care have been effective in reducing emergency department visits and depression. The programs have also promoted more appropriate care resulting in more favorable clinical outcomes toward the resident's end of life [19].

Palliative Care in Rural Areas

According to the American Telemedicine Association, telehealth saves patients', providers', and payers' money when compared to traditional care [10]. Telemedicine in palliative care can provide resources that can improve patient

outcomes and prevent avoidable use of healthcare resources. With telemedicine, palliative care patients can receive frequent assessment and support, access to a team member that can be used to prevent escalation of symptoms and crisis, receive education, information, and assist with in home management improving outcomes. Access to healthcare in rural areas is limited by structural, financial, personal, and cultural barriers. These barriers also play a major role in access and delivery of palliative care to seriously ill patients. Providing palliative care in the rural setting brings about its own challenges as well. Some examples of these challenges are funding, lack of clinicians, windshield time, and state regulations [9]. To bridge the gap, telemedicine is used to improve access in rural and underserved areas.

Advance Care Planning in the Community

As medicine continues to evolve, more and more options of care are presented to patients living with serious illness. Discussing patients’ goals are a vital part of the patient’s care plan. Advance care planning (ACP) is a discussion among patient, provider, family, and care team to clarify patient-centered goals of care. These conversations assess and provide clarification and understanding of disease process for patients and families. Patients are provided the opportunity to express their wishes regarding

their medical care to their medical team and family. The medical team also provides the patient with benefits and risk of therapy options and aligns them with patient’s goals. During this conversation, patients are encouraged to designate someone who can honor their decision when they are unable. It is also explained that the plan of care may change and will be frequently reassessed. While completion of legal documents such as directives to physicians, medical power of attorney, physician orders for life-sustaining treatment (POLST, and medical orders for life-sustaining treatment (MOLST), out-of-hospital do not resuscitate forms are important to physically document patient’s wishes; the most important part of the advance care planning is the conversation itself.

Palliative care team members receive specialized training to facilitate advance care planning conversations. They also educate other providers on how to effectively carry out the conversation. As this can be uncomfortable for some or time consuming, a variety of tools have been created to guide the conversations. Advance care planning can occur in any community-based setting.

Sample Palliative Care Screening Tool

Please complete on adult patients prior to patient being seen by provider.

Patient receives 1 point in each section for any yes answer.

MPOA/AD section do not receive a score

<p><u>Points</u> /1</p>	<p>In the last 30 days, have you been admitted to the hospital? Y / N In the last 30 days, have you had an ER visit? Y / N If so, how many visits? _____ Reason why: _____</p>
<p>/1</p>	<p>Are you currently, or in the past 24 hours have you, experienced uncontrolled: Pain Dyspnea Nausea/vomiting Diarrhea/constipation Anxiety/depression Fatigue</p>

/1	Are you currently having difficulty with: Stress/coping Medication access Transportation to medical visits Access to meals Assistance with activities of daily living at home
/1	Would you like to request spiritual or emotional support? Y / N
Total: /4	
Do you have a medical power of attorney (MPOA)? Y/N advance directives (AD)? Y/N If already in place, is there a copy in patient files? Y/ N Name and relation of MPOA _____	
Created by Scharlotte Spencer DNP, APRN, FNP-C, ACHPN	
Patient with 3 or more points: Consider palliative care referral	
Patients with 0–2 points: Re-evaluate on next visit	

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