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Background

Which Healthcare Problems Are Addressed by Palliative Care?

Palliative care addresses fundamental problems in the health-care system (such as sub-specialization, fragmentation, lack of training in care of the chronically and seriously ill, absent communication and coordination among providers and settings) by aligning the care delivered to patients with the care they desire, treating physical and psychosocial distress, focusing on skilled communication with patients, families, providers, and settings, and thereby improving the quality of care to the most frail, vulnerable patients in the society [1]. Numerous studies have shown that seriously ill patients often do not receive the kind of care they want [2, 3]. Specifically, in the last 6 months of life Medicare beneficiaries spend between 1.3 and 5.7 days in the Intensive Care Unit (ICU) [4] while 10.5–22.5 % of Medicare deaths were associated with an ICU admission [5] and approximately 20 % of Americans who died during a hospitalization spent time in an ICU during their final admission [6]. Intense healthcare utilization is not specific to the ICU—a retrospective review of Medicare data showed that 75 % of decedents visited an Emergency Department (ED) in the last 6 months of life; half visited the ED in the last month of life and 68 % of those patients who were admitted subsequently died in the hospital [7].

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Figure 6.1 shows national geographic variances in acute care admissions in the last 6 months of life for Medicare beneficiaries. Dying in the hospital is associated with poor quality of life for patients and portends an increased risk of psychiatric disorders in their bereaved caregivers [8]. Frail, elderly patients are also at risk of frequent and burdensome transfers between care sites, with an average of 3.2 transitions in the last 6 months of life. Such repeated transfers put patients at risk for adverse outcomes and lower family members' trust in healthcare professionals [9].

Which Patients Will Be Best Served by Palliative Care?

Seriously ill patients should be screened for common palliative care needs including pain, non-pain symptoms, practical needs such as transportation, food, housing, and financial support, family caregiver burden, and lack of understanding of the likely disease course and its associated treatment options. Palliative care services can be delivered by the patient's primary team if they have been appropriately trained and supported in the necessary knowledge and skills. A primary team may be unable to meet a patient's palliative care needs if they have received inadequate training on conducting successful goals of care discussions or managing physical symptoms or if they perceive they do not have the time to address the needs of seriously ill patients. Patients with more complex or challenging needs may require specialist-level palliative care teams working alongside and in support of the primary team [10]. Screening for palliative care may occur on a patient level where patients are identified based on their physical symptoms, psychological symptoms, spiritual distress, practical needs, or family distress. Alternatively, screening may occur via a systems-based approach using the presence of any potentially life-limiting or life-threatening condition in combination with past utilization (frequent readmissions for example) as a trigger for either primary palliative care (the basic skills required of all physicians and other

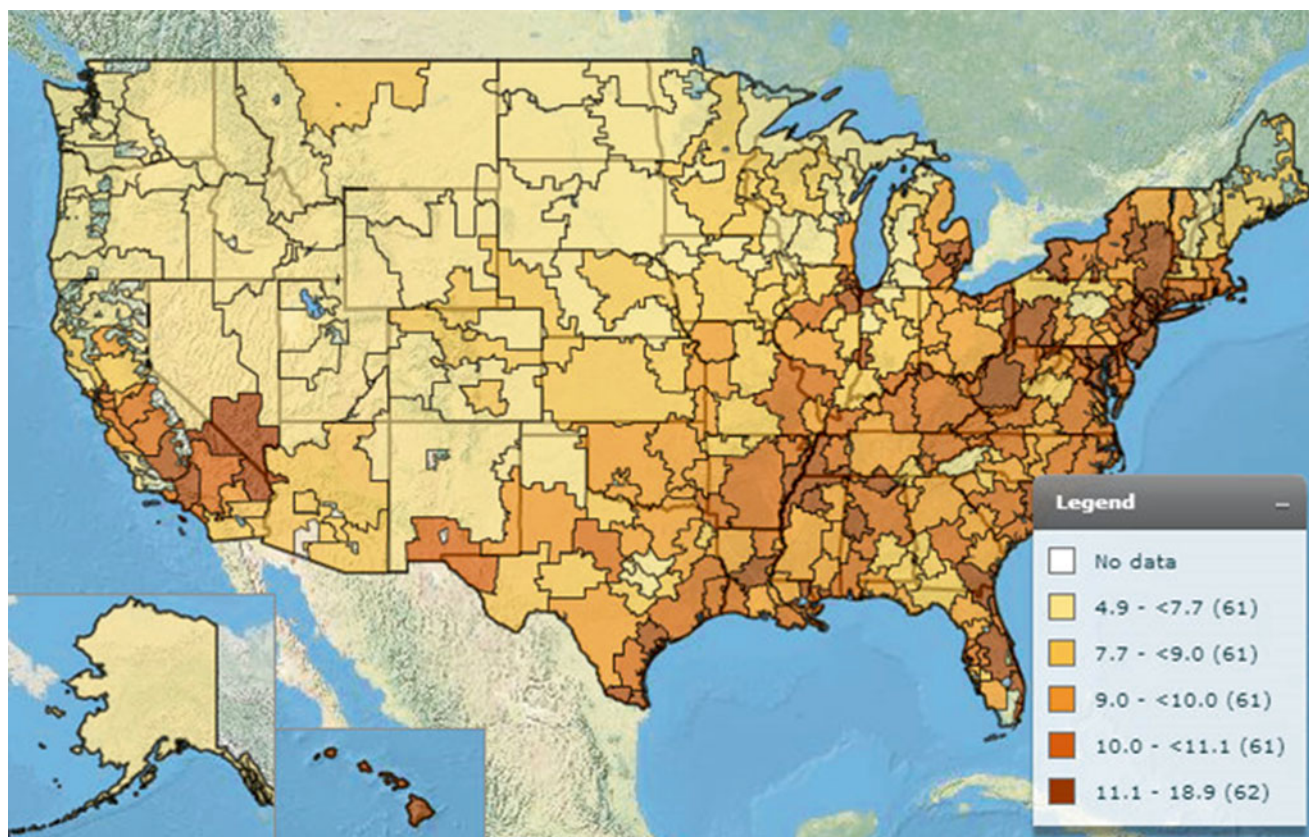


Fig. 6.1 Inpatient days per decedent during the last 6 months of life (Year: 2007) (from The Dartmouth Atlas Project, The Dartmouth Institute, <http://www.dartmouthatlas.org/data/topic/topic.aspx?cat=18> with permission)

healthcare professionals) or for a specialty level palliative care consultation. The provision of a palliative care consultation service that provides secondary (specialty level) or tertiary palliative care (provided at a tertiary medical center where specialist knowledge for complex symptom management and goals of care is taught, researched, and practiced) is critically important in caring for patients whose needs exceed those that can be met through primary palliative care [10]. For example, preliminary observations from a pilot program providing inpatient palliative care consultations to patients who met trigger criteria based on disease stage, readmission risk, or uncontrolled symptoms improved the frequency of palliative care consults while reducing readmission rates, increasing hospice use, and improving the mortality index for the patient population studied [11].

What Are the Barriers to the Provision of Palliative Care?

Access to palliative care may be decreased both by critical shortages in the workforce and misconceptions about palliative care.

Workforce Challenges

Despite a 150 % increase in the prevalence of palliative care programs in the US over the past decade [12], a shortage of trained palliative medicine physicians and nurses is still a major barrier to accessing palliative care. Approximately 2 % of hospitalizations in the United States end in the patient's death, and an additional 4–8 % of patients are discharged with serious illnesses—extrapolating from this, one could estimate that approximately 10 % of hospitalized patients require either primary or specialty level palliative care. Palliative care programs currently see a median of 2.6 % of all hospital admissions [13]; quadrupling the number of patients evaluated from this current rate to meet the estimated need of seeing 10 % of all hospitalized patients requires a major expansion in the available workforce [1]. A recent workforce shortage study estimated that between 2,787 and 7,510 full-time physicians are needed just to meet the immediate palliative care needs of the hospital and hospice population in the United States [14], and this does not include estimates of workforce demands for community-based palliative care now or in the future. In 20 of the 50 United States, no postgraduate medical education in

specialty level palliative care is available, and in states that do provide such training slots are limited to about 150 trainees per year, far short of current and projected demand [1].

Perception of Palliative Care

Lack of public and professional understanding about what palliative care entails or incorrectly equating palliative care with hospice are significant barriers to access to palliative care. National public opinion research revealed differences between how healthcare providers and the lay public view palliative care and the importance of using very specific language to define the type of care provided by a palliative medicine team. The language with the most positive impact for patients included that which described it as “specialized medical care and an added layer of support for people with serious illness focused on improving quality of life for both the patient and the family” [15]. Recent research also specifically compared the term “palliative care” with “supportive care” for oncology patients and found that the term “supportive care” was associated with better oncologist understanding and more favorable impression of the type of care provided by a palliative medicine team [16]. The misconceptions regarding the benefits of palliative care and the population of patients best served by this specialized care may lead to a mismatch between needs and access that is dependent upon an individual physician’s training, bias, and practice patterns [1] or upon patient and family misunderstanding of the benefits of palliative care alongside their regular medical care. Educating healthcare providers on the scope and benefits of palliative care while modeling behavior can effectively increase an individual’s understanding of palliative care. Oftentimes, physicians only fully appreciate the benefit of palliative care after receiving assistance with a particularly challenging case. This may be accomplished by having palliative care conduct a family meeting with the physician who requested the palliative care consult present, so he can witness first-hand how effectively specialty-level palliative care can meet the needs of the patient and family.

What Are the Benefits of Palliative Care?

There is an increasing literature on the benefits of palliative care on quality of life for patients and caregivers, survival, and cost savings [2, 17, 18].

Quality Outcomes

Palliative care has been shown to improve symptom management, caregiver burden, satisfaction with communication, and emotional and spiritual support during serious illness. Patients receiving palliative care have also been shown to have higher satisfaction with their hospital care and are more likely to have advance directives when compared to patients

who receive usual care [2, 17, 18]. One randomized controlled trial showed that patients who received an inpatient palliative care consultation had higher patient satisfaction scores, fewer ICU admissions if readmitted to the hospital, and longer hospice stays compared with patients who received usual hospital care [17]. One randomized controlled trial of patients with newly diagnosed metastatic non-small cell lung cancer enrolled patients within 8 weeks of diagnosis; those who were randomized to the palliative care group met with a palliative medicine specialist (either a physician or advanced-practice nurse) within 3 weeks of enrollment, in addition to usual oncology care. The patients who received early palliative care concurrently with standard oncologic care had improved quality of life, less depression, and were more likely to have resuscitation preferences documented compared with patients who received standard oncologic care alone. In addition, the patients randomized to receive early palliative care had significantly longer survival than those who received standard oncologic care only despite (or perhaps because of) receiving less hospital-based care near end of life [19].

Cost Outcomes

Healthcare value is defined as the ratio of the quality of care to the cost of care. Palliative care increases the value of care by improving responsiveness to patient and family needs, resulting in reduced emergencies, 911 calls, and hospitalizations [1]. In the current US healthcare system’s method of reimbursing higher fees for procedural interventions, palliative care and other so-called “cognitive services” remain relatively poorly compensated, requiring supplementation from both health system operating dollars and philanthropy.

A review of data from eight hospitals with established palliative care programs showed the clear benefits in cost savings due to palliative care consultations. The cost savings for a patient discharged alive who had an inpatient palliative consult averaged \$1,696 in direct costs per admission. Of patients who died during the admission, those who had been seen by a palliative care team had an adjusted net savings of \$4,908 in direct costs per admission. Based on these statistics, an average 400-bed hospital with a palliative care consultation team that sees 500 patients a year could reap a net savings (costs avoided) of 1.3 million dollars per year. Part of the cost savings comes from a natural reduction in unwanted tests, procedures, and intensive care unit use as palliative care aligns treatments with informed patient goals and preferences [20].

How Does Palliative Care Help Align the Care Delivered to Patients with the Care They Desire?

Conducting successful goals of care discussions involves open communication and information-sharing to facilitate

delivery of care the patient wants. Each team member (physician/advanced practice nurse (APN), social worker, chaplain) has a different skill set, making the most productive family meetings those in which all members of the interdisciplinary team are present. When team members have a seamless working relationship, they can each respond to the concerns the patient may have (a social worker may address home situation, coping with illness, or realistic discharge planning; a chaplain may help to explore how religion or spirituality affects the patient or caregiver's coping style or may identify the presence of existential suffering). There are several key steps for conducting a successful goals of care discussion. One method often used is "SPIKES" with six standard steps outlined below [21]:

1. *Setting*: Before meeting with a patient, discuss the case with the other providers involved in the patient's care so that the most current clinical information (i.e., diagnosis or potential treatment plans) is known. Although it may seem like common sense, the importance of creating the appropriate setting for a serious conversation cannot be underestimated. Hospitals and outpatient practices are under increasing time and space constraints, so one must ensure that there is enough time and space for the patient, his loved ones, and the entire healthcare team to sit down together to discuss the case. Part of this initial process often involves asking non-medical questions about the patient to assess what is most important to the patient and family while building rapport. The information garnered during this time can become critical to helping the physician keep the meeting on track later on by focusing on the patient's goals and personal values.
2. *Perception*: Assess the patient's view and understanding of the medical situation—this allows the physician to develop a picture of what the patient understands, the level of healthcare literacy, and any elements of denial that may be present. All of these components can alter the manner in which information is shared during the meeting.
3. *Invitation*: Obtain permission to share information before doing so. While many patients may want detailed information, others may only want the "big picture" of their illness, and some may want information-sharing deferred to their surrogate or healthcare proxy.
4. *Knowledge and information-sharing*: Warn the patient that you are about to share bad news. When information is shared, avoid medical jargon. Give information in small pieces, allowing time for the patient to process it and respond before continuing.
5. *Emotions and Empathy*: Prepare for patients and family members to become emotional as news is shared. Respond to the emotion by empathically naming the emotion and using silence to allow the patient to express whatever emotions are most prominent. Addressing the emotion is often a critical way of moving the conversation forward efficiently.
6. *Strategy and Summary*: After hearing new information, some patients become immediately focused on the next steps, while others may be too overwhelmed to even think of what will happen next. Assess if the patient is ready to discuss a treatment plan or whether he needs more time to process the information shared. If the patient is not ready to discuss next steps, set a time to regroup and do so. For a hospitalized patient this may happen the following day, while for an outpatient this may happen days to weeks later depending on the urgency of the situation.

Notably, these steps may not always occur in the exact order outlined above or even in one meeting. A physician with a longstanding relationship with a patient may already know how the patient perceives his illness, making the "assessment of perception" a smaller part of the process. An emotional response may occur at any time during a conversation and a physician should not wait to try and address all the emotions after delivering information; the emotion must be addressed in real-time [21].

The length of time for a family meeting depends on both the physician's skill in eliciting values first to frame the conversation and stay on target with medical recommendations and on "where the family is"—whether patient and family members are aligned in what they hope for and if they have already discussed the issue at hand. Focusing the family on the acute problem and addressing the underlying emotion helps move the conversation forward, and responding to emotion has been shown to lengthen a typical physician-patient encounter by less than 30 s [22]. In addition, taking a few minutes to first let the patient verbalize his hopes actually saves time later on, because it allows the healthcare team to make a recommendation for care based on the patient's individual values and preferences. A sample conversation is outlined below:

Mr. Benning is an 89-year-old man with dementia who requires assistance with ADLs and is declining oral intake. He is living at home and has a home health aide 5 h per day 5 days per week. His daughter, Lisa, lives with him and cares for him when the home health aide is not working. This is his third admission in the last 5 months for pneumonia, he has lost 15 lb and now has a BMI of 20. The primary team requests a palliative care consultation for assistance with decision-making as the daughter is requesting PEG placement.

MD: Lisa, I am just meeting you and your father. I'd like to take a step back and hear a little bit about what your father was like before he developed dementia. Can you paint me a picture of what was most meaningful and enjoyable to him before he got sick?

Lisa: He was always outdoors...he used to take my son fishing every weekend in the spring, and he loved reading the

paper and doing the daily crossword puzzle. He never gave up on that puzzle until it was completed! [tearful].

Chaplain: It sounds like there were a lot of things he loved to do, and I can see that this is really hard for you.

Lisa: Yes, it is.

MD: The doctors caring for your father asked us to talk with you about a feeding tube. Can you tell me what you've heard from them about the risks and benefits?

Lisa: Well, I don't want him to starve to death. And now that he can't eat on his own, he needs the tube so he won't starve. I don't see any risks to that. I think a tube will also help keep him out of the hospital. I don't want him to have to keep coming back here every time he isn't eating normally.

MD: I hear that you are worried about him "starving" and that you want to keep him at home if possible. Can I share some other information with you about a stomach tube for someone who has dementia, so we can decide if a tube will help you achieve your goals for him?

Lisa: Sure.

MD: Actually, there's a lot we know about what happens with people who have dementia and get pneumonia [shares medical information] [23]. One of the things I hear you saying is that you want to keep him out of the hospital if possible—I'm worried a stomach tube will not help you achieve this goal because of the risk of pneumonia associated with it [*MD first elicited Lisa's goals for her father and then used this information to show how a PEG is not aligned with this goal*].

Lisa: I hadn't really thought about it like that before. If he doesn't get the tube, how is he going to stay at home?

SW: I see that your father has Medicare insurance but not Medicaid. After we finish talking with the doctor, why don't you and I speak about some of the options for home care, and if home care isn't possible we can talk about nursing facilities.

MD: I think we covered a lot of information today. You don't need to make a decision now; why don't we give you some time and check in with you tomorrow to see what other questions you may have.

In this example, the physician was able to quickly elicit the patient's previously demonstrated values and the daughter's understanding of a PEG and then provides specific information on how a PEG would not help her achieve her goals. By eliciting the daughter's hopes and understanding first, the conversation is efficiently tailored to these specific issues.

With So Many Choices, How Do Hospitals and Health Systems Know Which Model to Pick?

Every hospital and health system will need to choose a model of care that is best suited to meet the needs of their patient

population while helping the hospital system achieve its own goals and overall mission. Some of the choice may be based on operational issues (for example, not having the available staff or hospital beds for a dedicated inpatient unit) while the culture of the institution may also play a role. A system assessment can identify strengths and areas for improvement within an institution and help guide planners to the palliative care model that best fits their existing framework. Some of the basic components of a system assessment include:

- Overall vision—does the hospital system's strategic plan include palliative care?
- Practice standards—Do standardized policies support advance care planning, expert pain and symptom management, interdisciplinary palliative care, bereavement support, psychosocial and emotional support, communication between patients and providers and amongst providers?
- Education—Do continuing education programs include palliative care content for interdisciplinary staff members, patients, and families?[24]

Funding and Building a Program

How Do You Get Buy-in From Health System Leaders?

Buy-in from leadership starts with an assessment of what the health system needs to meet its goals, whether these goals are to lower cost by improving quality of care for highest risk, highest cost patients, increase patient satisfaction, decrease unnecessary healthcare utilization, or any combination of these outcomes. First, gather hospital-level data on clinical outcomes and financial impact to understand the global needs of the system. Next, speak with colleagues within the institution to identify their needs and how they view the needs of their most complex patients. It is helpful to speak with people in various leadership roles (chief medical and nursing officers, case management, local hospice agencies; directors of oncology, geriatrics, critical care, and social work). The most successful proposal will be one that can demonstrate how a palliative medicine team serves as a solution to system problems and fills a gap in the care provided by the current system. Finally, a persuasive proposal should show how the program can be piloted to fit local realities, scaled to meet need, leverage existing staff resources in the hospital system, be viable over time, and have a low risk of failure [24].

How Do You Develop a Business Plan to Determine the Costs and Benefits of the Model?

A good business plan is one that is tailored to the hospital's needs and contains the language used by the institution with

the level of detail desired by hospital leadership. The required components are:

1. Executive summary, including a statement of program goals, milestone, and strategy
2. A financial/budget summary
3. An operational plan for implementation
4. Institutional and market analysis (a summary of the system and needs assessment)
5. Marketing plan
6. Appendix

Highlighting the value of care is important, as is including other locations of care throughout the health system (hospice, long term care, home care) that may experience higher future demand and utilization as a result of palliative care consultations for hospitalized patients [24].

Figure 6.2 shows an example of a palliative care business plan [24]; guidelines can also be found online at: <https://www.capc.org/payers/palliative-care-payer-provider-toolkit/> [25].

“What Can We Implement and How Can We Get It for the Least Cost?”

When developing a new palliative care consultation service, it is vital to accurately estimate costs based on current needs and projected future growth while being creative in accessing various funding sources. This process ensures that a program implements everything feasible in the most cost-effective manner. An operational plan must describe the resources needed for the program to succeed and estimate the revenues it will generate over time. Each program needs to assume and prepare for rapid growth in order to meet the expectations of the physicians and patients who will continue to request palliative care consultations over time. For example, cost considerations may influence a decision on whether to open an inpatient unit or outpatient practice, as both require extensive staffing and infrastructure needs in comparison with an inpatient consultation service.

Two other ways to be cost-efficient are to leverage current hospital resources by collaborating with volunteer organizations and starting philanthropic efforts to support a new or growing program. Philanthropy can be particularly important as clinical income from physician and APN billing may not be sufficient to cover staff salaries and hospital funding may be unreliable. Philanthropic support—whether from an individual donor, corporation, or foundation—provides an additional source of funding that can help ensure the palliative care program is supported and sustained over time. To garner donations, palliative care leadership staff must prepare to commit the time necessary to forge personal relationships with potential donors and granting entities, while marketing the need for, and benefits of, palliative care [24].

The basic steps that lead to major gifts are:

1. Prospect identification: Identify sources of potential gifts. Sources may include patients, family members, volunteers, or community businesses or organizations.
2. Prospect research: Conduct background research on prospective sources to understand the source and what is important to the individual person or organization.
3. Cultivation and education: Build relationships and provide education on palliative care.
4. Preparing the case: Be prepared, at any time, to be able to explain the needs of the patients and families who benefit from palliative care, the competency and training of the interdisciplinary team members, and how vital philanthropic gifts are to ensuring the long-term success and feasibility of the program.
5. Solicitation: When a potential donor offers to help, set a time to follow-up and ask for a financial gift. When making a request, have data to show how gifts in varying amounts will benefit the program and the population it serves. Do not hesitate or avoid eye contact before asking for money—direct, confident requests are the most successful ones.
6. Stewardship: After someone has supported the program, maintain regular contact. Tailor the method of contact—by phone, email, or in person—to the donor’s wishes. Engage willing donors in future activities to ensure they see the tremendous value of, and need for, ongoing philanthropy [24].

Will the Care Be Paid for Under the Medicare Fee-for-Service Program and Who Will Bear the Costs as Health Systems Transition to Value-Based Purchasing?

Palliative care consults and follow-up visits from physicians and advance practice nurses are reimbursed under Medicare Part B fee-for-service payment. The actual reimbursement rate varies depending on the payer’s fee schedule and the copayment (determined in advance by a negotiation between the hospital system and insurance companies). The Current Procedural Terminology (CPT) codes used most often by palliative medicine providers are evaluation and management (E&M) codes. CPT E&M codes establish the history, physical examination, decision-making, and counseling conducted during a physician’s visit. Palliative care physicians may bill based on visit complexity or on time spent counseling patients. The extent of the history and physical examination and the complexity level of medical decision-making determine the overall intensity of the visit. Palliative medicine visits often have a high level of complex medical decision making; components include the number and stability of medical problems, the complexity of data reviewed (including

Category	Year 1				
	Start-Up Expense	Outreach Activities	Patient Care	Systems Support	Total Year 1
Revenue:					
Professional fees					
Inpatient Hospice Revenue					
Donors & grants					
Contracted services (nursing homes, etc)					
Institutional support (hospital)					
Department support					
Total					
Expenses (should be organized to reflect direct and indirect classifications of institution):					
Program Director					
Physician time					
Staff/team time					
Supplies/software/computers					
Patient materials/education outreach					
Physician & caregiver education					
Billing & reporting service					
Space costs for beds, offices, etc					
Overhead charges (rent, utilities, insurance)					
Travel & conferences					
Total					
Contribution/deficit (before cost avoidance)					
Cost Avoidance Impact Targets:					
Cost avoidance (LOS)					
Cost avoidance (cost per day)					
Capacity management (ICU usage)					
Total Estimated Impact (Indirect \$)					

Fig. 6.2 Financial summary for a palliative care program (from Center to Advance Palliative Care with permission)

chart review, discussing the case with another provider, or discussion of test results with the performing physician, such as a radiologist) and the level of risk for the patient. Palliative care patients are high risk if they are critically ill, have multiple chronic conditions and organ failure(s), have a severe exacerbation of an underlying illness, are on parenteral-controlled substances, have a code status changed to do-not-resuscitate, or are receiving any drug therapy that requires intensive monitoring for toxicity—all of which may apply to patients hospitalized with a serious illness while requiring intravenous administration of opioids or benzodiazepines for intensive symptom management [26].

Alternatively, a lengthy palliative care consultation including counseling and exploring goals of care for a patient who is neither critically ill nor actively dying may be billed based on face-to-face *time* spent counseling the patient. Regardless of whether the visit is billed based on complexity or time spent counseling, the medical record must contain enough documentation to support the level of billing being submitted. APN billing varies by state, but APNs can bill for inpatient palliative care services only if they are paid by a non-hospital budget source. They cannot bill if they are paid from the hospital budget because hospital budgets are required to pay for all nursing care under Medicare's DRG payment to the hospital [27].

In contrast to the fee-for-service model that renders payment for the quantity of services delivered, value-based purchasing (VBP) pays based on outcomes. A change from fee-for-service to VBP is anticipated to reduce Medicare spending by approximately \$214 billion over the next 10 years. There are several key features of VBP:[28]

- *Standardized measurements:* Crucial to measuring outcomes in VBP—if payment depends on outcomes, the manner of measuring outcomes must be standardized across various systems
- *Data collection:* Allows system-wide data sharing
- *Publicly reported results:* Measurement and reporting facilitate quality improvement and foster collaboration and shared accountability
- *Reforming the payment system to reward quality, value, and ongoing improvement:* A change from rewarding the high-volume service delivery under the current fee-for-service model, VBP rewards and motivates systems for engaging in practices that improve the quality outcomes and value of care over time
- *Engaging purchasers/consumers:* Physicians and patients may define quality in different ways; both patients and physicians must be engaged in health care in the VBP system
- *Managing expenses (providers):* Cost containment is critical; the focus shifts from providing more care and tests of low quality to truly focusing on high quality care and good outcomes.

The concept behind VBP—providing high quality care and rewarding good outcomes rather than incentivizing

increased volume of healthcare utilization—is aligned with the type of care already provided by palliative medicine.

Developing a Program to Meet the Hospital's Needs

What Are the Key Components and How Does the Model Work?

An effective consultation team must meet the needs of the patients, families, and staff as well as align with the mission and strategic plan of the hospital. Consider asking these questions when determining how the model will work [24]:

- *Who are the team members?* A 100-bed hospital may start a program with a part-time physician or APN, while a 1,000-bed hospital may need to start with a full interdisciplinary team. Regardless of the scale on which it starts each system needs to be prepared for growth over time. When starting a new service, including individuals who are respected by their colleagues and known and liked throughout the institution may help cultivate trust in and respect for the program. Collaboration with colleagues from many backgrounds (internal medicine, hospitalists, oncologists, cardiologists, surgeons, social work, nursing leadership) may increase the likelihood that physicians from multiple disciplines throughout the institution will refer patients to a new program [24].
- *How will the program be marketed?* Building a palliative care program is not enough to generate referrals. Hospital staff members must know that the program exists, how to contact the program to generate a new consult/referral, and which issues the palliative care team will address. Education and outreach, *prior* to the program's launch, is a vital part of success. Attending physicians, physicians-in-training, nurses, social workers, and patients and families all must know how to reach the palliative care team so that consults can be generated immediately [24].
- *How will patients be referred for consultation?* Depending on the hospital's individual culture, referrals may be generated based on current needs of the patient (symptom management, advance care planning) or via predetermined triggers for unmet needs (patients at high risk of readmission, high symptom burden, or with a DRG diagnosis that has a high inpatient mortality risk). Decide in advance if referrals will be accepted only from the primary attending physician (thereby ensuring that physician's buy-in for palliative care to see the patient) or if consults may be requested by any member of the patient's primary team and whether patients and family members may request a consult directly [24, 29].
- *How does the team interact with referring providers?* Determining the method by which the palliative care team will interact with referring providers is key to maintaining

open communication regarding patient care. It ensures that referring physicians have a consistently positive experience regardless of which member of the palliative care team evaluates a particular patient. Depending on hospital culture and acuity of the patient, palliative care team members should (in addition to leaving clear, concise, and timely consult notes in the medical record) call the referring provider, speak with the referring provider in person, or send an email or other secure communication with a brief update, thanking him or her for the consultation and ensuring that the reason for consultation was indeed addressed [24].

- *Where will the consultation service see patients?* Many consultation programs are housed within a hospital and see patients throughout the hospital. Some programs may include a dedicated inpatient palliative care unit or see patients in an outpatient palliative care practice (which may be housed within another department, such as oncology or geriatrics, or function as a stand-alone practice). Other programs may exist primarily as an inpatient consultation service in the hospital while partnering with a local hospice agency to seamlessly transfer patients across care sites. Each model has its own strengths and weaknesses and must be developed in the context of the local realities [24].
- *Which patients will “qualify” for palliative care consultation?* Any seriously ill patient may benefit from palliative care. A palliative care consultation is a request for help and signals that the primary team caring for a seriously ill patient recognizes unmet needs and wants assistance, whether with expert symptom management, goals of care discussions, or addressing another unmet need of the patient. Even if the individual calling the consult cannot eloquently describe the issue at hand, the success of the palliative care team depends on providing timely, respectful assistance when it is requested. Simply acknowledging the complexity and challenges of care for a colleague’s patient can reduce professional distress and burnout (the so-called “blessing of the second opinion”). A palliative care team member should be available 24 h/day, 7 days/week (even if only by phone at night depending on staffing availability) to provide assistance to colleagues in need. To turn down a request for palliative care involvement is to close the door on someone who needs help. Once this door is closed, it is unlikely the requesting physician will reach out to palliative care in the future. The longevity and reputation of the palliative care consultation service depends on a willingness to help and reliable availability [24].

Who Are the Interdisciplinary Team Members?

The team structure varies depending on the available resources. In addition to a prescribing physician or APN, potential team members may include a social worker, chap-

lain, psychiatrist or psychologist, massage therapist, art and music therapist, and/or child life specialist. If funding is not available for all complementary services, volunteers may be leveraged until funding can be secured.

Social Work

Palliative care social workers fill a critical and unique role on the team. Social determinants (such as housing, transportation, literacy, history of trauma, access to food) account for nearly 50 % of all healthcare spending. While a hospitalized patient may have an assigned social worker as part of his care, this general social worker’s role may be to primarily focus on discharge planning or logistical aspects of care rather than on providing practical and psychosocial support to seriously ill patients and caregivers in need. In addition, although other palliative care team members may uncover psychosocial issues, they may not have the specialized training in clinical counseling that is provided by a palliative care social worker. The palliative care social worker has a discrete role in patient care that is not provided by either the regular hospital social worker or the rest of the palliative care team [30].

Spiritual Care

Questions of meaning and purpose are of highest priority for people living with serious illness, and skilled chaplains are trained to help patients and families articulate and explore these issues. Spiritual support provided as part of a palliative care team can have benefits even for patients who already have a personal relationship with a community religious leader. Spiritual care provided by a member of the medical team has been shown to be associated with better quality of life before death and higher hospice use for patients who are terminally ill [31], in contrast to the outcomes of patients reporting high spiritual support from a member of their religious community [32].

Complementary Therapists

Many patients may be interested in complementary therapies as an adjunct to pharmacologic management of symptoms, to manage non-physical aspects of suffering, or due to a desire to avoid medications for personal, religious or cultural beliefs. Patients who suffer from “total pain” (existential, spiritual, family, physical, practical, and emotional distress) seek “inner stillness or peace” which may be fostered by complementary therapy. Massage, art, and music therapy may be used to treat both physical symptoms and meet emotional and existential needs. Even small studies have shown statistically significant improvement in symptom burden as reported by patients, suggesting that the results may be clinically significant since the outcome is subjective in nature [33].

A massage therapist also serves a role in educating family members about the benefits of massage and safe ways to touch very ill patients. Oftentimes, caregivers are at a loss for what they can offer a loved one in times of need; a recent study showed that education via a massage DVD or reading

materials resulted in a decrease in symptoms. Caregivers also showed increased confidence, comfort, and self-efficacy in using massage as a form of care [34].

Art therapy and child-life specialists also help patients and families cope with serious illnesses. Art therapy provides an opportunity for both patients and their family members to explore existential suffering and have a creative outlet for feelings that may be difficult to articulate in words [35]. Child-life specialists fill a crucial role in providing support and exploring fears of children who either have a seriously ill family member or are seriously ill themselves [36, 37].

How Do Interdisciplinary Team Members Work Together?

For an interdisciplinary palliative care consult team to truly succeed each individual must have a clear and well delineated role on the team and regular structured inter-team communication should occur. Patients often share important details of their lives with social workers and complementary therapists, and these details may be vital to facilitating goals of care discussions and understanding the factors that influence the patient's decisions about care. Ideally all team members can view and document in the same medical record system. Each department should also ensure interdisciplinary team rounds are held and decide how often team members should meet together to discuss their active patients.

Ensuring that each team member understands his or her value in providing patient care is vital to the long-term success of the team. The literature on interdisciplinary team dynamics has revealed several common themes, including the importance of clear role boundaries and how to maintain them amongst team members. One example of this is in the challenge of physicians, nurses, social workers, and chaplains all attempting to provide psychosocial and spiritual support to a patient. O'Connor et al. raised the idea of a "contested role" with each team member struggling to find their niche in providing psychosocial support [38]. Outlining clear role boundaries while seamlessly working together as a team requires a delicate balance and an intentional, proactive plan for fostering interdisciplinary teamwork.

Leveraging the Electronic Medical Record

Electronic Medical Records (EMRs) are increasingly used in hospitals and outpatient practices. EMRs may improve the quality of care [39] and can be a powerful tool for collecting data to improve patient outcomes and enact change throughout a healthcare system. Electronic note templates can improve workflow efficacy and ensure consistency and reliability between palliative care providers of the same team. They can

track symptom burden, record discussions regarding advance care planning, and monitor changes in patient outcomes including intensity of care, hospice use, and mortality. Figure 6.3 shows an example of an electronic note template:

Can Adult Patients/Family Caregivers Be Involved in the Planning and Advising of the Model of Care?

Both patients and caregivers may be involved in planning a new palliative care consultation service. Once the target patient population for palliative care consultations is identified, it may be helpful to form a focus group or advisory board of similar patients in the community. The group may be surveyed to determine their baseline beliefs about and expectations of palliative care. The input from older adults and family caregivers provides critical insight into the planning process and what will be most effective for the community's patient population [24].

What Training Is Required for Providers?

Each team member should have training and/or work experience in palliative care or hospice. Physicians should be board certified/board eligible in hospice and palliative medicine. If they have not already been grandfathered into board eligibility they will have to complete an ACGME-accredited fellowship program in palliative medicine. Other care providers including nurses, APNs, chaplains, and social workers should also seek training and specialty certification in palliative care. Basic competencies include expert communication skills, strong symptom management capabilities, skill in handling complicated family dynamics, mediating distress between (and among) primary teams and patients/families, providing support (emotional, spiritual, and psychosocial), discussing and honoring patient wishes to assist with discharge planning and treatment decisions, and an ability to think broadly and see the big picture in complicated situations [24].

How Can the Fidelity of the Implementation be Maintained?

To scale up to meet the needs of seriously ill patients and their families, a palliative care consult service must conduct frequent needs re-assessments and track outcomes to ensure that the service is fulfilling its mission statement. These actions will secure the role of palliative care in the broader healthcare system. Questions to ask include:[24]

- *Have there been changes in patient population?* Evaluate whether referral volume is decreasing, increasing or

Mount Sinai Palliative Medicine Initial Consult Note

Referred by:

Reason for referral:

Referring physician will be alerted to this visit and have access to this note.

History

Chief Complaint:

History obtained from (patient, family, chart, discussion with referring provider):

HPI:

Review of Symptoms:

ESAS:

Source: ESAS SOURCE: (patient, team, family):

Depression: (0-none, 1-mild, 2-moderate, 3-severe):

Anorexia: (0-none, 1-mild, 2-moderate, 3-severe):

Inactivity: (0-none, 1-mild, 2-moderate, 3-severe):

Dyspnea: (0-none, 1-mild, 2-moderate, 3-severe):

Anxiety: (0-none, 1-mild, 2-moderate, 3-severe):

Nausea: (0-none, 1-mild, 2-moderate, 3-severe):

Drowsiness: (0-none, 1-mild, 2-moderate, 3-severe):

Constipation: (0-none, 1-mild, 2-moderate, 3-severe):

Agitation: (0-none, 1-mild, 2-moderate, 3-severe):

Physical Discomfort: (0-none, 1-mild, 2-moderate, 3-severe):

Dementia: Yes/No:

Delirium: Yes/No:

Coma: Yes/No:

Review of Systems:

Constitutional:

Ears, Nose, Mouth, Throat:

Cardiovascular:

Respiratory:

GI:

GU:

Musculoskeletal:

Skin:

Neurological:

Endocrine:

Hematological/Lymphatic:

All other ROS have been reviewed and are negative.

Past Medical History:

Family History:

Social History:

Medications:

Allergies:

Complementary Therapies:

Fig. 6.3 Electronic note template

Spiritual History

Religious/spiritual orientation:

Involvement in Spiritual Community:

Need for further Chaplaincy support:

Are you religious or spiritual? Yes/No:

Where do you draw your strength from in difficult times like these?

Advance Care Planning**Awareness and Information Sharing**

Patient's awareness/understanding of illness:

Information-sharing preferences:

Family's awareness of illness:

Information shared:**Advanced directives**

Health Care Proxy:

Location of Proxy document:

Primary decision maker other than HCP:

Durable Power of Attorney:

Attitude towards place of death:

Funeral arrangements:

Limitations on Life Sustaining Treatments:**Data**

I have personally reviewed and interpreted the following studies:

Radiology:

Labs:

PHYSICAL EXAM

Vitals:

Constitutional:

Ears, Nose, Mouth, Throat:

Eyes:

Neck:

Cardiovascular:

Pulmonary/Chest:

Breast:

Gastrointestinal:

Genitourinary:

Musculoskeletal:

Neurological:

Skin:

Psychiatric:

Fig. 6.3 (continued)

ASSESSMENT & PLAN

@name@ is a @age@ @sex@ with a history of *** who is seen by palliative care today for:

Physical Symptoms:**Advance Care Planning:**

Extensive discussion, including both disease-directed treatment plans and plans for care if disease advances without being controlled by current treatment

- Will follow up with referring physician
- Encourage completion to end-of-life care tasks, including legal issues, legacy and leave-taking
- DPOA and code status discussed***

Counseling:**TIME SPENT**

Visit consisted primarily of counseling and education dealing with the complex and emotionally intense issues of symptom management and palliative care in the setting of serious and potentially life-threatening illness.

Total MD face-to-face time: ***

Total MD counseling/education time: ***

Start time: ***

End time: ***

More than 50% time spent on counseling on education as noted above.

Fig. 6.3 (continued)

remaining stable and if there are particular specialties that refer frequently or do not refer at all [24]. If there are physicians who do not refer patients for palliative care, it may be necessary to conduct another needs assessment to identify barriers to collaboration and find ways to provide primary and specialist-level palliative care to patients in need.

- *Have there been changes in the hospital system?* A major change in the health system, such as a change in leadership, the addition of a new intensive care unit, nursing home, or hospice agency, will also change the demographics of the population. In addition, a new practice within the hospital (including pain management, volunteer services, or major staffing changes) may also begin to change the culture and resources available to patients. Ensure that there is ongoing education about palliative care and how it interacts with other disciplines in the hospital [24].
- *How is palliative care accountable for its outcomes within its own department and throughout the greater hospital system?* Accountability for outcomes requires constant reevaluation of how well the palliative care team is serving the needs of patients, families and colleagues. Monitoring data on clinical and financial impact of the service is important to hospital leadership and is prerequisite to securing ongoing support for the program. Outcome data may also be used to prompt changes in the program, whether from clinical staffing or fiscal support [24].

What Is the Role of the Geriatrician in Developing and Leading the Model?

A palliative care team that serves patients who are frail, elderly, and have multiple chronic co-morbidities will need to work closely with geriatricians in the health system. Collaboration is particularly important as patients transfer between care sites. Some palliative care programs may include physicians who are board certified in both geriatrics and palliative medicine. Geriatricians often lead programs designed to provide inclusive care to the elderly or work at local nursing homes, which would allow palliative care to be provided seamlessly across care sites [24].

How Can Health Systems Integrate the Geriatrics and Palliative Medicine Practice Models to Provide a Portfolio of Strategies to Address the Needs of Patients?

Interdisciplinary geriatric practice models are ideally suited to integrate palliative care principles and practices because they focus on quality of care, quality of life, patient values, and psychosocial needs of patients and families. Geriatric practice models in different care settings (i.e., an acute care hospital, subacute rehabilitation facility, long-term nursing facility, home or inpatient hospice) may

leverage the expertise of both geriatricians and palliative medicine physicians to provide seamless transitions of care across care sites. This allows patients and caregivers to feel comfortable knowing that pertinent information related to chronic co-morbid conditions, symptom management, or advance care planning is communicated across care sites [40]. Hospital-based palliative care programs can facilitate communication with external agencies (nursing homes or office-based practices) that may assume care for a patient after discharge. However, even finely tuned discharge plans can fall apart for unpredictable reasons, which may lead to unnecessary readmission or unintentional lack of compliance with discharge regimens due to patient, family, and/or provider confusion. Some healthcare systems have piloted post-discharge interventions to facilitate the transition of care in the weeks or months after hospital discharge. These programs may be led by nurses who met the patient during the hospitalization, providing patients with an extra layer of support from a healthcare provider who is inherently familiar with their recent hospitalization, medical co-morbidities, and any critical medication changes made during the admission [41].

Monitoring Outcomes and Planning for Future Directions

Is the Model Scalable?

Most palliative care consult programs are started on a small or pilot scale, affording the opportunity to refine operational flow and document positive impacts of the program before expanding to a larger scale. A program may start with only one physician and as consult volume grows it becomes more feasible to support both additional physicians and full-time non-physician team members. All aspects of a palliative care program are scalable and can be tailored to meet the specific needs of each community's patient population [42].

How Do We Know the Model Is Improving Care?

Monitoring outcomes is necessary to sustain a program over time and ensure that the program is meeting the needs of the patients it serves, the physicians requesting consultations, and the hospital or health system. Different data need to be collected depending on the concerns and priorities of the audience to whom it is being presented. Palliative care providers and patients may be most interested in clinical data such as symptom control, while healthcare leadership may want financial data on cost savings, 30-day readmissions, hospital mortality rates, or decreases in unnecessary health-

care utilization. Both patients and healthcare system leadership may be interested in qualitative data such as patient satisfaction surveys [43].

What Are the Future Directions of Palliative Care Consultation Services?

Once a palliative care consultation program demonstrates its benefits to the health system by providing high quality care to frail hospitalized patients, there are opportunities to move palliative care consultations upstream and see patients before they are sick enough to be admitted to the hospital. There is growing evidence that outpatient palliative care programs improve the symptom control, satisfaction, and quality of life for patients while reducing healthcare utilization by preventing need for crisis hospitalizations [44] and in certain populations may prolong survival [19].

Outpatient palliative medicine may be particularly important for patients at high risk of frequent hospitalizations. Small outpatient palliative care programs have begun to document the role of outpatient palliative care in addressing symptom burden and exploring advance care planning including resuscitation status and hospice [45]. Benefits of outpatient palliative care are also noted by patients and families, who have reported improved quality of life for patients and lower caregiver burden [46]. In the context of healthcare reform, value-based purchasing and new delivery and payment models focused on improving value by increasing quality and in so doing, reducing costs, the opportunity for bringing palliative medicine to scale is unprecedented. Both providers and payers accepting financial risk (Accountable Care Organizations, patient centered medical homes, bundled payments, Medicare Advantage, managed Medicaid, and commercial insurers) have aligned interests in improving quality for the sickest most complex patients driving more than half of all health spending [1]. Examples of payer-provider relationships driving improved access to palliative care may be found (see <http://www.capc.org/payertoolkit/>). The key issue is making sure that costs are reduced as a consequence of better quality as opposed to stinting on needed care for vulnerable populations. Close monitoring of valid and standardized quality measures is critical to achieving this goal [1].

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