Chapter 12

Starting a Palliative Care Program at a Cancer Center

Laura Shoemaker and Susan McInnes

Background

While previously a resource only found in large academic hospitals or specialized community-based healthcare agencies, palliative care (PC) has become an essential part of modern health care in the United States (US) and around the world. A status report in the *Journal of Palliative Medicine* in 2016 reported that 67% of US hospitals with 50 or more total facility beds and 90% of hospitals with 300 beds or more reported the presence of a palliative care program [1]. The presence of inpatient PC programs varied regionally, with the highest percentage in the Northeast and the lowest in the South [1]. Outpatient access to PC has also grown, both in the clinic setting and in the community [2, 3]. As clinical access has grown, so has the body of evidence about the positive impact of PC. A wide range of data demonstrates the important role PC plays in care quality, patient and family satisfaction, clinician experience, and healthcare resource utilization [4–7]. Alignment with this “quadruple aim” positions PC to be a key player in future healthcare transformation and the movement toward value-based care [8].

The Center to Advance Palliative Care (CAPC) defines “palliative care” as specialized medical care for people living with a serious illness. The term was coined in 1974 by Dr. Balfour Mount, a surgical oncologist at The Royal Victoria Hospital of McGill University in Montreal, Canada. Mount likely created the new term to circumvent existing negative connotations many had with hospice. Dame Cicely Saunders, considered the founder of both the modern hospice movement and the field of PC, developed and propagated the clinical practice around her concept of “Total Pain.” Total Pain refers to the comprehensive, multifaceted experience of suffering associated with serious illness, which Saunders further divided into four

L. Shoemaker (✉) · S. McInnes

Department of Palliative & Supportive Care, Taussig Cancer Institute, Cleveland Clinic, Cleveland, OH, USA

e-mail: shoemal@ccf.org; mcinnes@ccf.org

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domains: physical, emotional, social, and spiritual [9]. A commitment to improve quality of life by attending to all of these dimensions of suffering remains central to the practice of PC today. Consistent with this comprehensive approach, interdisciplinary team-based care by physicians, nurses (including advance practice nurses), social workers, chaplains, and complementary therapists is fundamental. PC is appropriate at any age and at any stage in a serious illness and is provided along with curative treatment. Thus, the provision of PC is based on the needs of the patient, not on the patient's prognosis.

Palliative care has played a central role in the delivery of high-quality cancer care for some time, likely stemming from the fact that many of the early PC practitioners were oncologists. While specialty PC practice and training has grown to encompass serious illnesses of all types, PC remains heavily focused on supportive cancer care. The National Comprehensive Cancer Network (NCCN) guidelines direct: "institutions should develop processes for integrating palliative care into cancer care, both as part of usual oncology care and for patients with specialty palliative care needs." [10] A wide body of evidence has demonstrated PC's impact on cancer care quality throughout the trajectory of cancer care in a wide variety of malignancies and care settings [11–14]. In addition to addressing the aim to palliate symptoms, systematic early integration of PC has shown to prolong survival [15]. Consistent with PC's aim to facilitate individualized, patient-centered plans of care, research has demonstrated that those who receive PC consultations have care plans aligned with their goals and care that costs less overall [6, 16, 17]. As a result, PC metrics have been incorporated into cancer-focused, value-based care approaches, like the Center for Medicare and Medicaid's Advanced Alternative Payment Model, the Oncology Care Model (<https://innovation.cms.gov/innovation-models/oncology-care>).

Although specialty PC has become an integral part of high-quality cancer care, PC services are not ubiquitous, and access to PC is still limited in many areas and care settings. The reasons for limited access vary by locale and include specialty PC workforce constraints, lack of financial support for PC staffing resources, and variable engagement by clinicians and healthcare leadership. Despite these challenges, many healthcare professionals and institutions remain committed to establishing new specialty PC service lines, a complex but worthwhile endeavor. The following sections of this chapter will focus on the steps and anticipated challenges in initiating and integrating specialty PC within a cancer care entity. The stages have been broken into Planning (early and late), Launch and Integration, and Monitoring and Sustainability.

Planning

Early Planning

The first step in starting a new PC service line is engaging PC champions and institutional leadership. Quite often, new PC programs or service lines are created in response to requests, or even, demands from existing clinicians (physicians, nurses,

care managers). Engaging these frontline allies simultaneously as one petitions institutional leadership for financial support can be effective in generating support for the initiation of a new PC service line. Fortunately, “making the [financial] case” for the integration of PC in cancer care is no longer a difficult task. As described above, a wide variety of evidence exists to support PC’s role in supporting outcomes around care quality, patient/provider satisfaction, and healthcare utilization. These published outcomes can be complemented by analysis of local data, including:

- Clinical volumes by cancer diagnosis.
- Acute admissions and/or ED visits.
- Hospital and/or ICU length of stay (LOS).
- Hospice utilization (referral rates and LOS on hospice).
- Prevalence of moderate to severe symptoms.
- Rate of advance directive completion.

Subjective reports from patients, families, and providers about care gaps can also be compelling data when advocating for resource allocation to a new PC service line. As organizational leadership is engaged, it is essential to understand and then align PC service line goals with those of the larger institution.

Once conceptual alignment between organizational and PC leadership is achieved, early planning should also include a focused “needs assessment” to identify what the patients, families, clinicians, and institution want and need most from a specialty PC team. There are a wide variety of reasons to start PC programs, and no inaugural program can address all possible needs from the start. Building comprehensive PC programs across care settings takes years to decades. When starting a new PC program, it is important to identify focused, key aims that address high-priority patient care or provider practice needs. The following list represents only a few of the many possible “needs” for initiating a new PC service:

- Management of complex, time-consuming cancer-related pain, especially in the setting of increasing regulatory requirements around opioid prescribing.
- Underutilization of hospice care, including low rates referrals and/or short length of stay on hospice care.
- High-level psychosocial distress in patients in families around coping with the challenges of cancer care.
- Facilitation of conversations around care goals and preferences in patients with long hospital length of stay or those identified as “high utilizers” of healthcare resources.

Designing the PC service line according to the most pressing needs will increase the likelihood of successful achievement of shared goals. Once there is alignment around focused goals, shared outcome measures can be created. Clearly outlining the anticipated “deliverables” is an important next step in considering the design of a new PC service line. Typical deliverables include clinical symptom management (pain and non-pain symptoms), facilitation of discussions about patient care goals and preferences, transitions from disease-directed therapy to comfort-focused care, the provision of comfort focused and end-of-life care, psychosocial support,

spiritual support, and complementary therapies like music, art, Reiki, meditation. An effective PC service does not need to include all components listed here in order to be successful, especially at the start of the service. On the contrary, PC services that are built piece by piece, starting where needs and engagement are highest, are most likely to be successful. Teams or institutions who try to tackle every PC need, everywhere (outpatient, inpatient, and in the community) all at once may be quickly overrun by unmanageable referral volumes, unmet expectations, and strained clinical teams. Depending on available resources and primary aims, goals can further be tailored to a specific malignancy or stage (e.g., allogeneic stem cell transplantation or metastatic lung cancer). The importance of the early planning stage, including engagement of institutional leadership and alignment around shared goals, cannot be underestimated. The Center to Advance Palliative Care has a robust collection of materials available online for members for PC program planning, design, and execution (www.CAPC.org).

Late Planning

Once primary objectives and outcomes have been established, the next step is designing the PC service line, with consideration to care setting and staffing scheme. While staffing models may ultimately be limited by resource allocation, it is important to design a service line that will address the primary objectives. For example, if the primary objective is complex pain and symptom management in patients with advanced solid tumors, starting an outpatient PC service with an experienced physician embedded within the outpatient oncology clinic would be an advisable first step. If the primary need is symptom management during an admission for an allogeneic stem cell transplant, then embedding a PC clinician (either physician or advance practice provider (APP, includes nurse practitioner or physician assistant)) on the transplant unit may be more appropriate. If the resources and request for PC are coming from hospital leadership, the needs may be centered on ICU throughput, hospital length of stay, or inpatient readmissions. In this case, a consultative interdisciplinary inpatient PC team to help facilitate conversations around care goals and preferences may be the right place to start. Alternatively, if the resources and engagement are from an institutional or community-based hospice organization with an aim to increase timely referrals and offer earlier service to high-risk patients in the community, it may make sense to start with an interdisciplinary community-based PC team to capture referrals upon hospital discharge or via insurance claims-based data. Table 12.1 outlines the primary PC delivery models and the associated target outcomes, team composition, and support needs. These PC delivery models can include:

- Inpatient consultation.
- Inpatient primary admitting service, with or without a designated physical space or unit.

Table 12.1 Palliative care delivery models

Service type	Target outcomes	Team clinicians	Support needs
Inpatient consultation	Hospital-based metrics like hospital or ICU LOS or readmissions Facilitation of discussion about care goals and preferences Transitions from disease-directed plan of care to comfort-focused plan of care Symptom management	Physician and/or APP Social work Spiritual care	Team office space Administrative practice management
Inpatient admitting	Consultative needs as above Desire to “hand-off” PC patients from medical, surgical and ICU services Physical space to attend to the care of actively dying patients	Physician APP (per service volumes) Social work Spiritual care Dedicated RN workforce Care manager Hospice liaison	Inpatient space/unit Team office space Administrative practice management Alignment with institutional or collaborating hospice agency
Outpatient clinic	Symptom management Support for conversations regarding care goals and preferences Disease or malignancy specific integration	Physician or APP RN care coordinator Social work (if not already available within cancer center)	Clinic space Scheduling staff Staff for patient check-in and rooming Administrative practice management
Community-based	Facilitation of discussion about care goals and preferences Transitions from disease-directed plan of care to comfort-focused plan of care Symptom management Acute care utilization metrics ^a	Physician or APP Social work Spiritual care RN care coordinator	Team office space Scheduling staff Administrative practice management

^aThe ability to impact acute care utilization metrics depends on the design of a community-based PC program

- Outpatient clinic, either embedded within a target specialty or stand-alone.
- Community-based, offering visits to patients in home and facilities, in person or virtually.

The decision about staffing the service with a physician or an APP depends on a number of factors including clinical acuity, healthcare system culture, and available workforce. A team that includes *both* a physician and an APP supports both the interdisciplinary practice of PC and facilitates management of higher clinical volumes.

Decisions should be made early about what kind of symptoms and which patient populations the PC team will manage. For example, will an inpatient PC team's services be available to all patients, only patients with an identifiable serious illness, patients in the ICU or RNF, or focused on particular diagnoses like cancer? This is especially important when considering pain management, which can quickly consume staffing resources. Will the team manage cancer pain, pain related to serious illness, chronic pain, postsurgical pain, complex or refractory pain syndromes?

Once a commitment has been made about resource allocation, care delivery setting, and staffing scheme, it is time to plan the implementation of the PC service by establishing a timeline. Due to specialty PC workforce constraints and training needs, recruitment is often the limiting step in service initiation. In the United States, it may take 6–24 months to recruit a fellowship-trained PC physician. APP staffing is often available within a much shorter time frame; however, many APP recruits do not have specialty PC training or experience. Therefore, a 6–12 month period for training must be allowed. For institutions who do not have existing PC specialists, it is advisable to start with an experienced or fellowship-trained PC physician. This provider will come equipped to deliver specialty PC from the start of their employment and may serve as a resource to train APP hires as the service grows. CAPC has extensive online training resources to support the development of the entire interdisciplinary team. PC certification pathways (available for physicians, nurse practitioners, social workers, and chaplains) offer additional opportunities for professional development of the PC team.

If not already in existence (and engaged with planning the service line), an administrative team should be assembled after the clinical team is recruited. The administrative team can support service integration by identifying team space, coordinating credentialing, reviewing pertinent hospital bylaws and standard operating procedures, and setting up meetings with potential referral sources and PC service champions. Furthermore, developing an integration “Steering Committee” composed of the institutions’ PC champions, healthcare system leadership, and other key stakeholders will help facilitate a successful launch. Typical steering committee members include leadership, chief nursing officers, finance, marketing and communications, pharmacy, spiritual care, and complementary care services.

Prior to service launch, it is important to clarify operational standards around service hours, evening on call and weekend coverage, the time frame within which to see new referrals, follow-up frequency and duration, and communication processes for referral sources and other bedside caregivers. Routine team workflows, such as clinical huddles and interdisciplinary team meetings, can then be designed to support these expectations and facilitate effective communication within the PC team.

Launch and Integration

Despite the wider access to and presence of PC, many healthcare professionals and lay public still lack an understanding of what PC encompasses. PC is often confused with hospice or end-of-life care, such that physicians who refer to PC sometimes

have trouble articulating to patients why they are making the referral and what outcomes to expect from the referral. Simply put, palliative care is specialized medical care for people living with a serious illness. The ultimate goal is to improve quality of life for both the patient and the family, which is often achieved through palliation of symptoms and enhanced communication with patients and families about their care preferences, goals, and plans. While end-of-life care is a critical part of PC, it is only a part of what PC envelops. Addressing this knowledge deficit about PC is essential when launching a new specialty PC service. In addition to clearly communicating what PC is, it is helpful to share simple, concise language (e.g., an “elevator speech”) for referring clinicians, healthcare leadership, and other PC champions to use when interacting with patients and other healthcare professionals.

At or just prior to service launch, one should organize meetings or schedule presentations for stakeholders, like institutional leadership, shared governance teams, medical and nursing staff, medical educators, and care management. These engagements serve several functions by creating a forum to: (1) address the existing gaps in understanding about what PC is, (2) set expectations about what this new service line will deliver, and (3) clarify referral processes. Attendees need to leave these presentations understanding: (1) who may place referrals (is referral limited to physicians or can other clinicians refer?), (2) why to refer a patient (what are the clinical eligibility criteria?), (3) when to refer a patient (either during a hospital stay or along their trajectory of serious illness), and (4) how to communicate a new patient referral to the patient and PC team (electronic, telephone, etc.).

A successful service line launch is ultimately dependent on the development of meaningful relationships between the PC team and other clinicians within the care setting. Intentional steps to enhance visibility, like presence in clinical care areas, participation with hospital or clinic committees, and supporting educational or training efforts go a long way in helping establish the PC team. Prioritizing thoughtful, effective communication with referring providers and other bedside clinicians also helps develop trust and service line success.

Monitoring and Sustainability

Monitoring the activities of the PC service entails collecting data from a number of sources. An “Advisory Committee,” composed of stakeholders and high utilizers of the service can be a key source of information. While this committee may include some of the participants from the Steering Committee, it can envelop a larger scope to include key referral sources, such as large medical or specialty practices, ICU clinicians, and patient/family councils. The goal is to get real-time input from end users for early identification of best practices, service gaps, or emerging challenges. The PC team itself will be another great source of data. Scheduling regular team meetings with the aim of collecting experiential feedback supplements standard data points like clinical volumes, service outcomes, and patient/family experience

scores. PC team meetings also create a forum for team members to share successes and best practices and collaborate around challenges in care delivery.

Successful integration of the PC service is often marked by increasing referral volumes over time. Developing thresholds for hiring additional staff supports ongoing incremental growth. Understanding the reasons for referral, the average number of visits per referral, and the referral sources themselves will direct what kind of additional staff is needed. Often, PC team bandwidth can be expanded by adding interdisciplinary clinicians like APPs, social workers, chaplains, and care coordinators. If the service is started in one care setting (inpatient or outpatient), the next step for expansion may be a complementary PC service in the alternate setting. Building a comprehensive PC program with clinical services available in a variety of care settings ultimately creates a continuum of support to follow a patient across care transitions and throughout the trajectory of a serious illness. When considering the most advanced stages of a serious illness, it is important to either provide hospice care (or similar end-of-life care) or partner closely with a high-quality hospice organization. This will assure that patients and families receive optional care throughout the duration of their illness.

Quality

The availability of PC services is essential to quality cancer care. Organizations such as the Multinational Agency for Supportive Care in Cancer (MASCC), American Society for Clinical Oncology (ASCO), the NCCN, and the American College of Surgeons Commission on Cancer (CoC) have issued guidelines and standards for the provision of PC services to cancer patients from early in the course of illness, throughout the disease course and at end of life [10, 16, 18, 19]. ASCO had also issued guidelines for PC in the global setting, stratified by resource availability [20]. This guideline outlines quality PC for patients with cancer in resource-constrained settings under various models of care. Consistent among all guidelines and standards are recommendations and/or requirements including the following:

- Interdisciplinary care is essential to identify and address physical, psychological, spiritual, social, and cultural aspects of care.
- PC services are ideally available on-site at a cancer center but may also be provided by referral to care partners in the community.
- PC begins at diagnosis and may be initially provided by the oncology team (primary palliative care) with availability of specialist palliative care team consultation.
- Quality PC should be provided in accordance with established evidence-based national and international guidelines.

The most robust recently updated guidelines were developed as a national consensus project among 13 member organizations and are summarized in Table 12.2 [21].

Table 12.2 Guidelines for quality palliative care

Domain	Guideline
Structure and process of care	Interdisciplinary team (IDT)
	Comprehensive palliative care assessment
	Palliative care plan
	Continuity of palliative care
	Care settings
	IDT education
	Coordination of care and care transitions
	Emotional support to the IDT
	Continuous quality improvement
	Stability, sustainability, and growth
Physical aspects of care	Global
	Screening and assessment
	Treatment
	Ongoing care
Psychological and psychiatric aspects of care	Global
	Screening and assessment
	Treatment
	Ongoing care
Social aspects of care	Global
	Screening and assessment
	Treatment
	Ongoing care
Spiritual, religious, and existential aspects of care	Global
	Screening and assessment
	Treatment
	Ongoing care
Cultural aspects of care	Global
	Communication and language
	Screening and assessment
	Treatment
Care of the patient nearing end of life	Interdisciplinary team
	Screening and assessment
	Treatment before death
	Treatment during the dying process and immediately after death
	Bereavement
Ethical and legal aspects of care	Global
	Legal considerations
	Screening and assessment
	Treatment and ongoing decision-making

Table adapted from: Ferrell et al. [21]

Palliative care programs have many resources available to help determine how to assess and improve quality of their care. Palliative provider education is integral to quality care, and palliative certification ensures a strong knowledge base for the interdisciplinary team, including physicians, advance practice providers, nurses, social workers, and chaplains. There are abundant online opportunities for ongoing education through the American Academy for Hospice and Palliative Medicine (www.AAHPM.org), the Center to Advance Palliative Care (www.capc.org), MASCC (<https://www.mascc.org/palliative-care>), and the World Health Organization (<https://www.who.int/cancer/palliative/en/>).

As a palliative program is developed, it is critical to include evaluation of the structure, process and outcomes of the program from the outset. This ensures that the best care is provided to those who need it most. Importantly, ongoing evaluation identifies best practices and opportunities for ongoing quality improvement initiatives. Recently, several national quality registries in the United States have been merged to become the Palliative Care Quality Collaborative and plan to establish the Palliative Care Quality Initiative (PCQC), a registry anticipated to open in 2021 to capture both patient and program quality data.

Metrics specific to palliative care have been proposed by AAHPM in the Measuring What Matters project [22]. The top ten metrics are: comprehensive assessment, screening for physical symptoms, pain treatment, dyspnea screening and management, discussion of emotional or psychological needs, discussion of spiritual/religious concerns, documentation of surrogate, treatment preferences, care consistency with documented care preferences, and a global measure such as quality of life [23]. CAPC has published updated suggested quality metrics which is shown in Table 12.3 [24]. Key illustrations of patient quality are access to palliative care, pain assessment and management, safe opioid prescribing practices, and documentation of advance directives (ADs). Program quality measures may include patient satisfaction scores, hospital readmission rate, ICU utilization near end of life, and days on hospice care. Palliative programs can select areas they wish to prioritize based on their care delivery models.

Ongoing continuous improvement is the mainstay of quality care. In fact, a focus on improving quality is intrinsic to the patient-centered discipline of palliative care [25]. Tracking quality metrics allows for rapid recognition of areas a program can improve care. Quality improvement (QI) projects can then be tailored to improving care in a specific area such as AD completion rates or accurate, safe opioid prescribing. QI projects are best accomplished by a multidisciplinary team of engaged stakeholders who wish to facilitate sustainable change. Basic QI methodology includes identification of a problem to be addressed, measuring and defining goals, root cause analysis, rapid cycle plan-do-study-act interventions and plans for sustainability and spread. The Institute for Healthcare Improvement Open School initiative offers free courses in QI methodology to support programs wishing to learn a model for improvement (www.ihl.org).

Table 12.3 Quality measures recommended by the Center to Advance Palliative Care [24]

Measure category	Measure type	Measure/measure area
Access	Structure	Availability of interdisciplinary palliative care team, with 24/7 response of some kind in selected facility(ies)
Satisfaction	Patient experience	Consumer assessment of health providers and systems (CAHPS)
Satisfaction	Outcome	Likelihood to recommend the services or program (i.e., net promoter score)
Advance care planning	Process	Rates of patients who have an advance care plan or surrogate decision maker documented in the medical record or documentation in the medical record that an advance care plan was discussed but the patient did not wish or was not able to name a surrogate decision maker or provide an advance care plan
Clinical quality	Process	Proportion of patients with pain screening or assessment (and/or with pain plan of care)
Clinical quality	Process	Proportion of patients with functional assessment (ability to perform activities of daily living and instrumental activities of daily living)
Clinical quality	Process	Proportion of patients with their caregiver burden formally assessed
Utilization	Outcome	Rates of avoidable hospital and/or emergency department utilization; risk-adjusted as appropriate
Utilization	Outcome	Days at home: Number of days a patient remains outside of an institutional care setting during a standardized time period
Utilization	Process	Appropriate hospice utilization (e.g., hospice referral rate or hospice length of stay (LOS) for those referred or proportion of hospice LOS less than 7 days or more than 180 days for those referred)

Additional details and resources are available at <https://www.capc.org/defining-and-measuring-quality/>

Research

Establishing a research framework is foundational to developing and sustaining palliative care services. The concept of research begins with asking questions and discovering new knowledge to help better care for our patients. Creating a database of patients for QI purposes at the outset allows for evaluation of quality and can also help identify areas for future research in symptom management, novel care delivery models, and palliative care education. Such a database should incorporate assessments, measurements, and outcomes. Any new research protocol would need to be approved by an institutional review board (IRB), which may be on-site or affiliated.

Palliative care research has expanded significantly over the past decade. Competitive funding sources support well-designed palliative clinical trials that are

published in high-impact journals and result in practice-changing outcomes. A prime example of this is the randomized trial of early palliative care for outpatients with metastatic non-small cell lung cancer [15]. Patients who received early specialist palliative care had better quality of life, less depressive symptoms, less aggressive end-of-life care, and longer median survival than those with usual care. Now early palliative care for such patients is recognized as the standard of care and a best practice. More recent examples are the randomized trials of integration of palliative care into the care of patients undergoing hematopoietic stem cell transplantation and acute myeloid leukemia induction, affirming better quality of life and less anxiety for those who received palliative care [26–28].

In order for research to have impact, findings must be shared. There are multiple venues to share QI and clinical trial results. AAHPM, CAPC, National Hospice and Palliative Care Organization (NHPCO), ASCO, and IHI have annual assemblies with opportunities to present posters and oral abstracts. In addition, McGill University in Montreal, Canada, offers a long-running International Congress on Palliative Care with written and oral presentations. In addition, there are many palliative journals dedicated to palliative research, and cancer-specific journals such as *Journal of Clinical Oncology* (JCO), *JCO Oncology Practice*, *JAMA Oncology*, and others which also publish impactful palliative oncology research.

Conclusion

Palliative care, focused on the optimization of quality of life, has become an essential part of cancer care. While the prevalence of PC has grown, access is still limited in a variety of care settings, institutions, and geographic locations. Developing and launching a specialty PC service enhances cancer care and helps address unmet needs related to cancer symptoms, communication about care goals and preferences, and transitions in care. Planning for the integration of a new palliative care service is a complex process that requires attention to thorough planning, as well as attentive execution and monitoring to assure delivery of sustainable, interdisciplinary, and high-quality care. Cancer centers need to strategically invest in this area as they progress towards provision of comprehensive cancer care services to patients.

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