

CLINICAL SERVICES

PALLIATIVE CARE

Contributors: Breffni Hannon, Camilla Zimmermann,
Amanda Chudak, Evelyne Jhung, Joann Trypuc, Mary Gospodarowicz

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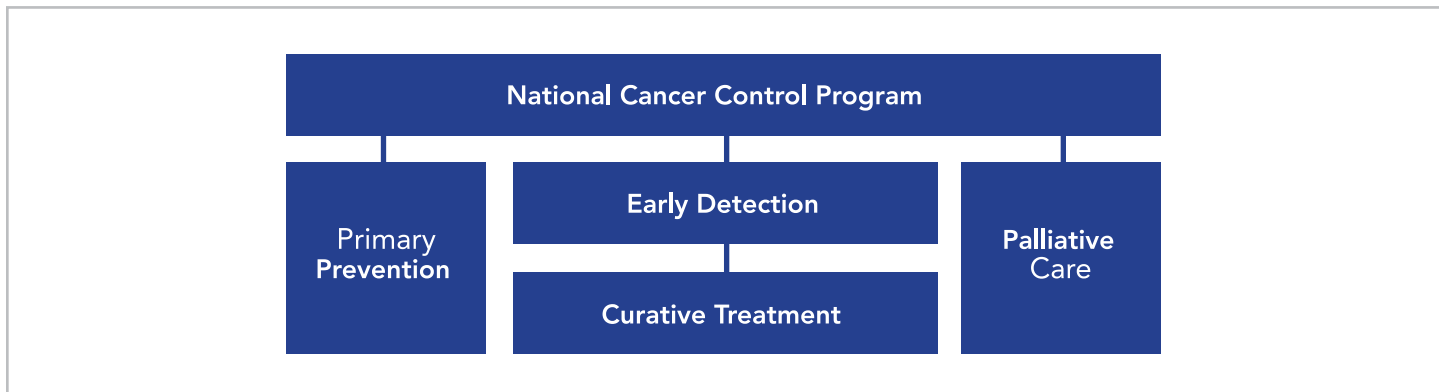
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A. INTRODUCTION

Palliative care is “an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.”¹

As illustrated in Figure 1, the World Health Organization’s Public Health Strategy includes palliative care as one of the four key components, or pillars, of comprehensive cancer care, along with primary prevention, early detection and curative treatment. It has developed guidelines for governments on how to implement national palliative care programs and national cancer control programs.

Figure 1: The Four Key Components of Comprehensive Cancer Care²



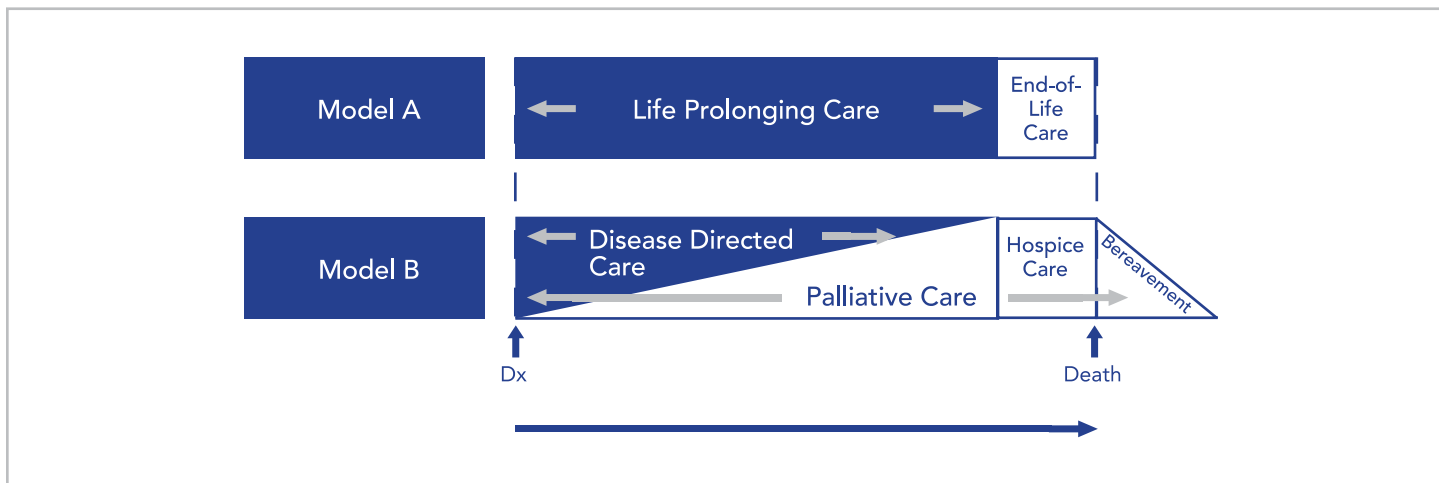
This chapter addresses how to integrate palliative care into cancer services at both the individual patient and hospital levels.

B. CLINICAL SERVICES

1. MODELS

Traditionally, palliative care services have been aligned with care at the later stages of a patient’s cancer journey, as illustrated in Figure 2 - Model A. In these later stages, all active cancer treatments have usually been exhausted and palliative care is essentially end-of-life care, typically provided by hospital inpatient and community-based hospice services. It is, however, now recognized that cancer patients have a myriad of physical, psychological, social, functional and spiritual challenges at all stages of their illness, and that palliative care should begin much earlier and in tandem with active cancer treatments, as illustrated in Figure 2 - Model B.^{3,4}

Figure 2: Palliative Care and the Disease Course⁵



Several randomized controlled trials have demonstrated the benefits of early palliative care. Temel et al. (2010) assigned patients with newly-diagnosed metastatic non-small cell lung cancer to either standard oncology care or to standard oncology care plus early palliative care. They found that the early palliative care group experienced a better quality of life and mood, less aggressive care at the end-of-life and prolonged survival.⁶ Bakitas et al. (2009) and Zimmermann et al. (2014) also found that patients who receive early palliative care experience an improved quality of life and satisfaction with care, compared with those who receive standard oncology care alone.^{7,8}

The American Society of Clinical Oncology's clinical practice guideline recommends that "inpatients and outpatients with advanced cancer should receive dedicated palliative care services, early in the disease course, concurrent with active treatment."⁹

2. LEVELS

There are three basic levels of palliative care services for patients with advanced cancer and their families:

- **Primary:** community-based care provided by general practitioners and family physicians.
- **Secondary:** more complex care incorporating symptom management directly related to cancer or its treatments. This care is provided mainly in hospitals or cancer centres by oncologists, in conjunction with primary and tertiary palliative care providers.
- **Tertiary:** specialized care to address the most complex needs of patients, provided by specialist palliative care providers working as part of an interdisciplinary team. This specialist-level care should be available at all stages of illness and in all settings, to provide consultant-level advice to secondary and primary care providers.¹⁰

It is important that every clinician working within an oncology setting be proficient in the core palliative care skills outlined in Table 1.

Table 1: Core Palliative Care Skills¹¹

1.	Basic pain/symptom assessment and management
2.	Basic psychological/social/spiritual assessment
3.	An understanding of the illness, potential treatment options and likely trajectory
4.	Identification of patient-centred goals of care, including matching treatment options to patient goals of care and discussing advanced care planning with the patient and their family
5.	Ensuring a safe, sustainable transition of care from one setting to another following discharge

Tertiary palliative care is provided to patients who have more complex care needs – such as physical, social, psychological or spiritual needs – that do not respond to simple, established care protocols. Patients with complex palliative care needs represent a variable, but minor proportion of individuals living with a life-limiting illness, but represent a significant number of patients with advanced cancer. These patients usually require highly-individualized care plans that should be developed, implemented and evaluated by skilled specialist practitioners, in partnership with primary care providers and oncology teams.^{10,12,13} Although mostly limited to tertiary medical centres, some services have the ability to provide tertiary palliative care to patients at home or in community-based palliative care units.

Bereavement support for caregivers and families is a core component of palliative care and should be available across all three levels of palliative care.

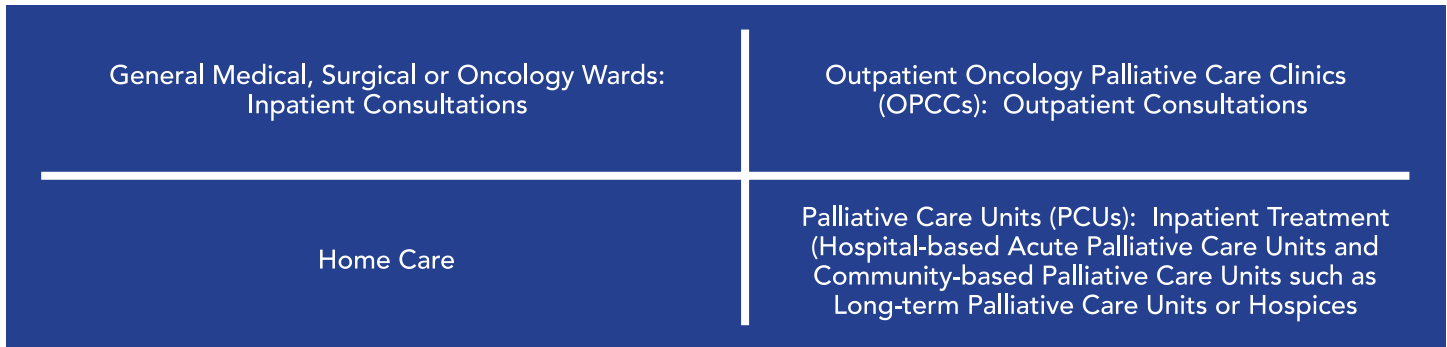
3. SETTINGS

Palliative care is generally delivered in four settings, as illustrated in Figure 3, each of which corresponds to different levels of palliative care services.

Setting 1: Inpatient General Medical, Surgical or Oncology Units

Despite the fact that most cancer therapy is now delivered in outpatient settings, patient rates of attendance at emergency departments and admission to hospital during cancer treatment are high.¹⁴ Inpatient palliative consultation teams (IPCTs) are ideally placed to provide high-quality clinical care to cancer inpatients on general medical, surgical or oncology units in acute care hospitals, as well as ongoing education and support to staff working on these units.

Figure 3: Settings for Palliative Care



IPCTs have a positive effect on patient symptom outcomes, identifying previously unmanaged symptoms, insufficient treatment of pain, opioid neurotoxicity and delirium with greater frequency than the referring team in many cases.^{15,16} From an institutional perspective, IPCTs reduce the aggressiveness of care at the end-of-life, including admission to intensive care units. This reduces the overall hospital length of stay and lowers overall hospital stay costs.¹⁷⁻¹⁹

Setting 2: Outpatient Oncology Palliative Care Clinics

Outpatient oncology palliative care clinics (OPCCs) are a recent addition to the model of palliative care delivery in medical centres. OPCCs are generally the first referral site for patients with cancer, providing concurrent early palliative care alongside outpatient cancer care.²⁰ Some hospital centres have mobile outpatient teams – which tend to be extensions of the ICPT – that provide consultations on-site in oncology outpatient clinics; others have stand-alone palliative care clinics. Early referral through an OPCC has been shown to result in fewer emergency hospital visits, fewer and shorter hospital admissions, and less inappropriately aggressive care at the end-of-life.²¹ OPCCs not only benefit patients and caregivers, but provide an important, complementary role alongside traditional oncology care.²²

Setting 3: Inpatient Palliative Care Units and Facilities

Inpatient palliative care units (PCUs) and facilities are specialized inpatient treatment units for patients with complex symptoms, or for those who require admission for end-of-life care. PCUs include:

- Acute Palliative Care Units (APCUs), situated in acute hospitals
- Community-based PCUs, such as long-term PCUs and residential hospices

An APCU in a cancer centre differs in several important ways from a traditional hospice. In a hospice, all active cancer treatment has been discontinued and the philosophy of care is directed solely towards symptom management and comfort care. In an APCU, although the administration of intravenous chemotherapy is usually not facilitated and patients must accept a do not resuscitate (DNR) order, intravenous hydration, antibiotics and blood products as well as oral chemotherapy are typically facilitated, while continuing to maintain a philosophy of patient-centred, holistic, multidisciplinary care. APCUs also allow for more complex pain and symptom management strategies.

APCUs are not well-established in North American medical centres, nor is there significant data about their frequency within medical centres internationally. They have evolved from a growing recognition that many patients with advanced cancer have serious physical or psychosocial symptoms requiring comprehensive interdisciplinary care, and that an increasing number of patients are continuing to pursue aggressive cancer treatment even in the face of advanced cancer and proximity to death, ultimately dying in acute care settings.²³ Dedicated palliative care beds within acute settings allow specialist palliative care teams to deliver comprehensive, but clinically appropriate, care while simultaneously facilitating the close relationship between patients and their oncology teams.^{24,25}

In addition to the general services provided by APCUs and hospices, as outlined above, some also provide specialist palliative day care. Palliative day care provides: rehabilitation, occupational therapy, physiotherapy, the management and monitoring of symptoms and psychosocial support; continuity between outpatient and inpatient care for patients discharged from the inpatient setting; access to members of the allied healthcare team, who may not be available to see them at home; and an element of social interaction and carer respite.²⁶

Setting 4: Patient's Home

With more than 50 per cent of people expressing a preference to receive care and die at home, palliative home care services are vitally important.²⁷ Palliative home care services are provided by physicians, nurses and other allied health professionals who deliver palliative care directly in the patient's home. A 2013 Cochrane review demonstrated that receipt of palliative home care significantly increased the likelihood of dying at home and was associated with a reduced symptom burden. In addition, home care services have been shown to reduce emergency department visits and hospitalizations, and overall healthcare costs at the end-of-life.^{28,29}

Other Settings

Palliative care in the emergency department (ED) is an area of growing interest. As more cancer care is delivered in the outpatient setting and patients pursue aggressive cancer treatments for longer periods of time, patients with symptoms directly or indirectly related to their cancer or treatment are increasingly presenting to EDs. At present, there is no strong evidence demonstrating the effect of ED-based palliative care on the rate of hospital admissions, or patient quality of life or symptom management; one study showed that early involvement of palliative care services could shorten the overall hospital length of stay.^{30,31} More research in this area is needed.

C. RESOURCES

The resources required to implement and expand a palliative care program depend on the settings within which palliative care is being delivered. Most specialist palliative care teams begin with an IPCT (i.e., the least resource-intensive palliative care service) and expand over time to include an OPCC and/or APCU (i.e., the most resource-intensive and complex service). Ideally, all three elements should be incorporated into a cancer centre, to provide the most inclusive, all-encompassing model of care. This model is based on developmental work originating from Edmonton, Alberta, Canada in the mid-1990s, which aimed to measure the access of patients with terminal cancer to palliative care services and decrease the number of cancer-related deaths in acute care facilities.³² It has been successfully replicated in a number of tertiary cancer centres and is considered the gold standard for a successful integration between palliative care and oncology.³³ The resources required to implement each element of the model are discussed in greater detail below.

4. FACILITIES AND EQUIPMENT

Setting 1: Inpatient General Medical, Surgical or Oncology Units

IPCTs are the most common palliative care service found in acute care facilities, and are the simplest to initiate from an infrastructure and manpower perspective. IPCTs require the least amount of physical infrastructure, as they primarily consist of a mobile team of staff who review patients on a consultative basis on general medical, surgical or oncology inpatient units. IPCTs do require office space with computer, telephone and fax access for

team members; in the initial stages of service development, these facilities and equipment may be shared with other services. See the *Cancerpedia: Inpatient Care* chapter for more information about the overall infrastructure required for cancer inpatient care.

Setting 2: Outpatient Oncology Palliative Care Clinics

Setting up an outpatient OPCC requires a fairly limited amount of resources in the initial stages. Most OPCCs start as a half- or single-day clinic, and expand based on service demand and growth over time. In medical centres, referrals to OPCCs tend to constitute the largest area of growth year over year.³⁴⁻³⁶ It is important to consider this anticipated growth from the outset, and to plan for the infrastructure required to meet these needs.

Although most OPCCs start by sharing space with other services, such as oncology or chronic pain clinics, they should ideally have designated clinical space of their own. This space should take into consideration the particular needs of patients and their families attending palliative care clinics, including:

- A reception area where patients can wait prior to their designated appointment time, including space for patient resource material
- Rooms that are sufficiently large to accommodate the patient and their family, as well as several members of the multidisciplinary team
- Rooms that are accessible for patients in wheelchairs or stretchers
- Low or adjustable examination couches, which provide greater ease for transferring patients who are fatigued or symptomatic
- Additional space for members of the multidisciplinary team to meet separately with patients and families
- Facilities for rapid access to medications, medical supplies, and oxygen and suction for the immediate management of physical symptoms, wound care, etc.
- Space for written resources specific to palliative care, including patient information leaflets, referral paperwork for other services, advance care planning information and symptom assessment screening materials
- Additional workspace with computer and telephone access for staff to review patient notes, dictate consultation notes and liaise with other team members, as appropriate

See the *Cancerpedia: Outpatient/Ambulatory Care* chapter for more information about the overall infrastructure required for cancer outpatient care.

Setting 3: Inpatient Palliative Care Units and Facilities

A hospital-based APCU is the most expensive palliative care service to implement, from both an infrastructure and clinical perspective. Most APCUs consist of single occupancy rooms, with sufficient space for family members to stay overnight. Rooms should accommodate high-dependency equipment, including wheelchairs and hoists. Studies have suggested that the most cost-effective APCUs have at least 10 beds.³⁷ APCUs should also have a reception area, a nursing station, a nursing staff room, a conference room for multidisciplinary team meetings, and a family room. Facilities for the storage of medications and confidential patient records as well as computer access (i.e., for centres using electronic patient records) should form part of the unit design.

Designated APCU beds allow the service to be measured against typical hospital benchmarks, including minimum bed occupancy levels and budget management.³⁸ For this reason, APCUs rarely form part of the initial model of palliative care program development, but rather tend to come later, once the service is well-established and adequately staffed.

Residential hospices should utilize design, equipment and staffing features similar to APCUs, but in a home-like atmosphere. The purpose-built design and flexibility of residential hospices with regard to holistic food services and family support make them a hybrid of home and hospital care that is appealing to many patients and their families.³⁹ Ten beds are usually the minimum capacity required for hospices to be cost-efficient. Since hospices are generally free-standing, planning is required for access to support services and resources typically provided by a hospital. These include pharmacy support, laundry and kitchen facilities. Some hospices are connected to long-term care institutions and academic centres, allowing for the sharing of facilities between institutions, and teaching and research in the hospice environment. Volunteers often occupy uniquely important roles in residential hospices.⁴⁰

Setting 4: Patient's Home

Specialist palliative care teams who visit patients in their homes require office support, to receive referrals and for administrative work. Teams generally travel to the patient's home by car and require mobile phone or pager services, both to allow accessibility while travelling and for personal safety. They also require access to a community agency that provides equipment for use in the home (e.g. wheelchairs, walkers, dressings, ambulatory infusion pumps) and to pharmacy support, which may be based either in the community or at an affiliated hospital. Any medications or prescription pads carried by the team must be securely stored (especially in the case of opioids, which should be kept in a lockbox). Equipment for the safe disposal of medications, needles and syringes is also essential. Teams should keep a detailed record of all medications that are carried, administered and disposed. Many home hospice and palliative care teams dispense medication kits for managing symptomatic emergencies in the home.⁴¹ Family members may be directed to use medications from these kits in urgent situations, upon the advice of palliative care nurses or physicians.

5. HUMAN RESOURCES

Human resource requirements for palliative care vary depending on the settings within which care is being delivered.

Setting 1: Inpatient General Medical, Surgical or Oncology Units

IPCTs should consist of at least one designated palliative care Physician and a Nurse, available Monday to Friday for consultations, with 24-7 telephone support available to patients as needed. In this setting, palliative care staff generally provide consultative services only and do not assume primary responsibility for patients. Ideally, IPCTs should include, or have access to, a wide range of multidisciplinary personnel; teams that only include a Physician and a Nurse should have access to other allied health professionals and medical specialties from the consulting service or the larger institution, as needed and available (e.g., social workers, pharmacists, physiotherapists, occupational therapists, psychologists, nutritionists, psychiatry). Since the IPCT draws upon existing resources on general units, it has limited administrative overhead, primarily limited to managing billing, collecting and managing consultation requests, and managing outcomes data.

In some centres, the IPCT assumes primary care of selected patients. In this case, the IPCT must be available to provide comprehensive, 24-hour care to patients, and additional staff are required to manage both the day-to-day care of patients as well as out-of-hours coverage.^{38,42} Research suggests that one consultant or staff palliative care Physician per 40 cancer centre beds is sufficient for services that have reached a steady number of new referrals. For specialist palliative care nurses, a figure of one per 30 cancer centre beds has been suggested.⁴³

Setting 2: Outpatient Oncology Palliative Care Clinics

OPCCs require both healthcare professional and administrative staff support to function effectively and efficiently. As referrals to the OPCC come from a combination of scheduled appointments and emergency requests for same-day reviews, sufficient medical staff must be assigned to provide predictable coverage as well as respond to urgent requests.

Depending on the services offered, human resource requirements will vary. For example, some OPCCs offer a drop-in option for patients already known to the clinic, for the assessment and management of acute or uncontrolled symptoms without a scheduled appointment.³³ Others see predominantly pre-booked patients, with urgent referrals handled on a case-by-case basis following a discussion between the referring Physician and the palliative care Physician.²⁰

In addition to clinical staff, dedicated administrative support is required. Administrative support should include administrative assistants to handle referral requests, make initial scheduling appointments and answer telephone calls, as well as a Patient Flow Co-ordinator to cover the reception area, check-in patients and make return appointment bookings.

Setting 3: Inpatient Palliative Care Units and Facilities

Human resource requirements may vary depending on the type of palliative care unit.

Staffing levels in a hospital-based APCU should reflect the multidisciplinary ethos of palliative care. Palliative care physicians should be available to do daily rounds and to admit patients to the unit, assess symptom management issues regularly, and meet with families. Data from the United Kingdom suggests that 2.³¹ physicians are required for APCUs with 10 beds.⁴³ Highly-trained nurses are essential; most APCUs apply a three patients per nurse ratio; however, staffing ratios vary across jurisdictions and depend on local resources and practice.

Designated allied healthcare professionals, such as social workers, physiotherapists, occupational therapists, dietitians and pharmacists, should be readily available. At least one Psychologist or Psychiatrist should be available, either dedicated to the unit or as part of the larger psychosocial oncology team. Each specialist palliative care unit should have access to at least two suitably trained spiritual care advisors, who are available to meet the spiritual needs of patients and families 24 hours a day, seven days a week.¹³ Bereavement counsellors should be available as dedicated staff, as part of the larger cancer program, or through community referral.

Residential hospices must be staffed by healthcare personnel with palliative care training and experience. At minimum, a hospice requires an Intake Nurse, who screens and triages referrals, a Nurse Manager, a Medical Director, a Social Worker and dedicated nursing staff, as well as access to pharmacy support. Patient dependency levels in hospices – where patients are predominantly admitted for end-of-life care, are more likely to be bedbound and require greater assistance with the activities of daily living – are higher than in APCUs, where some patients admitted for respite or symptom control may be more independent; as such, higher nursing levels may be required in hospice settings compared with APCUs.⁴⁴

A robust volunteer program is an important component of all residential hospices, as is access to spiritual care and bereavement support. Complementary therapies, such as massage and music therapy, may also be provided and tend to be more prevalent in hospices than in medically-oriented APCUs.⁴⁵ These complementary therapies are often provided through private support or by volunteers. Many hospices are linked to community care programs and may use human resources that are also allocated to home care support.

Setting 4: Patient's Home

Home-visiting palliative care physicians work closely with local community-based nurses and other allied health professionals, such as social workers and physiotherapists, as well as with primary care providers who provide primary palliative care.⁴⁶ Nurses are often the backbone of a home palliative care program, with physicians providing expert advice and oversight. It is important for home palliative care programs to have an adequately trained staff of advanced practice nurses, who can provide primary support for patients and their families on a day-to-day basis as well as after hours. One guideline suggests that one Physician per 160,000 patients supported by one community Nurse per 25,000 patients represents a sufficient staffing ratio.¹³ The staff required for a home palliative care program will depend to a large extent on whether primary palliative care is provided by the patient's Primary Care Provider, with the palliative care team providing expert advice, or whether the palliative care team is the sole provider of palliative care in the home.

D. MANAGEMENT

6. LEADERSHIP

Palliative care should be represented at the executive level of the cancer centre, either by the Department Head of Palliative Care or by the Department Head of a larger unit, of which palliative care forms a part (e.g. Palliative Care and Rehabilitation Medicine, Psychosocial Oncology and Palliative Care, or Supportive Care). In the latter case, a specific Division Head should be assigned for the overall palliative care program or division, and report directly to the Department Head. The Head of Palliative Care represents the program at the hospital level and beyond, providing a vision and direction for the program, ensuring that quality benchmarks are being achieved, performing annual staff reviews, and providing general clinical and academic oversight.

7. STANDARDS, GUIDELINES, POLICIES, PROCEDURES AND PROCESSES

Most countries with well-developed palliative care programs have national accreditation standards for palliative care, which must be adhered to and reported on every three years or at another regular interval. In Canada, these standards encompass the broad areas of investment in quality services, building a competent team, providing safe and effective services, maintaining accessible and efficient information systems, and monitoring and ensuring quality.⁴⁷ Cancer centre accreditation normally forms part of the broader, routine hospital accreditation procedure.

Evidence-based guidelines for the delivery of palliative care have been developed in several countries and are excellent resources for those developing a clinical palliative care program. These include the American National Comprehensive Cancer Network palliative care guidelines and evidence-based guidelines for the management of specific symptoms developed by Cancer Care Ontario.^{48,49}

It is also important to develop institutional policies and procedures related to the delivery of palliative care in the cancer centre. These may include referral guidelines for the IPCT and the OPCC, admission policies for the APCU, written procedures for transferring patients from one setting to another, and more specific policies and procedures regarding the use of pain pumps, administration of methadone or ketamine, and palliative sedation. Cancer centres should also have policies regarding advance care planning, discussion of advance directives and DNR orders. Members of the palliative care team should be involved in their development.

8. MANAGEMENT OF PATIENT FLOW

Successful initiation of palliative care services requires careful management and planning. Several steps have been identified to optimize growth in the early stages of a new palliative care service, as listed in Figure 4.

Figure 4: Ten Steps for Expanding Palliative Care Referrals⁵⁰

1.	Assess interest in and support for the service from the outset
2.	Recruit key personnel
3.	Include team members from a variety of disciplines and departments
4.	Treat the referring Physician as your client
5.	Consider how the proposed service will integrate into the broader institutional culture
6.	Engage with prospective referring teams through education
7.	Clearly delineate between teams with overlapping roles (e.g., acute pain services)
8.	Make the referral process as easy as possible
9.	Anticipate and plan for projected growth
10.	Conduct regular service reviews

From the outset, it is important to consider how the service is expected to grow and to plan adequately for this anticipated growth. This will help to ensure that all appropriate referrals can be accepted and seen by the service in a timely fashion, and that additional staff recruitment is budgeted for.

Recognizing the needs of referring physicians and providing an accessible, responsive and collaborative model of care increases the likelihood of maximizing referrals. Promoting palliative care through educational opportunities (e.g., presenting at grand rounds or developing palliative care rotations for other specialty trainees, nurses and allied health professionals in training) is beneficial in terms of raising the profile of the service and for teaching basic, primary-level palliative care skills.⁵¹ These strategies have been shown to positively influence oncologists' referral practices.⁵²

In all settings, patient symptoms should be assessed systematically using validated symptom assessment tools, some of which include: i) the Edmonton Symptom Assessment System (ESAS)⁵³; ii) the Memorial Symptom Assessment Scale (MSAS)⁵⁴; and iii) the Palliative Care Outcome Scale⁵⁵. Patients should then be treated according to symptom management guidelines (e.g., Cancer Care Ontario 2016; National Cancer Institute 2016).^{49,56} In addition to assessing and managing symptoms, institution-based palliative care services should – as part of their initial assessment – identify any need for home-based supports (e.g., nursing, occupational therapy, physiotherapy, personal support, or other supportive care) and make appropriate referrals as needed.

The full range of palliative care services are designed to provide a seamless transition of care from the outpatient setting through to acute inpatient admissions, managing end-of-life issues or transitioning to hospice- or home-based care.

Setting 1: Inpatient General Medical, Surgical or Oncology Units

It is important to establish a consistent referral system so that it is clear to referring providers how referrals should be made. Referral forms should be brief (i.e., a single page, if possible) and contain patient demographics, the reason for referral and the urgency of the request. Instructions about whom to contact, expected response times, out-of-hours coverage and contact details, as well as educational materials for staff and patients should be readily available. The palliative care team should also provide regular feedback on patient management to referring teams as a way to educate, foster greater trust in the palliative care service and demonstrate a dedication to ongoing collaboration. Clearly differentiating between the role of the palliative care team and other services, such as acute pain services, is important to minimizing inappropriate referrals and enabling collaborative working relationships.

Inpatients referrals should be seen on a same-day basis by the IPCT, with regular follow-up throughout the patient's hospital stay.³⁴ The patient's Most Responsible Provider use his or her discretion to implement any suggestions, ultimately deciding on the preferred course of treatment. The potential for poor uptake of suggestions from the palliative care team represents a potential disadvantage of the IPCT model; some studies show as few as 20 per cent of suggestions may be used by the Most Responsible Provider.^{57,58} Close liaison and clear communication between the IPCT and the referring team is critical to optimize patient care.⁵⁹

As outlined earlier, some palliative care physicians assume primary care of patients on acute oncology units. An advantage of this model is the additional autonomy afforded to the palliative care team, which can, under these circumstances, influence the patient's management directly rather than through recommendations that may or may not be carried out.³⁸

In addition to symptom management, the IPCT will often be consulted to assist with disposition planning. For those patients who are discharged home, follow-up in the OPCC or referral to community-based palliative care services may be necessary and should form part of the assessment. Patients may also be transferred from the oncology ward to the APCU, if necessary, to manage complex physical or psychological symptoms, or for end-of-life care.

Setting 2: Outpatient Oncology Palliative Care Clinics

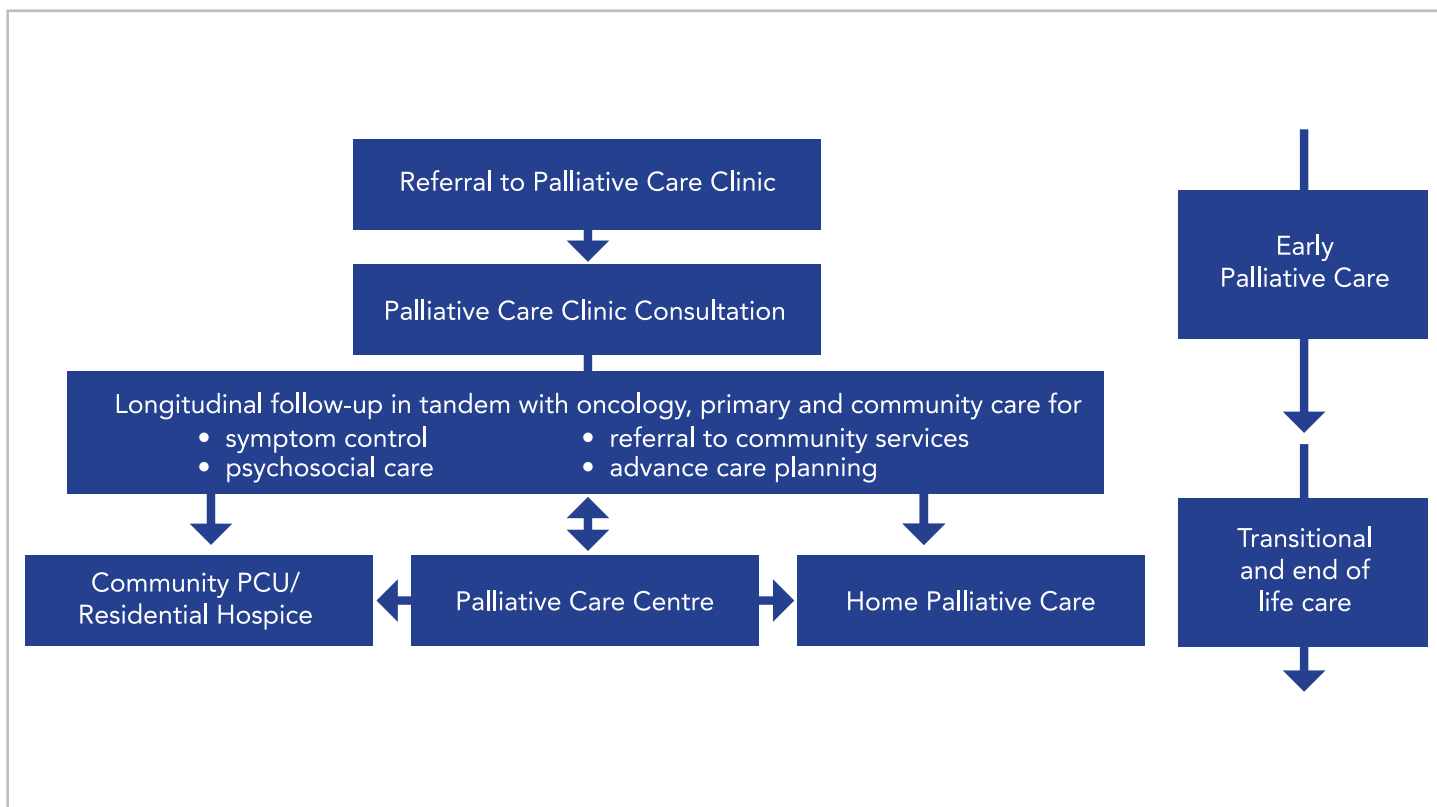
The Most Responsible Provider should initiate referral to the OPCC using a standardized referral form; alternatively, the IPCT or APCU team can arrange for follow-up in the OPCC following discharge from the hospital, if the patient has been followed by the palliative care team during the admission. Referrals to the OPCC should be triaged using a system in which patients with uncontrolled symptoms are prioritized. Ideally, all patients should be seen by the OPCC within two weeks of referral. If patients are referred earlier in an anticipatory fashion, as is recommended, and are asymptomatic at referral, then wait times up to a month are acceptable.⁹

A comprehensive, multidisciplinary approach to care should be adopted based on a biopsychosocial model.

Patients should be followed regularly in the OPCC for symptom management, psychosocial support and advance care planning while they continue to attend other oncology clinics.^{20,22} In addition, patients should receive information on emergency, out-of-hours and on-call services for the telephone management of urgent issues.

Transferring a patient from the OPCC to community-based palliative care or hospice team should be considered when the patient's performance status deteriorates or when the patient requests home-based care. In areas or districts that do not have access to home-based care, telephone contact should continue until the patient's death or admission to a hospice or PCU. If the patient is admitted to another service within the hospital, the IPCT should follow the patient and provide advice, as needed. Alternatively, patients may be admitted via the OPCC to the APCU for the management of acute symptom issues.²⁰

Figure 5: Pathways of Palliative Care After Referral to the OPCC²⁰



Setting 3: Inpatient Palliative Care Units and Facilities

Generally, patients are admitted to an APCU for the management of urgent problems, including physical or psychological distress, caregiver fatigue or end-of-life care for patients with an expected prognosis of less than two weeks. Patients may be transferred from the OPCC or from acute oncology wards within the hospital, or admitted directly from the community. Prior to admission, the following issues should be considered and discussed with the patient and their caregivers, as appropriate:

- Reason for admission (e.g., symptom management, respite, end-of-life care)
- Code status and documentation of DNR status, if appropriate
- Contingency planning for the placement of patients in community-based hospices if home discharge is not feasible and prognosis exceeds two weeks
- The services that may be provided, if deemed clinically appropriate, such as intravenous fluids or antibiotics, blood products, oral chemotherapy and palliative radiation
- The services that are not provided on the APCU, such as intravenous chemotherapy or total parenteral nutrition

All patients admitted to the APCU, and their symptoms and medications, should be reviewed daily by their palliative care Physician and members of the interdisciplinary team, as appropriate. They should also be seen by a Social Worker to identify any practical or financial concerns on the part of the patient or family. In addition, if home discharge is not expected or feasible, early social work input to discuss options for ongoing care in community-based, longer-term palliative care units or hospices is invaluable. Input from the patient's Oncologist should be sought, when necessary, to provide a cohesive, team-based approach to care and to help clarify care goals, especially if they have changed. Discussions around discontinuation of cancer treatment, if appropriate, should include – and ideally be led by – the primary Oncologist, with input from other interdisciplinary team members.

For patients who are discharged home, a complete care plan, including follow-up in the OPCC or the provision of home palliative care services, should be agreed upon prior to discharge. Patients should undergo a multidisciplinary assessment during their APCU stay, which should culminate in a family meeting to summarize the goals achieved during the admission, address patient or caregiver concerns, outline changes in medications or goals of care, and provide detailed information about post-discharge follow-up.

For some palliative patients admitted to an acute hospital unit or APCU, home discharge is not feasible. Similarly, for some patients at home, a home death cannot be achieved due to uncontrolled physical symptoms, lack of support or patient preference. In these instances, admission to a residential hospice should be considered. In contrast to APCUs, patients are usually admitted to a hospice at the end-of-life, when all active cancer treatment options have been exhausted and the patient's prognosis is estimated to be short (e.g., less than three months). Longer-term facilities or those that provide respite care may exist in some areas for patients whose prognosis is longer than three months, but who are having difficulty managing at home. Generally, the administration of chemotherapy, intravenous fluids, parenteral antibiotics or blood products is not supported in residential hospices, where the emphasis is on comfort care only. These practices may vary internationally.

Setting 4: Patient's Home

When patients become too unwell to attend the OPCC – estimated as a patient-reported Eastern Cooperative Oncology Group (ECOG) Performance Status score of more than or equal to three – or upon patient request, primary care of the patient should be transferred to local, community-based palliative care under the supervision of either the Primary Care Provider or a dedicated group of physicians specialized in palliative care for the local community.^{20,60} All relevant patient information related to diagnosis, treatments to date, future treatment plans or options, preferences regarding end-of-life care and place of death, and current medications (including information about opioids previously trialled unsuccessfully) should be transferred promptly to the community-based palliative care team once a referral is initiated.

Most community-based palliative care physicians work closely with the home care team, which includes local community care nurses, advanced practice nurses and other allied health professionals, as needed. Physicians should perform an initial comprehensive assessment upon each patient referral, and review patients on an as-needed basis with regular (i.e., usually weekly) nursing input. As with hospital-based teams, timely referral to community-based palliative care teams can provide the opportunity for healthcare providers to build rapport with the patient and their family.

Managing physical symptoms and providing information and emotional support to patients and their families are the primary roles of the community-based palliative care team; uncontrolled symptoms and lack of information have been shown to be the most common reasons for unplanned hospital admissions in the last days of life.⁶¹ A proactive approach to symptom management should be adopted by the home-based team, where possible. This includes considering medications that can be administered by alternative routes, rather than orally (for patients who may become unable to swallow pills) and that address the more common, predictable symptoms at the end-of-life, such as pain, nausea and vomiting, agitation or delirium, respiratory secretions and seizures. In some instances, pre-emptively placing a “medication kit” in the patient’s home that contains the medications most likely to be required by an individual patient can improve home death rates.^{41,62}

E. QUALITY

It is important for healthcare providers to demonstrate that they deliver high-quality services and to be accountable to patients and their caregivers for their performance. This includes making robust clinical and managerial decisions, managing resources efficiently, and measuring performance against local and national benchmarks.

Palliative care services within a general hospital or cancer centre should align their quality performance efforts with those of the larger institution, with cancer care as a broad area and with palliative care as a speciality. See the *Cancerpedia: Quality* chapter for more information.

Hospital / Cancer Centre

Increasingly, hospitals and cancer centres use a scorecard-type management tool, consisting of measures that describe critical aspects of quality across a number of key areas of the organization. Many of these key performance areas are applicable to quality in palliative care services and can be assessed in comparison with other services in the organization, including:

- How staff view the organization, measured through employee opinion surveys, staff turnover rates, sick leave, and overtime hours
- How patients view the organization, measured through, for example, patient satisfaction surveys, emergency department wait times, hospital-acquired infection rates and medication error incidents
- Research and innovation, measured by the number of new or ongoing clinical trials, and papers published or cited
- Hospital costs and fiscal management, measured through wait times, average monthly patient transfers, energy use and cost per weighted case

Cancer Care

As the interface between cancer care and early palliative care continues to grow, it is important that palliative care be included in cancer care quality performance assessments. The 2012 American Society of Clinical Oncology Collaborative Cancer Measure Summit was convened to develop a comprehensive set of oncology quality measures that were not specific to individual cancer types or clinical settings. Ten topics were identified, several of which overlapped with palliative care, including:⁶³

- Interdisciplinary and multidisciplinary co-ordinated care
- Comprehensive symptom assessment
- Use of palliative care and hospice services

Palliative Care

A recent systematic review of quality measures for palliative care in patients with cancer found that more than 200 individual performance measures are in use, and that these measures are predominantly focused on the physical aspects of care and care of the imminently dying.⁶⁴ The use of broad-based national or international guidelines, which may be adapted for each jurisdiction, is recommended. For example, the National Quality Forum in the United States developed *A National Framework and Preferred Practices for Palliative and Hospice Care Quality*.⁶⁵ This framework identifies eight distinct domains or aspects of care that can be used to measure quality performance: physical; structures and processes of care; care of the imminently dying; ethical and legal; psychiatric and psychological; social; spiritual and existential; and cultural.

A subsequent consensus report from the Centre to Advance Palliative Care (CAPC) identified four basic metrics to ensure that each palliative care program maintains the highest possible standards, and that the service is sustained over time.⁴²

- **Operational metrics:** These include the collection of individual patient data, such as: the date of referral to palliative care; details on the referring team; patient diagnosis and other demographics; reason for referral; and hospital length of stay.
- **Clinical metrics:** These relate to the use of validated tools to measure physical and psychological symptoms, as well as the development and upkeep of departmental guidelines, standard operating procedures, and policies regarding all aspects of patient care delivery.
- **Customer metrics:** These can be measured using satisfaction feedback from patients, their families and referring teams.
- **Financial metrics:** These include hospital direct costs pre- and post-referral to the palliative care service (e.g., radiological or laboratory tests, procedures), case-mix index and inpatient death rates.

Collection of these data over time enables teams to track service growth, identify the need for service expansion and additional recruitment, demonstrate the benefits of the service, and compare performance with peers in other organizations. CAPC also identified a set of 12 operational domains necessary to sustain high-quality, hospital-based palliative care programs. These include “must-have” and “should-have” components, recognizing that individual programs are at different stages of development.⁴² Separate documents were developed for use by IPCTs and PCUs.^{42,66} Unfortunately, little has been published regarding community-based palliative care services, but many of the same principles can be applied. The same group subsequently developed clinical care and customer satisfaction metrics that provide a framework for evaluating programs from a clinical perspective, and demonstrate the impact of the program to stakeholders.⁶⁷

Of the 12 operational domains identified by Weismann et al., four represent the core of inpatient palliative care clinical services.

- **Symptom assessment and management documentation**, which includes evidence that: a comprehensive symptom assessment was completed at the initial patient review; a daily reassessment was conducted for moderate to severe symptoms; a reassessment was conducted of all symptoms at least every three days; and a clearly documented plan was developed to manage all moderate to severe symptoms. Validated symptom assessment tools (described earlier) should be used, where possible.
- **Documentation of patient-centred goals of care**, or a discussion about treatment goals.
- **Documentation of support to patients and caregivers** that recognizes the important role frequently played by informal caregivers, including identifying unmet caregiver needs and initiating strategies to address these needs.
- **Documentation about the management of transitional stages** for patients who are transferred between different sites (e.g., from an acute hospital setting to home or a community-based hospice). Clear and accurate communication between teams is essential. This includes sharing relevant information about symptom management or ongoing symptom issues, agreed-upon goals of care, advance directives and substitute decision-makers (if appropriate), the needs of the family or caregiver, and any follow-up plans.

With regards to customer or consumer domains or metrics, different methods can be used to assess the perception of patients, caregivers, and healthcare providers or other staff. Validated patient and caregiver

satisfaction tools for use in different settings include: i) the FAMCARE Scale, which has separate patient and caregiver versions and has been validated for use in advanced cancer populations and outpatient settings; and ii) the Family Assessment of Treatment at End of Life Survey.⁶⁸⁻⁷⁰

Staff opinions of the palliative care service can be measured through referring physician feedback as well as through regular staff meetings, informal feedback and suggestion boxes. Staff turnover, burnout and compassion fatigue are important considerations for palliative care settings, where constant exposure to death, inadequate time with dying patients, growing workload, inadequate coping with personal emotional response, an increasing number of deaths, communication difficulties with dying patients and families, and feelings of grief, depression and guilt have all been identified as possible contributors.⁷¹ Strategies should exist for preventing, identifying and managing these issues, and validated tools such as the Professional Quality of Life Scale can be useful.⁷² A number of other tools exist to measure provider satisfaction, although many have not yet been validated.⁷³

The frequency of satisfaction assessment may depend on the stage of development of the program. For a new program, more frequent assessments, such as quarterly, may be important, whereas for more established services data collection every two to three years may be sufficient.⁶⁷

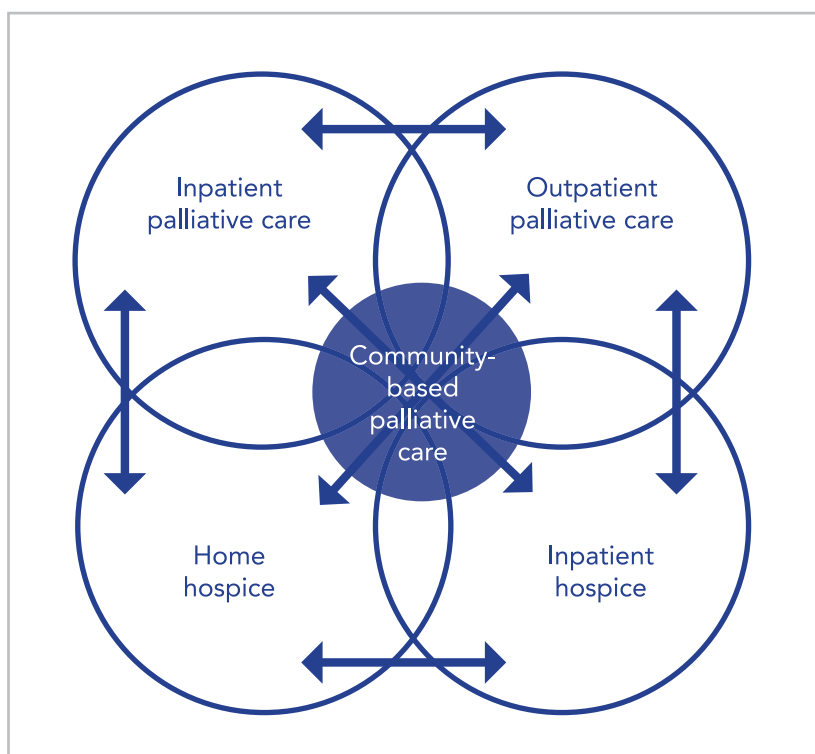
The National Institute for Health and Care Excellence in the United Kingdom has developed quality standards for end-of-life care for adults.⁷⁴ These are general standards, which can be applied across all four settings of palliative care. They are based on 16 statements that include: identifying patients likely to die within the next year; communicating and providing information; adopting a holistic, multidisciplinary approach to patients' physical and emotional needs, and the needs of families or other informal caregivers; providing consistent, co-ordinated care in keeping with the express wishes of the patient, where known; and including follow-up and support for families after the death of the patient.

In most cases, APCUs have targets related to admissions from various settings, discharges home, and the inpatient death rate and mean length of stay.^{25,32,75} Community-based palliative care units and hospices may have different targets based on the institutional philosophy of care; for example, a higher target for patients admitted to end-of-life care and little emphasis on live discharge or inpatient death rates.

F. INTEGRATION

The palliative care needs of cancer patients vary over time and based on the illness trajectory. Not only should palliative care services be available in a variety of settings, but these services should also be fully integrated to provide patients with seamless, continuous care. Since the majority of patients express a desire to die at home, access to primary, community-based palliative care should form the core of palliative care services, with easy access to IPCTs, OPCCs, and PCUs as required, as illustrated in Figure 6.⁷⁶ Since it is almost impossible for a single palliative care team to provide care in each of the four palliative care settings simultaneously, good communication between hospital- and community-based services is crucial. Prompt transfer of relevant information between settings, services and providers ensures the optimal continuity of care for patients and their families.

Figure 6: Palliative Care Service Integration⁷⁷



9. WITHIN THE CANCER CENTRE

International standards have been developed for the integration of palliative care into overall cancer care. In a recent Delphi survey, international experts in oncology and palliative care decided on indicators of palliative care integration at cancer centres, under the categories of structure, process, outcomes and education. More than 90 per cent agreed on the following major indicators: presence of an inpatient consultation team; presence of an outpatient palliative care clinic; routine symptom screening in oncology clinics; early referral to palliative care; a place of death consistent with the patient's preference; a didactic curriculum for oncology fellows provided by the palliative care team; continuing medical education in palliative care for oncologists; combined palliative care and oncology educational activities for fellows and trainees; and a routine rotation in palliative care for oncology fellows.⁷⁸

A competent, reliable, available and collaborative palliative care team is the most important ingredient for the integration of palliative care into the cancer centre. Although integration may be achieved to some extent through inpatient consultations, a full integration that is inclusive of patients at earlier stages of their illness is only possible through a robust outpatient palliative care program, including dedicated palliative care clinics.^{20,78} Combined tumour boards, rounds and educational activities are other venues for interaction between oncology and palliative care colleagues that promotes integration. The European Society for Medical Oncology has an accreditation program for Designated Centres of Integrated Oncology and Palliative Care.⁷⁹ Through this initiative, cancer centres can receive recognition for achieving a high standard of integration between medical oncology and palliative care.

The Princess Margaret Cancer Centre in Toronto, Canada has developed an electronic self-report screening tool comprised of four validated core measures, available in the public domain: the Edmonton Symptom Assessment System-revised (ESAS-r) for physical symptoms; the Patient Health Questionnaire-9 (PHQ-9) for depression; the Generalized Anxiety Disorders-7 (GAD-7) for anxiety; and the Social Difficulties Inventory-21 (SDI-21) for unmet needs.⁸⁰⁻⁸³ It also includes the patient-reported ECOG Scale of Performance Status, the informational and spiritual domains of the Canadian Problem Checklist, distress risk factors (e.g., current living situation, personal and family psychiatric history), current use of supportive care services, and a question about the desire for referral to support. This screening system, called the Distress Assessment and Response Tool (DART), is completed by patients at every outpatient appointment, with screening rates consistently exceeding 70 per cent.^{60,84,85} DART software is intelligently programmed to permit the inclusion of tumour site-specific measures and the triggered assessment of specific measures. For example PHQ-9 and GAD-7 are triggered only for ESAS-r depression and anxiety scores of ≥ 2 and ≥ 3 , respectively. Similar screening using the ESAS-r and patient-reported functional status has occurred at all 14 Ontario cancer centres since 2008, as mandated by Cancer Care Ontario.⁸⁶

Within the palliative care team at the cancer centre, the different settings in which palliative care is provided must also be integrated seamlessly. In some centres, the same palliative care physicians may cover both the OPCC and provide inpatient consultations or care in the APCU on a rotating basis, which permits excellent continuity of care. Elsewhere, palliative care physicians may rotate between all acute hospital units, OPCCs and PCUs separately for defined periods of time. The latter model requires more effort to ensure information is shared in a timely manner between all relevant physicians.

The individual steps necessary to develop palliative care services have been described earlier in this chapter. One report from Kenya has outlined the process of integrating palliative care services within government hospitals. This has highlighted the steps necessary to successfully initiate a palliative care program in low- and middle-income countries, including:⁸⁷

- Making a case for palliative care integration through advocacy and lobbying at both the local and hospital level and, in some cases, at the provincial or national levels
- Securing adequate and sustainable funding (i.e., public or ministry funding versus private funding)
- Identifying suitable space, resources and key personnel within the centre
- Accessing the necessary equipment and medications
- Providing care within the centre and making connections with external sources to ensure smooth transitions of care for patients discharged from the centre

10. BEYOND THE CANCER CENTRE

Beyond the hospital or cancer centre setting, access to palliative care services can differ widely, with wide geographical variations in access both nationally and internationally.⁸⁸⁻⁹² Since palliative care patients typically require both hospital- and community-based services, it is crucial to ensure co-ordination, integration and consistency between these services, as described above. Support from local and provincial or state governments and national organizations, as well as guidelines, policies and benchmarks, can aid the development of integrated, standardized palliative care models for all patients.²

The following models implemented in Ontario, Canada are good examples of projects that integrate palliative care services across a large area.

The Government of Ontario implemented an *End-of-Life Care Strategy* in 2005 to expand palliative care from predominantly acute care settings to more patient-directed, often community-based settings. This provincial strategy informed the development of Hospice Palliative Care Networks (HPCNs) in each provincial healthcare planning region. HPCNs are charged with improving regional palliative care delivery, developing and implementing strategic plans, and maximizing resource use to improve integration.

Cancer Care Ontario is the provincial government's chief cancer advisor and is dedicated to improving cancer care at regional and provincial levels. Cancer Care Ontario has had a palliative care program since 2004, which facilitates knowledge exchange regarding palliative care best practice across the province, has established a Provincial Palliative Care Program with regional representation, and had developed recommendations on the organization and delivery of palliative cancer care services in Ontario.

Elsewhere, in some low-and middle-income countries, enormous strides have been made in integrating community-based palliative care initiatives to improve access for all. In Kerala, India, for example, palliative care has been integrated into primary care models since 2008, with a resultant cohesive system of palliative care delivery across the province that now accounts for 90 per cent of all palliative care services across India.⁹⁰ Care is provided directly in patients' homes, in local clinics staffed by trained volunteers, or in PCUs. Educational initiatives have been set up alongside the clinical services to support patients and their families, as well as the broader community.

G. THE FUTURE

Emerging trends and innovation in palliative care span the areas of education, academic research and initiatives to address service gaps.

Education

Physicians across the cancer care continuum and in all specialties come into contact with dying patients at some point in their careers. The European Association for Palliative Care has suggested that shortcomings in palliative care education during medical school can ultimately hinder the delivery of high-quality palliative care to patients.⁹³ Lack of training in, or exposure to, palliative care may also be a barrier to early referral. Studies have shown that oncologists who complete a rotation in palliative care are more likely to refer patients with advanced cancer to palliative care services earlier than those who do not complete a rotation, and that oncologists' own comfort with end-of-life care positively influences referrals to palliative care services.^{52,94}

A number of organizations have recommended that all medical students receive core teaching on pain and symptom management, as well as caring for terminally ill patients (e.g., General Medical Council in the United Kingdom, 2003; educational boards in the United States such as the Liaison Committee on Medical Education).^{95,96} Studies have shown that the majority of medical students and physicians-in-training consider palliative care education as an important component of their training.^{97,98} Although some countries have developed consensus curricula, there is little guidance on how best to implement these curricula; as a result, the content and quantity of palliative care teaching can vary significantly.

At the postgraduate level, palliative care is increasingly being recognized as a medical specialty in its own right; for example, in the United Kingdom and Ireland, a four-year postgraduate training program must be completed by physicians wishing to work in palliative care. Other countries, such as Canada, Australia and the United States, recognize palliative care as a subspecialty. Training workshops for oncology fellows, such as VITALtalk – a program aimed at teaching basic palliative care skills under supervision – and Education in Palliative and End-of-Life Care - Oncology (EPEC-O) – a multimedia curriculum that can be presented by seminar or webinar, or used for self-study – are increasingly being developed and recommended across all medical specialities.^{99,100} These workshops aim to provide oncologists with primary palliative care competencies, as outlined in Table 1. The Canadian Learning Essential Approaches to Palliative Care (LEAP ONCO) program is interdisciplinary and provides palliative care training for all healthcare professionals, as well as caregivers and educators.¹⁰¹ These training programs ensure that palliative care training can extend beyond residency and fellowship to the entire career continuum.¹⁰²

For other healthcare professionals working within cancer centres, education and training in palliative and end-of-life care are crucial. The End-of-Life Nursing Education Consortium course has provided undergraduate and graduate palliative care training internationally since 2000.¹⁰³ Elsewhere, multi-professional programs and organizations, such as the European Certificate in Essential Palliative Care and the de Souza Institute, provide basic palliative care training in a distance learning format.^{104,105}

Academic Research

Internationally, there are relatively few palliative care research centres, largely due to limitations in infrastructure or funding.⁸⁸ The lack of a strong academic research base has made it difficult to tangibly demonstrate the benefits of palliative care services to policy-makers and hospital managers. In recent years, however, a number of landmark studies have demonstrated the benefits of early palliative care services, particularly for patients with advanced cancer.⁶⁻⁸ As a result, a number of influential medical groups have developed consensus statements endorsing the merits of early palliative care referral.^{1,9} It is crucially important to build upon this momentum and for a larger number of palliative care centres to lead in research. Collaboration between palliative care centres, especially in conjunction with palliative care providers in low- and middle-income countries, and the growth of international palliative care conferences, which enable the sharing and dissemination of ideas and projects, will continue to strengthen much-needed academic research in palliative care.

Initiatives to Address Service Gaps

As the evidence for early palliative care continues to strengthen, initiatives that provide palliative care for all those who can benefit should be explored. Potential options are described below.

Increasing the number of specialist palliative care teams: It is expected that the increasing demand for palliative care will rapidly outpace the supply of providers; some estimate that the number of new trainees will barely replace those retiring in the coming years.¹⁰² Increasing fellowship opportunities and funding, and the development of alternative pathways to training and certification have been suggested as possible solutions; for example, in the United Kingdom and Ireland, physicians who have completed training programs in internal medicine, family medicine or anaesthesia are eligible to apply for palliative care programs. It is recognized that expanding specialist workforces may be challenging in many publicly funded healthcare services.¹⁰²

Enabling generalists to provide palliative care: As described earlier, every healthcare provider should have core palliative care skills to meet the needs of the majority of patients with progressive and advanced disease. In the United Kingdom, actions have been taken to improve primary palliative care through the Gold Standards Framework (GSF). This systematic, evidence-based approach uses generalist providers to optimize the care of patients nearing end-of-life. General practitioners are engaged in the GSF through a voluntary annual reward and incentive program.¹⁰⁶ Practices can claim financial rewards based on the quality of care they provide, as measured by a set of clinical, organizational, patient experience and additional services indicators.

The GSF has resulted in:¹⁰⁷

- Improved delivery of high-quality patient care that is aligned to patient choice
- More patients dying in their preferred place (i.e., more home deaths, fewer hospital deaths)
- Improved cost-effectiveness, by reducing hospital admissions and bed days
- Improved identification, co-ordination and earlier planning of care
- More patients with advance care planning discussions
- Workload improvements, including practice teams “working smarter” and having a better and more satisfying work life
- Increased staff confidence and teamwork as progress becomes evident

In Canada, enhanced palliative care teams (EPCTs) – a collaboration between general practitioners and specialist palliative care teams comprised of an Advanced Practice Nurse, a part-time palliative care Physician, a Spiritual Care Advisor, a Bereavement Counsellor and a Community Care Case Manager – have resulted in patients’ preferences for place of death being accommodated more often. General practitioners reported that the EPCT improved quality, communication, co-ordination, continuity and integration, while allowing them to maintain their role as primary care providers. Community nurses reported that the EPCT fostered stronger relationships between healthcare providers, left them feeling less alone in handling complex issues, and enhanced their problem-solving skills. EPCTs were so well received that they are being disseminated through a larger geographic area in Ontario, Canada.¹⁰⁸

The use of telemedicine: Videoconferencing has been successfully used to provide specialized palliative care services (SPCS) to cancer patients in rural settings. In one project, patients attended their local healthcare facility, where they: completed a number of tools, including ESAS, a cognitive screening test and a number of performance status indicators; had a physical examination; and had their medications reviewed. This information was relayed to the SPCS team at a regional tertiary cancer centre. The SPCS then interviewed the patient via videoconference link and participated in a healthcare team conference to develop a clinical management plan that was subsequently discussed with the patient. A full consultation note was later sent to the patient’s Primary Care Provider. The project resulted in improved symptoms, cost savings to patients and families due to less frequent trips to the cancer centre, and high levels of patient and physician satisfaction. This type of model could potentially be applied to other settings, where distance is a barrier to accessing specialized palliative care services.¹⁰⁹

Extrapolation of successful cancer models to non-malignant conditions: The focus of this chapter has been to outline the development and expansion of palliative care services within cancer centres. Beyond cancer, palliative care services are limited in scope and variable in both access and quality, and programs for education and research are much less developed. Successful models from cancer settings could be used as templates for other, non-malignant settings, to help expand services to all patients who might benefit from such an approach.

H. SUGGESTED READING

Cherny N, Fallon M, Kaasa S, Portenoy RK, Currow DC, editors. Oxford Textbook of Palliative Medicine (5th edition). Oxford: Oxford University Press; 2015.

Davis M, Feyer P, Ortner P, Zimmermann C, editors. Supportive Oncology. Philadelphia (PA): Saunders; 2011.

I. REFERENCES

1. Palliative definition. World Health Organization; [cited 2013 February 28]. Available from: <http://www.who.int/cancer/palliative/definition/en/>.
2. Stjernswärd J, Foley KM, Ferris FD. The public health strategy for palliative care. *Journal of Pain and Symptom Management*. 2007;33(5):486-93.
3. Storey DJ, Fallon MT, Smyth JF. The interface between medical oncology and supportive and palliative cancer care. *Seminars in Oncology*. 2011;38(3):337-42.
4. Von Roenn JH, Temel J. The integration of palliative care and oncology: the evidence. *Oncology (Williston Park)*. 2011;25(13):1258-65.
5. Epstein AS, Goldberg GR, Meier DE. Palliative care and hematologic oncology: the promise of collaboration. *Blood Reviews*. 2012;26(6):233-9.
6. Temel JS, Greer JA, Muzikansky A, Gallagher ER, Admane S, Jackson VA, et al. Early palliative care for patients with metastatic non-small-cell lung cancer. *New England Journal of Medicine*. 2010;363(8):733-42.
7. Bakitas M, Lyons KD, Hegel MT, Balan S, Brokaw FC, Seville J, et al. Effects of a palliative care intervention on clinical outcomes in patients with advanced cancer. *JAMA*. 2009;302(7):741.
8. Zimmermann C, Swami N, Krzyzanowska M, Hannon B, Leigh N, Oza A, et al. Early palliative care for patients with advanced cancer: a cluster-randomised controlled trial. *The Lancet*. 2014;383(9930):1721-30.
9. Ferrell BR, Temel J, Temin S, Alesi ER, Balboni TA, Basch E, et al. Integration of palliative care into standard oncology Care: American Society of Clinical Oncology clinical practice guideline update. *Journal of Clinical Oncology*. 2017;35(1):96-112.
10. Ferris F, Bruera E, Cherny N, Cummings C, Currow D, Dudgeon D, et al. Palliative cancer care a decade later: accomplishments, the need, next steps. *Journal of Clinical Oncology*. 2009;27(18):3052-8.
11. Weissman DE. Consultation in palliative medicine. *Archives of Internal Medicine*. 1997;157(7):733.
12. Currow D. A guide to palliative care service development: a population based approach. *Palliative Care Australia*; 2005 [cited 2013 March 19]. Available from: <http://www.palliativecare.org.au/Portals/46/A%20guide%20to%20palliative%20care%20service%20development%20-%20a%20population%20based%20approach.pdf>.
13. Report of the national advisory committee on palliative care. Department of Health and Children, Ireland.
14. Warrington L, Holch P, Kenyon L, Hector C, Kozłowska K, Kenny AM, et al. An audit of acute oncology services: patient experiences of admission procedures and staff utilisation of a new telephone triage system. *Supportive Care in Cancer*. 2016;24(12):5041-8.
15. Braiteh F, El Osta B, Palmer JL, Reddy SK, Bruera E. Characteristics, findings, and outcomes of palliative care inpatient consultations at a comprehensive cancer center. *Journal of Palliative Medicine*. 2007;10(4):948-55.
16. Yennurajalingam S, Zhang T, Bruera E. The impact of the palliative care mobile team on symptom assessment and medication profiles in patients admitted to a comprehensive cancer center. *Supportive Care in Cancer*. 2006;15(5):471-5.
17. Morrison RS. Cost savings associated with US hospital palliative care consultation programs. *Archives of Internal Medicine*. 2008;168(16):1783.
18. Thomas J. Smith, J. Brian Cassel. Cost and non-clinical outcomes of palliative care. *Journal of Pain and Symptom Management*. 2009;38(1):32-44.
19. May P, Garrido MM, Cassel JB, Kelley AS, Meier DE, Normand C, et al. Prospective cohort study of hospital palliative care teams for inpatients with advanced cancer: earlier consultation is associated with larger cost-saving effect. *Journal of Clinical Oncology*. 2015;33(25):2745-52.
20. Hannon B, Swami N, Pope A, Rodin G, Dougherty E, Mak E, et al. The oncology palliative care clinic at the Princess Margaret Cancer Centre: an early intervention model for patients with advanced cancer. *Supportive Care in Cancer*. 2014;23(4):1073-80.
21. Meier DE, Beresford L. Outpatient clinics are a new frontier for palliative care. *Journal of Palliative Medicine*. 2008;11(6):823-8.
22. Hannon B, Swami N, Rodin G, Pope A, Zimmermann C. Experiences of patients and caregivers with early palliative care: a qualitative study. *Palliative Medicine*. 2016;31(1):72-81.
23. Earle CC, Neville BA, Landrum MB, Ayanian JZ, Block SD, Weeks JC. Trends in the aggressiveness of cancer care near the end of life. *Journal of Clinical Oncology*. 2004;22(2):315-21.
24. Mercadante S, Adile C, Caruselli A, Ferrera P, Costanzi A, Marchetti P, et al. The palliative-supportive care unit in a comprehensive cancer center as crossroad for patients' oncological pathway. *PLOS ONE*. 2016;11(6):e0157300.

25. Bryson J, Coe G, Swami N, Murphy-Kane P, Seccareccia D, Le LW, et al. Administrative outcomes five years after opening an acute palliative care unit at a comprehensive cancer center. *Journal of Palliative Medicine*. 2010;13(5):559-65.
26. Wilkes E, Crowther AG, Greaves CW. A different kind of day hospital--for patients with preterminal cancer and chronic disease. *BMJ*. 1978;2(6144):1053-6.
27. Gomes B, Calanzani N, Curiale V, McCrone P, Higginson IJ. Effectiveness and cost-effectiveness of home palliative care services for adults with advanced illness and their caregivers. *Cochrane Database of Systematic Reviews*. 2013.
28. Brumley RD, Enguidanos S, Cherin DA. Effectiveness of a home-based palliative care program for end-of-life. *Journal of Palliative Medicine*. 2003;6(5):715-24.
29. Lustbader D, Mudra M, Romano C, Lukoski E, Chang A, Mittelberger J, et al. The impact of a home-based palliative care program in an accountable care organization. *Journal of Palliative Medicine*. 2017;20(1):23-8.
30. da Silva Soares D, Nunes CM, Gomes B. Effectiveness of emergency department based palliative care for adults with advanced disease: a systematic review. *Journal of Palliative Medicine*. 2016;19(6):601-9.
31. Wu FM, Newman JM, Lasher A, Brody AA. Effects of initiating palliative care consultation in the emergency department on inpatient length of stay. *Journal of Palliative Medicine*. 2013;16(11):1362-7.
32. Bruera E, Neumann CM, Gagnon B, Brenneis C, Kneisler P et al. Edmonton regional palliative care program: impact on patterns of terminal cancer care. *CMAJ*. 1999;161(3):290-3.
33. Bruera E, Hui D. Conceptual models for integrating palliative care at cancer centers. *Journal of Palliative Medicine*. 2012;15(11):1261-9.
34. Zimmermann C, Seccareccia D, Clarke A, Warr D, Rodin G. Bringing palliative care to a Canadian cancer center: the palliative care program at Princess Margaret Hospital. *Supportive Care in Cancer*. 2006;14(10):982-7.
35. Smith AK, Thai JN, Bakitas MA, Meier DE, Spragens LH, Temel JS, et al. The diverse landscape of palliative care clinics. *Journal of Palliative Medicine*. 2013;16(6):661-8.
36. Dev R, Fabbro ED, Miles M, Vala A, Hui D, Bruera E. Growth of an academic palliative medicine program: Patient encounters and clinical burden. *Journal of Pain and Symptom Management*. 2013;45(2):261-71.
37. National Institute for Clinical Excellence. Guidance on cancer services: improving supportive and palliative care for adults with cancer, the manual. London: National Institute for Clinical Excellence; 2004 March.
38. Smith TJ, Coyne PJ, Cassel JB. Practical guidelines for developing new palliative care services: resource management. *Annals of Oncology*. 2012;23(suppl 3):70-5.
39. Niedzielski OK, Rodin G, Emmerson D, Rutgers J, Sellen KM. Exploring sensory experiences and personalization in an inpatient residential hospice setting. *American Journal of Hospice and Palliative Medicine*. 2016;33(7):684-90.
40. Nissim R, Emmerson D, O'Neill B, Marchington K, Draper H, Rodin G. Motivations, satisfaction, and fears of death and dying in residential hospice volunteers. *American Journal of Hospice and Palliative Medicine*. 2016;33(4):335-9.
41. Bishop MF, Stephens L, Goodrich M, Byock I. Medication kits for managing symptomatic emergencies in the home: a survey of common hospice practice. *Journal of Palliative Medicine*. 2005;12(1):37-44.
42. Weissman DE, Meier D. Operational features for hospital palliative care programs: consensus recommendations. *Journal of Palliative Medicine*. 2008;11(9):1189-94.
43. Finlay IG. Developing a template to plan palliative care services: the Welsh experience. *Journal of Pain and Symptom Management*. 2009;38(1):81-6.
44. Roberts D, Hurst K. Evaluating palliative care ward staffing using bed occupancy, patient dependency, staff activity, service quality and cost data. *Palliative Medicine*. 2012;27(2):123-30.
45. Towns K, Dougherty E, Kevork N, Wiljer D, Seccareccia D, Rodin G, et al. Availability of services in Ontario hospices and hospitals providing inpatient palliative care. *Journal of Palliative Medicine*. 2012;15(5):527-34.
46. Rubin G, Berendsen A, Crawford SM, et al. The expanding role of primary care in cancer control. *The Lancet Oncology*. 2015;16(12):1231-72.
47. Accreditation Canada. Hospice, palliative and end-of-life services. 2017 [cited 2013 March 19]. Available from: <https://store.accreditation.ca/products/hospice-palliative-end-of-life-services>.
48. Levy M, NCCN Panel Members. NCCN Guidelines version 2016 palliative care. National Comprehensive Cancer Network Inc; 2015.
49. Ontario cancer screening performance report 2016. Cancer Care Ontario.

50. Meier DE. Ten steps to growing palliative care referrals. *Journal of Palliative Medicine*. 2005;8(4):706-8.
51. Radwany S, Mason H, Clarke JS, Clough L, Sims L, Albanese T. Optimizing the success of a palliative care consult service: How to average over 110 consults per month. *Journal of Pain and Symptom Management*. 2009;37(5):873-83.
52. Wentlandt K, Krzyzanowska MK, Swami N, Rodin GM, Le LW, Zimmermann C. Referral practices of oncologists to specialized palliative care. *Journal of Clinical Oncology*. 2012;30(35):4380-6.
53. Bruera E, Kuehn N, Miller MJ, Selmser P, Macmillan K. The Edmonton Symptom Assessment System (ESAS): a simple method for the assessment of palliative care patients. *J Palliat Care*. 1991;7(2):6-9.
54. Portenoy RK, Thaler HT, Kornblith AB, McCarthy Lepore J, Friedlander-Klar H, Kiyasu E, et al. The Memorial Symptom Assessment Scale: an instrument for the evaluation of symptom prevalence, characteristics and distress. *European Journal of Cancer*. 1994;30(9):1326-36.
55. Palliative care outcome scale. London, UK: Cicley Saunders Institute 2012.
56. National Cancer Institute. Phases of clinical trials. National Cancer Institute; 2016 [cited 2016 August 10]. Available from: <http://www.cancer.gov/about-cancer/treatment/clinical-trials/what-are-trials/phases>.
57. Steven Z Pantilat. Hospital-based palliative medicine consultation: a randomized controlled trial. *Archives of Internal Medicine*. 2010;170(22):2038.
58. Rabow MW, Dibble SL, Pantilat SZ, McPhee SJ. The comprehensive care team. *Archives of Internal Medicine*. 2004;164(1):83.
59. Norton SA, Power BA, Schmitt MH, Metzger M, Fairbanks E, DeLuca J, et al. Navigating tensions: integrating palliative care consultation services into an academic medical center setting. *Journal of Pain and Symptom Management*. 2011;42(5):680-90.
60. Oken MM, Creech RH, Tormey DC, Horton J, Davis TE, McFadden ET, et al. Toxicity and response criteria of the Eastern Cooperative Oncology Group. *American Journal of Oncology*. 1982;5(6):649-56.
61. Tiernan E, O'Connor M, O'Siorain L, Kearney M. A prospective study of preferred versus actual place of death among patients referred to a palliative care home-care service. *Irish Medical Journal*. 2002;95(8):232-5.
62. Wowchuk SM, Wilson EA, Embleton L, Garcia M, Harlos M, Chochinov HM. The palliative medication kit: an effective way of extending care in the home for patients nearing death. *Journal of Palliative Medicine*. 2009;12(9):797-803.
63. Hassett MJ, McNiff KK, Dicker AP, Gilligan T, Hendricks CB, Lennes I, et al. High-priority topics for cancer quality measure development: results of the 2012 American Society of clinical Oncology collaborative cancer measure summit. *Journal of Oncology Practice*. 2014;10(3):e160-e6.
64. Kamal AH, Gradison M, Maguire JM, Taylor D, Abernethy AP. Quality measures for palliative care in patients with cancer: a systematic review. *Journal of Oncology Practice*. 2014;10(4):281-7.
65. National Quality Forum. A national framework and preferred practices for palliative and hospice care quality. Washington, DC: National Quality Forum; 2006.
66. Weissman DE, Meier DE. Center to advance palliative care inpatient unit operational metrics: consensus recommendations. *Journal of Palliative Medicine*. 2009;12(1):21-5.
67. Weissman DE, Morrison RS, Meier DE. Center to Advance Palliative Care palliative care clinical care and customer satisfaction metrics consensus recommendations. *Journal of Palliative Medicine*. 2010;13(2):179-84.
68. Lo C, Burman D, Hales S, Swami N, Rodin G, Zimmermann C. The FAMCARE-Patient scale: measuring satisfaction with care of outpatients with advanced cancer. *European Journal of Cancer*. 2009;45(18):3182-8.
69. Kristjanson LJ. Validity and reliability testing of the FAMCARE scale: Measuring family satisfaction with advanced cancer care. *Social Science & Medicine*. 1993;36(5):693-701.
70. Casarett D, Pickard A, Bailey FA, Ritchie CS, Furman CD, Rosenfeld K, et al. A nationwide VA palliative care quality measure: the family assessment of treatment at the end of life. *Journal of Palliative Medicine*. 2008;11(1):68-75.
71. Kearney MK, Weininger RB, Vachon MLS, Harrison RL, Mount BM. Self-care of physicians caring for patients at the end of life. *JAMA*. 2009;301(11):1155.
72. The ProQOL precise manual. [cited 2013 March 15]. Available from: http://www.proqol.org/ProQOL_Test_Manuals.html.
73. National Cancer Institute. Laboratory of Pathology (LP) at the National Cancer Institute (NCI). Washington, DC: National Cancer Institute; [cited]. Available from: <http://home.ccr.cancer.gov/LOP/intranet/PolicyManual/GeneralPolicy/CAPCLIA.asp>.

74. National Institute for Health and Care Excellence. End of life care for adults. London, UK: National Institute for Health and Care Excellence.
75. Bruera E, Sweeney C. The development of palliative care at the University of Texas M.D. Anderson Cancer Center. *Supportive Care in Cancer*. 2001;9(5):330-4.
76. Higginson I. Priorities and preferences for end of life care in England, Wales and Scotland. London: National Council for Hospice and Specialist Palliative Care Services; 2003.
77. Kamal AH, Currow DC, Ritchie CS, Bull J, Abernethy AP. Community-based palliative care: the natural evolution for palliative care delivery in the U.S. *Journal of Pain and Symptom Management*. 2012;46(2):254-64.
78. Hui D, Bansal S, Strasser F, Morita T, Caraceni A, Davis M, et al. Indicators of integration of oncology and palliative care programs: an international consensus. *Annals of Oncology*. 2015;26(9):1953-9.
79. European Society for Medical Oncology. ESMO designated centres of integrated oncology & palliative care. Switzerland: European Society for Medical Oncology.
80. Watanabe SM, Nekolaichuk C, Beaumont C, Johnson L, Myers J, Strasser F. A multicenter study comparing two numerical versions of the Edmonton symptom assessment system in palliative care patients. *Journal of Pain and Symptom Management*. 2011;41(2):456-68.
81. Kroenke K, Spitzer RL, Williams JBW. The PHQ-9. *Journal of General Internal Medicine*. 2001;16(9):606-13.
82. Spitzer RL, Kroenke Kt, Williams JBW, Löwe B. A brief measure for assessing generalized anxiety disorder. *Archives of Internal Medicine*. 2006;166(10):1092.
83. Wright EP, Kiely M, Johnston C, Smith AB, Cull A, Selby PJ. Development and evaluation of an instrument to assess social difficulties in routine oncology practice. *Quality of Life Research*. 2005;14(2):373-86.
84. Bultz BD, Fitch GSM. Screening for distress toolkit working group. Canadian Problem Checklist. The guide to implementing screening for distress. 6 ed 2009.
85. Li M, Macedo A, Crawford S, Bagha S, Leung YW, Zimmermann C, et al. Easier said than done: keys to successful implementation of the Distress Assessment and Response Tool (DART) program. *Journal of Oncology Practice*. 2016;12(5):e513-e26.
86. Barbera L, Atzema C, Sutradhar R, Seow H, Howell D, Husain A, et al. Do patient-reported symptoms predict emergency department visits in cancer patients? A population-based analysis. *Annals of Emergency Medicine*. 2013;61(4):427-37.e5.
87. Zipporah Ali. Kenya Hospices and Palliative Care Association: integrating palliative care in public hospitals in Kenya. *ecancermedicalscience*. 2016;10.
88. Bee Wee. Models of delivering palliative and end-of-life care in the UK. *Current Opinion in Supportive and Palliative Care*. 2013;7(2):195-200.
89. Morita T, Kizawa Y. Palliative care in Japan. *Current Opinion in Supportive and Palliative Care*. 2013;7(2):207-15.
90. Kumar S. Models of delivering palliative and end-of-life care in India. *Current Opinion in Supportive and Palliative Care*. 2013;7(2):216-22.
91. Mwangi-Powell FN, Powell RA, Harding R. Models of delivering palliative and end-of-life care in sub-Saharan Africa. *Current Opinion in Supportive and Palliative Care*. 2013;7(2):223-8.
92. Hannon B, Zimmermann C, Knaul FM, Powell RA, Mwangi-Powell FN, Rodin G. Provision of palliative care in low- and middle-income countries: overcoming obstacles for effective treatment delivery. *Journal of Clinical Oncology*. 2016;34(1):62-8.
93. Schiessl C, Walshe M, Wildfeuer S, Larkin P, Voltz R, Juenger J. Undergraduate curricula in palliative medicine: a systematic analysis based on the palliative education assessment tool. *Journal of Palliative Medicine*. 2013;16(1):20-30.
94. Hui D, Meng Y, Bruera S, Geng Y, Hutchins R, Mori M, et al. Referral criteria for outpatient palliative cancer care: a systematic review. *The Oncologist*. 2016;21(7):895-901.
95. Tomorrow's doctors. London: General Medical Council; 2003.
96. Liaison Committee on Medical Education. Function and structure of a medical school. Liaison Committee on Medical Education: [cited 2013 February 26]. Available from.
97. AM Sullivan, MD Lakoma, Block SD. The status of medical education in end-of-life care. *Journal of General Internal Medicine*. 2003;18(9):685-95.
98. Wong A, Reddy A, Williams JL, Wu J, Liu D, Bruera E, et al. ReCAP: attitudes, beliefs, and awareness of graduate medical education trainees regarding palliative care at a comprehensive cancer center. *Journal of Oncology Practice*. 2016;12(2):149-50.

99. VITALtalk. [cited 2018 January 5]. Available from: <http://vitaltalk.org>.
100. Workshop – education in palliative and end-of-life care – oncology Toronto, ON: de Souza Institute [cited 2018 January 5]. Available from: <https://my.desouzainstitute.com/courseCodes/view/EPEC>.
101. LEAP ONCO learning essential approaches to palliative care. Ottawa, ON: Pallium Canada; [cited 2018 January 5]. Available from: <http://pallium.ca/leap-courses/leap-mini-onco/>.
102. Quill TE, Abernethy AP. Generalist plus specialist palliative care — creating a more sustainable model. *New England Journal of Medicine*. 2013;368(13):1173-5.
103. Ferrell B, Malloy P, Virani R. The end of life nursing education nursing consortium project. *Annals of palliative medicine*. 2015;4(2):61-9.
104. European Certificate in essential palliative care. Esher, UK: Princess Alice Hospice.
105. de Souza Institute. Toronto, ON: de Souza Institute; [cited 2018 January 5]. Available from: <https://www.desouzainstitute.com>.
106. National Health Service. Quality and outcomes framework. [cited]. Available from: <http://www.qof.ic.nhs.uk/>.
107. Gold standards framework. [cited 2013 March 14]. Available from: <http://www.goldstandardsframework.org.uk>.
108. Marshall D, Howell D, Brazil K, Howard M, Taniguchi A. Enhancing family physician capacity to deliver quality palliative home care: an end of life, shared care model. *Canadian Family Physician*. 2008;54(12).
109. Watanabe SM, Fairchild A, Pituskin E, Borgersen P, Hanson J, Fassbender K. Improving access to specialist multidisciplinary palliative care consultation for rural cancer patients by videoconferencing: report of a pilot project. *Supportive Care in Cancer*. 2012;21(4):1201-7.

