

ABSTRACT: Despite significant advances in understanding the benefits of early integration of palliative care with disease management, many people living with a chronic life-threatening illness either do not receive any palliative care service or receive services only in the last phase of their illness. In this article, I explore some of the reasons for failure to provide palliative care services and recommend some strategies to overcome these barriers, emphasizing the importance of describing palliative care accurately. I provide language which I hope will help health care professionals of all disciplines explain what palliative care has to offer and ensure wider access to palliative care, early in the course of their illness.

KEYWORDS: palliative care, health service delivery, models of care, barriers to care

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Introduction

Understanding how palliative care adds to a traditional medical model of disease management has advanced significantly in recent years. In 2014, the World Health Assembly Resolution on Palliative Care¹ called for all countries to incorporate palliative care provision into their health care systems—an initiative that was intended to ensure access to palliative care for all patients in need. Its desired outcomes have not yet been realized.

Why not? What can we do to make it happen?

First, we need to clarify what modern palliative care actually is.

Palliative care can be described briefly as a way of caring for people with life-threatening illnesses which focuses on quality of life. The full World Health Organization (WHO) definition² includes much more detail, but in summary palliative care addresses patient needs in the physical, social, psychological, and spiritual domains via 3 main components:

1. Meticulous prevention and management of symptoms, including pain;
2. Excellence in communication, in discussion of goals of care and advance care planning;
3. An extra layer of support for practical needs, particularly with respect to care provided at the patient's home.

There is now an overwhelming body of evidence that for patients with serious illness, receipt of palliative care is better in all respects than no access and that early access is better than late.³ Multiple studies of palliative care programs in different countries and health care systems show they can improve patient outcomes, including symptom control and quality of life, and

caregiver outcomes, such as reduced stress and dysfunctional grief. In addition, most studies show at least cost neutrality, with many showing substantial cost avoidance by transfer of care from acute care settings to patients' preferred locations—at home or in residential hospice.⁴ Palliative care is intended to prevent and relieve suffering; however, studies also show that patients who receive concurrent palliative care tend to live at least as long as those whose care is directed at disease management alone.^{5,6} Although life prolongation should not be a reason to refer, there should at least be no fear of shortening of life by making (or accepting) a referral to specialist palliative care services.

Contrary to what many people believe, modern palliative care can be provided alongside treatments targeting the underlying disease and may be needed from the time of diagnosis. Similarly, treatments targeting control of disease may be required alongside palliative care, right up to the time of death. Both approaches are necessary and should have equal value, whether in a high-resource health care system with many treatment options or in a developing setting where patients are diagnosed late in the course of illness and few curative treatments are available.

This concept of simultaneous disease-targeting and palliative approaches to care has taken a long time to become established, especially in areas other than cancer care. The needs of people with other life-threatening chronic conditions, such as heart or kidney failure, chronic lung disease, and neurodegenerative diseases, are only relatively recently becoming recognized by specialist palliative care programs.

Current Reach of Palliative Care

Palliative care services are not yet available to all patients with serious chronic illness, even in a high-resource system such as



in the United States. Nearly one-third of US hospitals with more than 50 beds do not have any palliative care service.⁷ A recent article described care patterns in the single largest US health care system (the Veterans Health Administration) in 2012. They found that patients received a palliative consultation care on average 38 days before death and received hospice care (at home or in a residential facility) only 20 days before death.⁸ Yet, in an accompanying editorial, these are described as “remarkable improvements” as compared with 2004–2006 data from a similar US health care network, and the achievements of the Veterans Affairs are quite justifiably described as “striking progress.”⁹ The potential benefits of early integrated palliative care have yet to be fully realized, and many health care networks and institutions have a very long way to go for services to be able to even be described as adequate.

Even where integrated programs have been developed, trends in timeliness of referral are not always going in the direction which would maximize the benefits. For example, British Columbia’s Fraser Health Palliative Care Program cares for a population experiencing about 10 000 deaths a year, with more than 5000 referrals per year in a variety of settings. The average length of stay of patients on the program has dropped from 108 days in 2007 to 68.5 days in 2016, with a median length of stay of just 22.5 days (Personal communication, N. Hilliard, Medical Director of the Fraser Health Palliative Care Program, September 2016). Personal communication with palliative care specialists from Australia, New Zealand, and the United Kingdom, and some published data,¹⁰ suggests that this backward trend is being noted consistently around the world as palliative care services become progressively more stretched.

This is just not enough time to deliver the full potential of palliative care; either from a patient and family perspective or from an economic perspective.

So, why aren’t all patients diagnosed with a life-threatening chronic illness clamoring for referral? Why aren’t health care organizations pouring resources into development of integrated palliative care services, especially now that the “baby-boomer” generation is entering their senior years.

Some previously well-described^{11–13} reasons are listed below:

- Lack of resources to refer to;
- Not knowing that resources exist;
- Ignorance regarding what palliative care is;
- Reluctance to refer;
- Reluctance of patient and/or family to be referred;
- Restrictive specialist palliative care service program eligibility criteria.

Resource Availability

In developed countries, cancer patients are relatively well provided for, with good access to palliative care units and hospices, at least in urban centers. Community hospitals and rural areas are, however, less well served, and people living with chronic noncancer diagnoses have much poorer access to specialist

palliative care programs. Health care professionals in these fields tend to have less training in the skills necessary to deliver at least basic palliative care than those in oncology. Home hospice is inconsistently available, and very few countries have enough palliative care specialists to meet their current workforce needs, let alone meet anticipated future needs.

In less developed health care systems, there may be additional administrative barriers to delivery of palliative care, particularly around access to opioids. Opioids are an essential tool for delivering adequate pain management, and all countries should ensure access to more than one opioid and appropriate adjuvant analgesics. There should be preparations available that can be delivered by oral and parenteral routes. Although often more expensive, transdermal, transmucosal, and rectally administered opioids should also be considered, especially where there is a paucity of nursing staff and/or sterile equipment for administering medicines by injection.

Ignorance and Lack of Awareness of Resources

The trend for residential hospices to be freestanding buildings in pleasant locations away from urban hospitals can lead to lack of awareness of their existence. Students and residents infrequently have access to palliative care rotations, and the paucity of palliative care teaching in many medical school and residency programs makes it difficult for physicians to understand what happens in a specialist palliative care setting. It is therefore important for palliative care teams to interact with their colleagues in other specialties on a regular basis, attending rounds, teaching, and participating in committee work. This can be challenging when added to the responsibilities of professionals who are already overloaded with clinical work and needs to be taken into consideration in workforce planning and staffing models.

Referrer Reluctance

There are many well-documented reasons for referrer reluctance, including the following:

- Fear of upsetting patients;
- Not wanting to abandon them;
- Seeing referral as an admission of failure;
- Not understanding the benefits of referral.

Many still do not understand that palliative care can be provided concurrently with disease-directed therapy, although there has been some progress with this in oncology, as shown in the Veterans Administration study⁷ and directives from a leading oncology society.^{14,15}

Integration is not easily defined or measured as a basic level of palliative care can often be provided by family doctors/general practitioners, nurse practitioners, or specialists in other areas of medicine and may entirely meet the patient’s and family’s needs. Integration of a palliative approach may therefore be difficult to identify when that care is delivered by

professionals who do not have a specialist designation, when care is delivered in community hospitals without designated palliative care beds, or when care is delivered in residential care homes that do not have designated hospice beds.

Specialist palliative care consultation should be considered either when the patient's or family's needs exceed the competence and confidence of the primary team or when it is required to access certain services. The proportion of patients and families needing specialist palliative care will vary from place to place depending on the skills and resources available through primary care. In an ideal world, all health care professionals' training would include basic palliative care competencies, but in reality this has yet to happen, so the threshold for specialist referral is appropriately quite variable. Recognition of when the point of unmet need occurs can be difficult, especially where there is no routine screening for unmet needs. Discretionary referral alone cannot be relied on to provide a timely and appropriate referral practice.

Triggers to refer can be activated automatically when transitions in care are documented (eg, on detection of metastases in cancer care) or by expression of distress recognized through use of screening tools. As distress can occur any time in the course of illness, screening should occur regularly from the time of diagnosis. Prompt referral for specialist palliative care support should be made at any time when physical, social, psychological, or spiritual unmet needs are not able to be satisfactorily resolved by the primary caring team (which may include a variety of specialists as well as family medicine/general practice), including when the goal of disease management is curative in intent.

Although this integrated model may appear to be new in some specialties, there are already examples of where it has been successfully implemented. The emergence of new disease-modifying modalities in many diseases has created prognostic uncertainty and a challenging environment for palliative care integration. For example, some children are living for many years with the possibility of imminent death at the same time as promising new treatments emerge. Specialized palliative care services are needed to collaborate closely with the teams providing disease management over often very extended periods. Some cancer patients have amazing responses to new targeted cancer treatments, even with very advanced disease, and are discharged from hospice services. People with human immunodeficiency virus whose disease used to be inevitably fatal are now living for a long time if they have access to highly active antiretroviral treatment (HAART). Access to HAART may be insecure; hence, prognosis can be unpredictable.

Patient and Family Reluctance

Reluctance to accept a referral for specialist palliative care on the part of the patient and family can vary from one culture to another, but there are common threads to this hesitation, namely, the association of palliative care with dying. "Magical thinking" is the idea that avoidance of talking about death will

allow avoidance of death itself or that discussing death may bring "bad karma." Patients may also not want to upset their regular doctor, thinking that their doctor will see them as giving up or worry that they may have disease-controlling treatment withdrawn. There may also be separation anxiety, with reluctance to lose a valued relationship with their familiar team.

The language used in health care is also very important. It is still thought by many that palliative care and hospice mean the same thing: "somewhere to go to die."¹⁶ The term "palliative care" (in French: *Soin Palliatif*) was coined by Canadian urologist Dr Balfour Mount in the 1970s because of the historical association in the Canadian francophone community of the term "hospice" with the destitute.¹⁷ This renaming facilitated the spread of palliative care programs in the latter part of the 20th century and the term served its purpose well. Originally intended to be a more socially acceptable term, the word "palliative" has unfortunately been misused as a euphemism for dying. Thus, palliative care has now become the new negatively associated term, equivalent to how hospice was originally perceived. As the benefits of early palliative care have been increasingly recognized, there is a need to reframe the language of palliative care.

The term "hospice" is still in use and over the last 40 years has usefully evolved to mean something a little different to "palliative care." In some settings, hospice refers to a freestanding residential care facility for people in the last weeks of life, whereas in other settings the word is used to describe end-of-life care delivered anywhere, especially in the home (home hospice). The consistent feature that now differentiates hospice from modern palliative care is that hospice care is understood to be for patients who are at end of life and have discontinued attempts to cure or control the illness. Hospice care is the last part of an integrated palliative approach to care, and transition from integrated palliative care to hospice may involve a new set of care providers.

To complicate the terminology further, in the United States, hospice usually refers to being on the hospice benefit, which is a financial program allowing care to be delivered in either a residential hospice or at the patients' home, but is quite restrictive. For example, to qualify for Medicare (Part A—Hospital Insurance), a person must¹⁸

- Be aged 65 years and above, or
- Be totally disabled for at least 2 years, or
- Have end-stage disease (eg, complete kidney failure).

To be eligible for Medicare Hospice Benefit, a person must

- Be enrolled in the Medicare Part A (see above);
- Have a doctor and the hospice medical director certify that they are terminally ill and probably have less than 6 months to live;
- Sign a statement choosing hospice care instead of routine Medicare-covered benefits for their terminal illness;

- Receive care from a Medicare-approved hospice program.

Once a person signs up for the Medicare Hospice Benefit, Medicare will not pay for treatments and medications intended to control the disease. Medicare will also not pay for medical care or services that are not arranged by the hospice. Even though there has been progress in US patients receiving concurrent palliative cancer treatments in recent years,⁶ and even if the hospice benefit will disappear tomorrow, it will take a long time for public perception of the role of hospice in the United States to change.

The patient characteristics used to ration scarce palliative care resources also perpetuate misperception of palliative care as being appropriate only at end of life when all efforts to cure or control have failed. Examples of language focusing on dying copied from the websites of typical large programs in Canada, Australia, and the United States include the following:

A seamless system of care for the dying.” Eligible patients require “Significantly decreased functional abilities (Palliative Performance Scale (PPS) score of 50% or less)” and “Are in the final stages of a life threatening illness (e.g. - metastatic cancer, end-stage cardiac or lung diseases, end-stage neurological disorders, end-stage organ failure, end-stage HIV/AIDS, etc.).

Palliative Care xxxx actively raises awareness and builds capacity for the community to address life limiting conditions, death and dying, grief and loss.

Palliative Care Program resources and services support and enhance the ability of the patient’s primary care team to continue to care for them at the end-of-life. Specialized units exist for patients whose needs cannot be met in other settings.

We give our patients and colleagues mixed messages:

- Refer early . . . but only when you are 100% sure your patient is dying;
- Refer early . . . but we don’t have room for any but the sickest;
- Palliative care will make you feel better . . . but you can only have it when there’s nothing else left to offer;
- Palliative care is better at home . . . but you will have to do a lot of all the work and shoulder much of the costs.

Restrictive Program Eligibility

Rationing of services according to patient characteristics is seen as an unfortunate necessity for palliative care and hospice programs; however, assumption of all aspects of care by specialist palliative care programs propagates an inefficient model of service delivery that is neither sustainable nor patient centered. Family doctors and referring specialists tend to drift away from providing care once a palliative care program becomes involved, either because of a perception that their skills are no longer relevant or that their involvement is not welcome.

Patients do best by having access to both disease-modifying treatments and palliative care simultaneously, so it makes no sense to hand over all aspects of care to a service with limited resources when a referral is made. The most efficient model of care is to have the right people delivering the care at the right time that most suits the circumstances. Who is “right” may change a number of times over the course of a long illness, and palliative care professionals can most efficiently and cost-effectively share their expertise at multiple points in the illness trajectory, stepping back when not needed, ensuring ongoing care is provided by the referring team.

Costs avoided by patients receiving palliative care are rarely redeployed to support the programs that create those savings, and palliative care specialists’ ability to assist those patients with long or indeterminate life expectancies will be severely constrained if a take-over model of care is practiced. This is going to become even more important as patients with increasingly unpredictable prognoses are included in specialist palliative care programs’ mandate.

So How Can We Overcome These Barriers?

Some suggestions have already been presented in discussing the barriers above, but I believe that lack of awareness of the role for modern palliative care is a key obstacle to patients receiving appropriate care. We need to “rebrand” palliative care and hospice.

Rebranding should focus on the benefits of early integration of palliative care into chronic disease management, emphasizing quality care for people living with serious chronic illness, and to use our dwindling public funds in the most responsible and cost-effective manner possible. This rebranding needs to include administrators and politicians. Too many people with the power to make a positive impact do not understand what modern palliative care is, and opportunities to cost-effectively relieve suffering are being lost.

Complex constructs are sometimes extremely difficult to convey in words, and pictorial representations can sometimes convey the necessary nuances of the issue more effectively than long explanations. New visual models of palliative care are emerging, including the bow tie model¹⁹ which emphasizes the inclusion of survivorship as a possible outcome (Figure 1).

This model illustrates the concurrent care of the patient alongside treatment of the disease. It provides a visual map of their potential course of illness and illustrates the dual reality of “hoping for the best, but planning for the worst.” Survivorship is a visibly possible outcome, but the reality of mortality is still present.

The words in the model can be adjusted to different cultures as an understanding of the wider applications of palliative care develops. For example, the term “palliative approach to care” has recently emerged and could potentially describe the middle diamond of the model. “Supportive care” might have previously been understood by some to be an appropriate term for that diamond, but the term has already been adopted

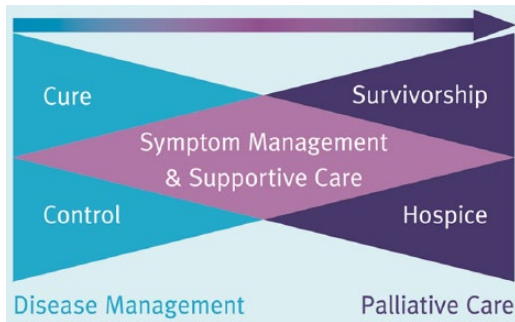


Figure 1. The bow tie model of 21st century palliative care.¹⁹

by the oncology world to mean the medical interventions (eg, transfusions and antiemetics) required to allow for delivery of toxic treatments aiming to cure cancer. It is therefore probably too late now to use it in a wider sense. Combining “supportive care” or “a palliative approach” with additional terms such as “pain and symptom management” not only makes the language unwieldy but also risks diminishing the role of palliative care specialists to being just symptomatologists and does not acknowledge the multidisciplinary teams’ important contributions to meeting patients’ needs. Hospice could be extended to “hospice care” in places where hospice is used to indicate a freestanding building, thereby emphasizing that end of life care can be delivered in patients’ homes, residential care facilities, freestanding residential hospices or even in hospital.

A suggested lexicon for programs to draw from for their mission and value statements, leaflets, Web sites, posters, presentations, and verbal communication includes the following terms.

A Palliative Approach to Care

Palliative care knowledge and expertise can be embedded upstream into the delivery of care across different health care sectors and professions by health care professionals who do not specialize in palliative care. A palliative approach to care is particularly important when the prognosis of the patient is uncertain, and survivorship is a possibility.

Hospice Care

Hospice care is care that focuses on relieving symptoms and supporting patients with incurable illnesses who have a life expectancy of weeks to months. In most cases, hospice care is provided to a patient in his or her own home. It also can be provided in freestanding hospices, hospitals, nursing homes, and other long-term care facilities.

Survivorship

Survivorship refers to a distinct phase in the illness trajectory between cessation of attempts to cure the disease and transition back to normal life or as near to the person’s normal as possible. Learning to live with stable illness may be one state of survivorship, and cure is not necessarily required. People who have been cured of a serious illness may be irreversibly damaged by

the disease or its treatment and may require significant multidisciplinary care to achieve their full subsequent potential.

An additional definition which may be helpful in describing what programs provide is that of a palliative care specialist, adapted from the WHO definition of palliative care.

Specialist Palliative Care

Specialist palliative care is provided by a specially trained team of doctors, nurse practitioners, nurses, social workers, and other health care professionals, who work together with a patient’s primary care team to provide an extra layer of support for people with serious illness. It focuses on providing relief from the symptoms and improving the quality of life of both the patient and the family. It is appropriate at any age and at any stage of a life-threatening illness and can be provided along with curative-intent treatment.

Recommendations

The time has come for modern health care systems to expand the reach of palliative care professional expertise outside of end-of-life care. Health care professionals should no longer use the term palliative as a euphemism for dying. Hospice care describes the part of palliative care that targets truly end of life and the term hospice should be used with pride and specific intent. The suffering of patients who enter the “limbo” of survivorship should be acknowledged and palliative care specialists have the skills to be able to contribute enormously to the care of these patients. Use of the visual bow tie model can help understand this new way of meeting patient needs.

Patients receiving curative and palliative disease-modifying treatments are generally ambulatory, and the most cost-effective way of meeting their needs will be in the outpatient clinic setting, either independently or in conjunction with other specialist visits such as oncologists. Administrators and funding agencies need to be made aware that these ambulatory and integrated services will need considerable expansion. The value of their investment will be seen in costs avoided as illness progresses.

The basic skills required to deliver a palliative approach to care need to be provided for all staff in health care settings where people with chronic illnesses may reside, particularly residential care homes and general hospitals. A palliative approach to care needs to be widely introduced into the training of all health care professionals involved with patients who have serious illnesses. This means that the small cadre of trained palliative care specialists already in practice will need to increase the proportion of their time spent teaching and mentoring. In-hospital consultation services need to be substantially expanded until other disciplines have acquired the knowledge and skills to deliver the palliative approach to care themselves when universal access to this kind of care can become the normal standard of care.

If the best time to start accessing palliative care is as soon as possible after diagnosis, palliative care programs have to start helping patients who may not die of their illness, certainly not in any predictable time frame—“dipping” in and out of their

care when needed. A Do Not Resuscitate order should be a goal for specialist palliative care program eligibility, not a prerequisite. When specialist palliative care programs can respond to need for their skillset on an as-needed basis, independent of prognosis, they can avoid being overwhelmed by the need to assume responsibility for all their needs until time of death.

With a consistent message, given the demographics that we are facing and the widely acknowledged stresses on public funding of health care, the time is right for a substantial shift in the way health care is delivered. In fact, it would be irresponsible not to change!

Author Contributions

PH reviewed and approved the final manuscript.

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