



AN INTEGRATED PALLIATIVE APPROACH TO CARE • DES SOINS QUI INTÈGRENT L'APPROCHE PALLIATIVE



INTEGRATING A PALLIATIVE APPROACH INTO THE MANAGEMENT
OF CHRONIC, LIFE-THREATENING DISEASES:
WHO, HOW AND WHEN?

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Quality End-of-Life
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La Coalition pour des soins
de fin de vie de qualité du Canada



Canadian Hospice Palliative Care Association
Association canadienne de soins palliatifs



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INTRODUCTION

Palliative care should be gold standard for all patients with progressive, life-threatening illness. We should advocate for an interdisciplinary approach that attends to psychosocial issues, advance care planning, and symptom management — the essence of palliative care — for all suitable patients. {Gillick, 2005}

Palliative care focuses on the relief of suffering and support for the best possible quality of life for persons facing serious life-threatening illness and their families. According to the World Health Organization, palliative care is an approach that improves the quality of life of patients and their families facing the problem 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.



PALLIATIVE CARE:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patient's illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, and includes those investigations needed to better understand and manage distressing clinical complications.

HOW PALLIATIVE CARE FITS IN CHRONIC DISEASE MANAGEMENT

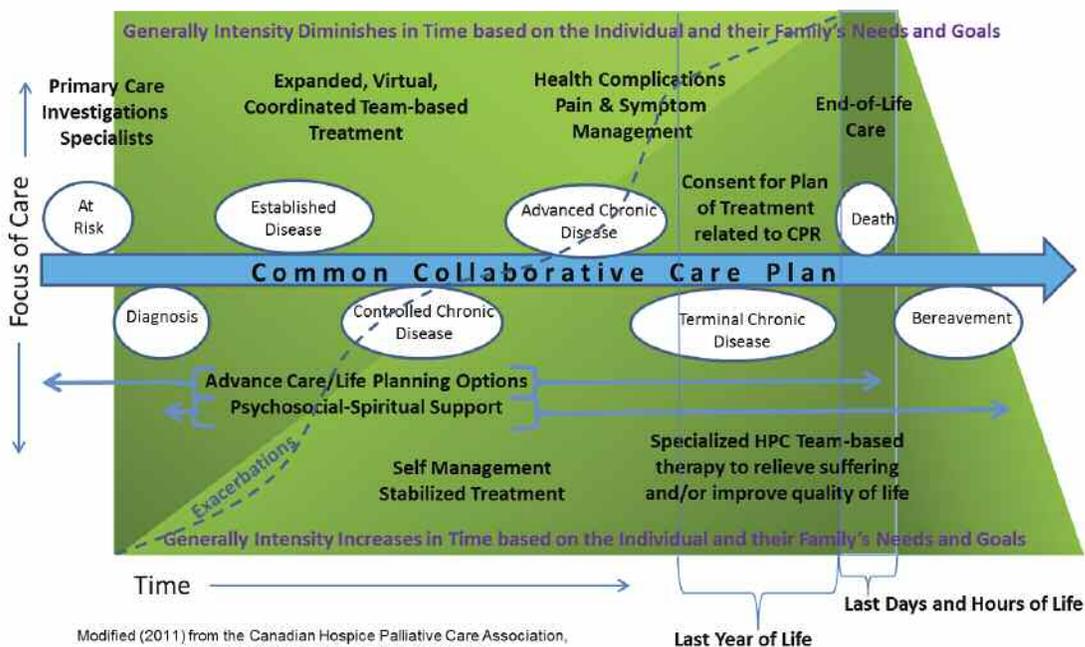
Palliative care goes beyond the traditional medical model to focus on psychosocial issues, spiritual matters, medical decision-making, {National Consensus Project for Quality Palliative Care, 2004} and on the relief of suffering in all its dimensions throughout a person’s illness. {Smith et al., 2012} Because of its focus on the whole person, more experts are advocating that a palliative approach to care could and should be integrated into care for all people with chronic, life-limiting conditions (including cancer) {Smith et al., 2012} and be available much earlier in the course of a disease to address their needs.

People with a chronic, life-limiting disease go through a psychological process of accepting their prognosis: a process that evolves throughout the course of the illness. {Pollock & Sands, 1997} In fact, they are more likely to experience psychological distress, depression and anxiety disorder when they are less aware of their prognosis and do not have opportunities to discuss and accept it. {Wilson et al., 2007; Chockinov et al., 2000; Thompson et al., 2009} For many, taking an active role in learning about and managing their illness and making preparations are active coping strategies that can reduce the psychological distress associated with chronic illness. {Thompson et al., 2009}

The following diagram, developed by the Ministry of Health and Long-Term Care, illustrates how a palliative approach can be incorporated at different stages of the illness:

- When the illness is first diagnosed, the person would be able to talk to someone openly about his or her illness and prognosis, and have the opportunity to discuss the kind of care they want and to develop an advance care plan.

CHILD & ADULT HOSPICE PALLIATIVE CARE - CHRONIC DISEASE CONTINUUM MODEL



Modified (2011) from the Canadian Hospice Palliative Care Association, *A Model to Guide Hospice Palliative Care, 2002*
 By the Care Pathing Across the Continuum of CDM Working Group, MOHLTC, Ontario

- Throughout the illness trajectory, the person would receive psychosocial and spiritual support as well as opportunities to revisit his or her goals and care plan.
- As the disease advances, the person may need pain and symptom management.
- As disease modifying treatment becomes less effective, he or she would receive more specialized palliative care services to relieve suffering and improve quality of life.
- As the person develops advanced chronic disease or enters the terminal phase of the illness, he or she would receive end-of-life care.

In the following model (see Figure 1) developed by the oncology system, people gradually move from a strong focus on treatments that modify the disease to a strong focus on care that helps enhance comfort and maintain function depending on their needs and goals.

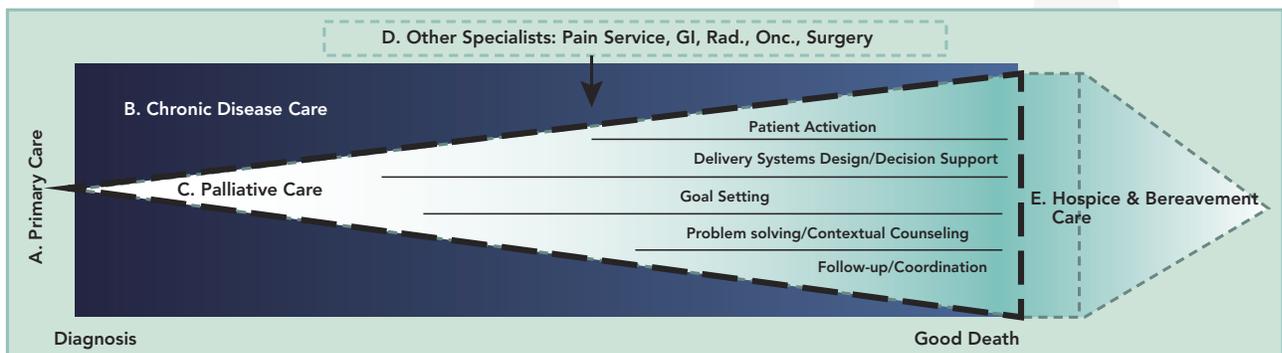


Figure 1: A model of concurrent chronic disease palliative care. © Marie Bakitas, DNSc, APRN; with permission. Modified by the Canadian Hospice Palliative Care Association.

Acknowledging the Unpredictability of Death

A century ago, death was typically quite sudden, and the leading causes were infections, accidents and childbirth. Today, sudden death is less common. Towards the end of life, most people will acquire a serious progressive illness such as heart disease, cancer or respiratory disorders ... that increasingly interferes with their activities until death. {Murray et al., 2005}

The rationale for integrating palliative care into chronic disease management is the recognition that people with chronic diseases often have a long illness trajectory and, during that time, may have different palliative care needs. {Fitzsimons et al., 2007} As their disease progresses, they may experience a complex range of social and emotional needs — including isolation, decreased independence and burden on family members (see Figure 2) — yet most people with chronic illnesses other than cancer often reach the terminal phase of their life without having been offered many of the physical and social resources available through palliative care. {Fitzsimons et al., 2007}

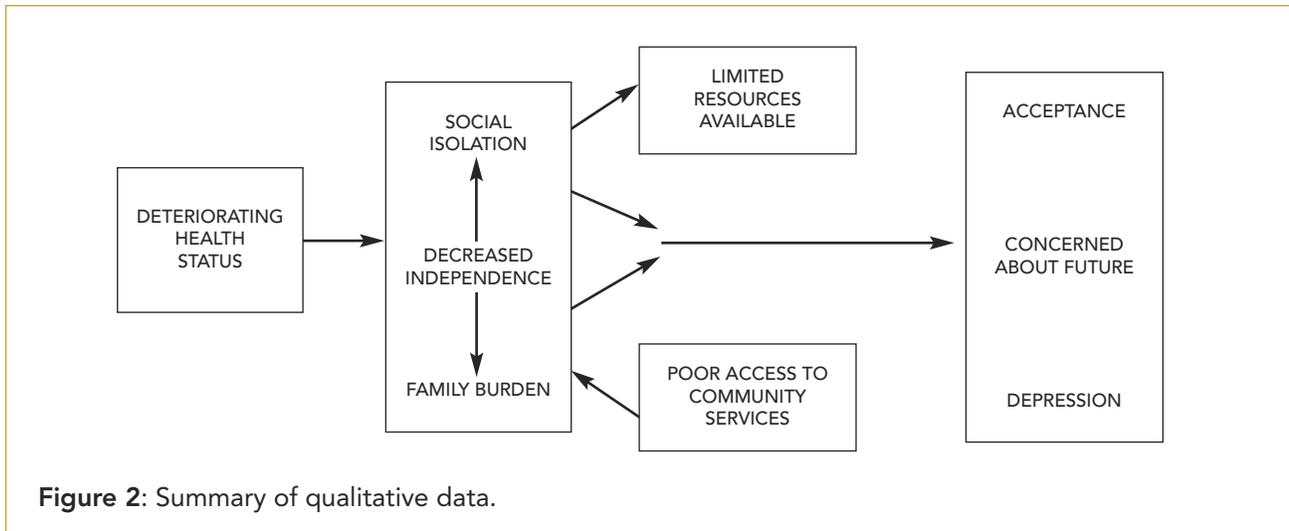


Figure 2: Summary of qualitative data.

Integrating a palliative care approach into chronic disease management recognizes three key trends within the health care system:

- advances in treatment are changing illness trajectories, allowing people with chronic, life-threatening illnesses to live many years — although often with pain, loss of function or other symptoms;
- the growing realization that palliative care is a highly holistic, person-centred approach that has something of value to offer all people with serious illness;
- the strong evidence that high quality palliative care can enhance health and quality of life, and reduce the utilization of more costly health services.

Better lifestyles, public health and medical interventions have given us the opportunity to grow old, accumulate chronic conditions, and die slowly. {Lynn & Forlini, 2001} As a result, people with chronic illnesses are living much longer between diagnosis and death and the burden of chronic disease on individuals, families, and the health care system is growing. {Glare & Virik, 2001} People with a life-limiting illness will likely live with that condition for many years, and during that time experience pain, discomfort, and other symptoms related both to the condition itself and its treatment. They are also likely to have psychosocial needs related to living with a life-threatening illness. {Cochrane et al., 2008} As a result, access to palliative care is becoming a growing public health issue. {Higginson et al., 2004}

Among care providers, there has been a growing realization that people with life-threatening illnesses, including cancer, could benefit from symptom management and psychological support much earlier — even when they are still pursuing disease modifying treatment {Gillick, 2005}, rather than waiting until the increasingly unpredictable last weeks or months of life. {Woodruff, 1999; Higginson et al., 2011}

Although people with chronic, life-threatening illnesses are living longer, the course of their illness and the time of their death will be unpredictable. It has never been easy — even with cancer — to predict when someone is within six months or a year of dying. With other illnesses, predicting death is even more difficult.

While their time of death may be uncertain, the issues they will face are not. Patients with chronic, life-threatening conditions may experience symptoms for a long period of time. {Murray et al., 2005; McGrew, 2001} They may also experience profound losses and have psychological, social, and spiritual needs that require support, often well before the period close to death. {Higginson et al., 2011} Usual care is sadly mismatched to their needs. {Lynn & Forlini, 2001} Being diagnosed as several weeks or months from death can no longer be the trigger for providing palliative care because it will mean that too many people with life threatening illnesses who die “unexpectedly” will not have access to care that could enhance both their living and dying.

THE PRACTICE CHALLENGES OF INTEGRATING A PALLIATIVE CARE APPROACH

In its 2012 policy brief, *The Palliative Approach: Improving Care for Canadians with Life-Limiting Illnesses*, the Canadian Hospice Palliative Care Association (CHPCA) makes a strong case for integrating a palliative approach into chronic disease management. The challenge becomes the best way to put that integrated approach to care into practice. Hospice palliative care has traditionally been considered its own specialty, with teams specifically trained in the skills and competencies required to deliver high quality care in the last weeks of life. But providing earlier access to palliative services integrated with other care will require a different approach.

The CHPCA brief states that: “This integrated palliative care should be provided by primary care, chronic care and long-term care practitioners and available early in the course of a disease (i.e., soon after diagnosis) and throughout the person’s illness trajectory.” That view is echoed in the literature: “[I]t is neither possible nor desirable for all patients to receive, from the time of diagnosis the type of care traditionally provided by palliative care services. Palliative care services need to recognize that their role is primarily a specialist one and that most ‘grass roots’ palliative care is more appropriately done by others, be they family and friends or other health care professionals.” (Glare & Virik, 2001)

However, there are many challenges to moving to this kind of integrated approach to palliative and chronic care — not least of which is the capacity of other health care professionals to incorporate a palliative approach into their care. “Clinicians-in-training are not systematically prepared to assess the clinical and psychosocial factors that indicate to what extent curative, life-prolonging and palliative care are appropriate for a patient, or how they are to be initiated and managed through the course of an illness. Lack of attention to skills in communication and shared decision-making remain a weakness of training in end-of-life care. Students receive little interdisciplinary education and are not coached in the use of a team approach to the care of dying patients and their families ... Students are not directed or encouraged to consider their own attitudes and those of their professions.” (Glare & Virik, 2001)

Making the shift to more integrated care will also challenge the people who are highly skilled in palliative care: “The specialist providers of care at the end of life, such as palliative care services, must be prepared to work flexibly with their colleagues, tailoring their approach to the knowledge, skills and attitudes of the referring physician.” (Glare & Virik, 2001)

There are also organizational challenges to integrating a palliative approach. As Glare & Virik note, “Listening and responding to the wishes of patients and families, discussing choices, assessing and relieving symptoms, providing family support and coordinating care within and across settings all take time.” In many settings, approaches to practice and financial incentives do not take into account the amount of time that will be required to integrate a palliative approach into chronic disease management.

Some care settings and providers — such as long-term care homes and home care providers — may be serving a critical mass of people with chronic, life-threatening illnesses and, therefore, be better able to create a culture of learning and practice that is able to integrate a palliative approach into chronic disease management. Other settings that are more focused on curative care — such as hospitals and even many primary care settings — may find it more challenging.

TOWARDS A NEW MODEL FOR INTEGRATING A PALLIATIVE APPROACH IN CHRONIC DISEASE MANAGEMENT

According to the readers of the *British Medical Journal*, providing palliative care to a larger group of people (i.e., beyond cancer) is the project that would make the greatest difference to health care. {Cochrane et al., 2008}

While a growing number of people inside and outside the health care system see the benefits of expanding access to a palliative approach to all people with chronic, life-threatening illnesses, the key challenge remains “how”? How will this model change practice? Who will be responsible for providing this care? What knowledge, skills, and resources will they need?

Learning from Experience

Over the past few years, a number of different settings and disease groups have tested the impact of integrating a palliative approach to care with chronic disease management. From these studies, there is strong and growing evidence that a palliative approach to care — when combined with disease modifying treatment and disease management — leads to better outcomes for persons and their family caregivers, including: improvement in symptoms, quality of life and patient satisfaction; less burden on caregivers; more appropriate referral to and use of hospice; and less use of futile intensive care. {Smith et al., 2012; Temel et al., 2010; Bakitas et al., 2009; Myers et al., 2011} Advance care planning also promotes choice and improves quality of care. {Sanders et al., 2008}

The benefits of the palliative approach were discussed in detail in the CHPCA brief. Here, we look in more depth at when, how and by whom that care was delivered. The goal is to see whether there are lessons that could be used to shape professional practice and education.

In a study with **patients severely affected by multiple sclerosis** (i.e., unresolved issues with symptom control, psychosocial needs, difficulties with nutrition, advanced planning needs), one group received a palliative care service within 48 hours of the issue/ being identified while others received best standard care for 12 weeks before receiving the palliative care service. The short-term palliative care intervention consisted of, on average, three visits over a six-week period. It was provided by a multidisciplinary team made up of a specialist in palliative care, a palliative care nurse, a psychosocial worker and a coordinator. Team members selected based on the patient’s needs visited the patient at home or where he/she was receiving care to: assess their needs, provide psychosocial support and set plans in place for future care or establish advance directives. Team members also liaised and provided advice to other professionals, including neurologists and community services, about managing the person’s care and symptoms. Both groups reported improvements in symptoms from the intervention; however, those who received the intervention earlier reported a significant decrease in caregiver burden and a trend toward better symptom control. In this case, earlier access to a palliative approach resulted in better outcomes. In particular, the impact of early referral to palliative care services on caregiver burden may indicate that this type of intervention may reduce morbidity during bereavement. While this short-term intervention was effective, its effects began to deteriorate 12-weeks post intervention, which suggests that patients either need interventions from the palliative care service over time or their regular care providers should be educated to provide palliative services as part of their ongoing care. {Higginson et al., 2011} The same researchers also cite two other studies that demonstrated

that earlier access to palliative services improved outcomes (i.e., fewer symptoms, less symptom distress, better quality of life) and reduced costs.

In another study, 151 patients newly diagnosed with **non-small cell lung cancer** were randomly assigned to early palliative care and standard oncology care or to standard oncology care alone. The palliative care intervention consisted of a baseline evaluation (using standardized assessment tools, such as the Edmonton Symptom Assessment Scale or the Condensed Memorial Symptom Assessment Scale) and follow-up at least once per month by members of a multidisciplinary palliative care team made up of seven palliative care clinicians: six physicians and one advanced practice nurse. The average initial consultation with a member of the team took 55 minutes, of which 20 minutes were spent on symptom management, 15 on patient and family coping, and 10 on education about the illness. Patients were also offered an informational visit to the hospice three to six months before the person was expected to die. Researchers measured the impact of the intervention on patients' quality of life, mood and aggressiveness of end-of-life care (e.g., chemotherapy within 14 days of death, lack of hospice care, hospice admission less than 3 days before death). Patients who received the intervention had significantly higher quality of life scores than those who received standard oncology care only. They experienced fewer depressive symptoms and less aggressive care, and — despite receiving less aggressive care — they survived, on average, 2.7 months longer. {Temel et al., 2010} It appears that understanding the prognosis and goals of treatment had the strongest impact on the patients' subsequent choices of therapy and their survival.

In an intervention for **ill people who were housebound**, patients were randomly assigned to usual care or usual care plus an in-home palliative care service, which was delivered by a team consisting of a physician, a nurse and a social worker. The team was responsible for coordinating and managing care, and discussing the goals of care, expected course of the disease, expected outcomes and success of treatment options. The intervention group reported greater satisfaction with care at 30 and 90 days and fewer emergency department or hospital visits. Patients who received the intervention were also more likely to die at home, and the mean cost of their care was lower. {Brumley et al., 2007}

In a Kaiser Permanente study conducted at three sites in three different cities, **seriously ill inpatients** were assigned to usual care or usual care plus an interdisciplinary palliative care service provided by a team made up of a palliative care physician, a nurse, a hospital social worker and a chaplain. The team saw the patient in the hospital, and then formulated a plan of care for the outpatient setting for the patient's primary care provider. Patients who received the intervention reported greater satisfaction with their care experience and with providers' communication, but no difference in symptoms, emotional support or quality of life. The intervention patients also had significantly fewer intensive care stays on readmission. {Gale et al., 2008}

The original Project ENABLE (Educate, Nurture, Advice Before Life Ends) intervention for people with cancer consisted of an advanced practice palliative care nurse and a series of in-person, group psychoeducational seminars called Charting Your Course. The nurse conducted a broad palliative care evaluation with each patient to assess their physical, psychosocial, spiritual and functional needs. The nurse was then responsible for coordinating care within the cancer center and in the patient's community to meet those needs. The seminars for patients and families covered a range of issues including problem solving skills, symptom management, financial

information, complementary therapies, nutrition, family issues, community resources, spiritual issues, advance care planning and communicating with clinicians. Although the intervention had good results, researchers found that one nurse could not evaluate and follow all the patients on a face-to-face basis. They also learned, however, that the intervention could be delivered by phone for patients for whom distance or transportation was an issue. In a randomized controlled trial, researchers tested the same intervention but delivered by a team, who focused on supporting people who were receiving most of their care from a primary care provider. In this model, specially trained palliative care advance practice nurses provide a curriculum to educate patients in problem-solving and communication skills, empowering them to: share their personal values, life circumstances and expectations for care with their clinicians; participate in decision-making; and get the information they need to manage the predictable symptoms of advanced cancer. With this group of patients, as the disease modifying treatments become less effective, the use of palliative care strategies increases. If complex needs arise, the team brings in other specialists (e.g., pain service, hospice). Compared with a usual care control group, patients who received this intervention reported higher quality of life and mood. They also had a lower risk of dying in the year after enrolling in the intervention. {Bakitas et al., 2010}

The PhoenixCare Intervention provided intensive home-based case management for patients with chronic obstructive pulmonary disease or chronic heart failure who had an estimated two-year life expectancy. The intervention, which was provided by registered nurse case managers (who had caseloads of 30 to 35 patients), focused on disease and symptom management, patient self-management and knowledge of illness-related resources, preparation for end of life, physical and mental functioning, and utilization of medical services. The nurses were selected based on their experience in both chronic disease management and end-of-life care. They were supported by a team that consisted of a medical director, a social worker and a pastoral counselor. The services were delivered through a combination of home visits and phone calls. Compared to a control group, PhoenixCare patients exhibited significantly better outcomes on self-management of illness, awareness of illness-related resources and legal preparation for end of life. They reported lower symptom distress, greater vitality, better physical functioning and higher self-rated health.

These studies reinforce that a palliative approach can be integrated into care in all care settings. In virtually all cases, the palliative care services were delivered by people who were highly skilled in palliative care.

How and by whom integrated palliative care is delivered appears to influence its effectiveness. In a 2002-03 study conducted in a hospital, 107 **seriously ill inpatients** were randomly assigned to usual care or usual care plus daily visits from a palliative medicine physician. Patients in both groups were satisfied with their care. The intervention group did not report any improvement in pain and only a minority reported having discussed their prognosis and preferences. The authors suggested the following possible reasons for the ineffectiveness of this intervention: being administered by a single physician rather than an interdisciplinary team, the types of patients recruited and the limited uptake of recommendations by the patients' usual care providers. A similar result occurred in a study of outpatients with **cancer, emphysema or congestive heart failure** who had an expected life span of 1 to 5 years and who were assigned to usual care or usual care plus service from a comprehensive palliative care team, made up of a social worker, nurse, chaplain, pharmacist, psychologist, art therapists, volunteer coordinator and three

physicians. The team addressed the person's physical, emotional and spiritual needs and made recommendations to the person's primary medical team. The intervention included classes, support groups, weekly telephone calls and monthly visits. However, the impact of the intervention was limited by the primary care team's apparent unwillingness to implement the recommendations. For example, the primary care provided prescribed the recommended opioid only one in 13 times, and recommended antidepressants for only three of 18 patients. As Smith et al. (2012) note, these findings reinforce the critical importance of coordination and communication when specialized primary care teams are involved, and for more information on the barriers to integrating a palliative approach to care.

Next Steps

The question remains, what is the best way to deliver integrated chronic and palliative care? Who should provide it? When? And what elements have the greatest impact? There are three possible models currently being explored:

1. Continue to give the primary care team discretion in introducing palliative care. Enhance primary care skills in psychosocial support and bereavement. Encourage primary care teams to make earlier referrals to specialized palliative care teams/programs
2. Take a simultaneous or synchronized approach to palliative care that involves both chronic disease management and palliative care teams. The chronic disease team will continue to be responsible for managing the illness and its treatment, while the palliative care team will be responsible for symptom control, advance care planning, and assisting with complex decision making.
3. Integrate the palliative care approach/skills into chronic disease management and maintain specialized palliative care teams who can consult on issues such as problems with symptom control and complex psychosocial and/or family needs.

Analysis of the Models

Model #1 represents common current practice. The responsibility for most chronic disease management (including palliative care) — particularly for people with illnesses other than cancer — rests with primary care providers. The primary care team or provider is responsible for providing palliative care services and/or making referrals for more specialized services such as symptom control.

Both Model #2 and Model #3 would represent a significant change in practice and improve access to palliative services. Both offer individuals and families the following benefits:

- Greater awareness from the beginning of the illness of the palliative services available and their benefits.
- Earlier discussion of the person's illness trajectory and end-of-life issues.
- More timely discussion and development of goals of care, advance care planning, and care plans.
- Ease in accessing palliative care services as needed (no referrals required) because palliative care is part of their care.

- Better pain and symptom management — throughout the course of the illness.
- Greater capacity to prevent or reduce suffering related to complex psychosocial needs or family dysfunction.
- Greater patient and family satisfaction.
- Less use of more invasive health services that are contrary to the person's goals of care.

For the health care system itself, both Model #2 and Model #3 have the potential to normalize end-of-life care planning, improve patient care and satisfaction, and reduce the use of more costly health care services. They also provide the opportunity to learn how best to integrate the palliative approach into chronic disease management and self-management.

In Model #2, palliative care teams would work side-by-side with the chronic disease teams. This is largely the model used in the studies described above. Experience with this model in other jurisdictions indicates that it improves individual choice and coordination of care. It also facilitates transitions from one service to another. {Myers et al., 2004} However, as most people have more than one chronic illness, this approach may increase the number of providers that a person and family will see, and could create confusion. It is also likely to create capacity issues for the health care system as a whole, given the relatively small number of specialized palliative care providers or teams currently in place. It is unlikely that existing palliative care providers would have the capacity to respond to all the requests to “team” with chronic care providers. Efforts to stretch an under-resourced service across more people are likely to have a negative effect on both the quality and consistency of the palliative services provided. However, looking at how this model has rolled out in other jurisdictions, it may be possible to develop certain palliative care interventions — such as workshops on goal setting, advance care planning, and decision-making — that could be delivered by palliative care providers (e.g., nurses) at key stages in chronic disease management. {Bakitas et al., 2010} Palliative information and support could be provided in the same way as self management resources and courses to equip people and families to prepare for the future and manage their symptoms.

In Model #3, the chronic disease management team would be responsible for integrating palliative care into their disease management program and palliative care would act as a consultant to the team and provide more specialized palliative services as required. The same team that provides care and support for the person's illness will also inform and support the person in dealing with the implications of the long-term prognosis for that illness. This approach has been used effectively in other jurisdictions and was shown to be acceptable to patients and did not overwhelm the service. {Cochrane et al., 2008}

Model #3 is — to some extent — what happens now in chronic disease management, depending on the degree to which chronic disease teams are aware of and adopt palliative care principles. However, the palliative care ‘role’ in chronic disease management teams has not been clearly defined and there are no national standards to guide practice or ensure that all individuals and families are offered these services in a consistent way.

Model #3 is likely to be less confusing for individuals and families — as all aspects of their care will be provided by the same team unless they require more specialized palliative supports. It is also likely to be more cost effective because it involves fewer practitioners and truly integrates palliative care into chronic disease management.

While Model #3 seems the most intuitive, its effectiveness will depend on: the enthusiasm of both the chronic disease teams and specialist palliative care staff, careful planning, stakeholder buy-in through extensive consultation, staff education, agreed referral criteria, goal setting as a tool for assessing ongoing attendance, and close collaboration among all care providers. {Cochrane et al., 2008} In particular, it is critical to educate members of chronic disease management teams in key aspects of palliative care, including:

- Early advance care planning, goal setting, and ongoing discussion of goals of care
- Discussing prognosis and illness trajectory
- Psychosocial support for individuals and families
- Pain and symptom management
- Changing care strategies near end-of-life
- Bereavement support for family and friends
- When to engage specialized palliative care providers (e.g., people with challenging physical, psychosocial, or spiritual symptoms, conflicts over goals of care or decision making, family distress).

It's important to note that any model to integrate palliative care into the management of all life-threatening, chronic diseases will require palliative care providers to become more knowledgeable about the symptoms and signs of and treatments for these advanced chronic diseases, in addition to the unique features of pain and symptom management associated with these conditions. It will also require the system to identify mechanisms to remunerate providers for the time required to deliver palliative services.

Policy Implications

Right now in Canada, only 16 to 30% of Canadians receive any end-of-life care and the care that many of them receive is too little, too late. The early integration of palliative services into chronic disease management combined with access to palliative care at end-of-life has the potential to: significantly improve patient satisfaction and quality of life, ensure people receive care that reflects their preferences and desires, and reduce the use of costly, invasive procedures during the last weeks and months of life. However, for this approach to be effective it requires strong policy support, including:

- 1. Develop a national policy:** The Public Health Agency of Canada should recognize access to palliative care as a public health issue and endorse palliative care as an integral part of chronic disease management. These are the first steps in developing a national policy on palliative care that could significantly improve the quality, consistency and accessibility of palliative care across Canada. It should also work with the provinces and territories to develop pan-Canadian policies to support integrated chronic and palliative care.
- 2. Research new models of integrated care:** The Public Health Agency of Canada should provide funding and work closely with researchers, clinicians and advocacy groups to identify and evaluate different models of integrated palliative care and diffuse effective models into practice. Different models should be assessed for their acceptability to persons, families and

providers, their impact on key measures of health quality and outcomes, their cost and resource utilization, and other implications for the health care system (e.g., education, remuneration).

- 3. Expand accreditation standards.** To reinforce the critical importance of integrating palliative care into chronic disease management, accreditation programs should make the integration of palliative care a standard for all chronic disease clinics and programs, focusing particularly on access to key services such as advance care planning, providing information on disease prognosis and trajectory, and regular discussions of goals of care at key stages in the disease. It should also adopt standards for symptom management, patient knowledge of disease and its implications, and advance care planning. These standards should apply across the health sector and not just to specialized chronic disease management clinics.
- 4. Educate practitioners.** The Academic Health Science Colleges should adopt and endorse palliative care as part of chronic disease management and provide the training practitioners will need to work in various models that integrate a palliative approach into chronic disease management. This training would include communication skills, decision-making skills, care planning skills and education in pain and symptom control.

CONCLUSION

Palliative care has a great deal to offer individuals and families faced with chronic, life-threatening illnesses. Medical advances means that many people will live many years with these illnesses; however, most will eventually die of these diseases and should have the right and support to make informed decisions about their care at the end-of-life. Rather than dimming people's hope, frank discussions about the prognosis and trajectory of these illnesses can help people enhance their quality of both living and dying with these diseases.

Over the past 15 years, Canada has made progress in providing high quality palliative care — particularly in the last months of life — to more of its citizens, but palliative care is still not a mainstream service available to all. The current model of leaving responsibility for palliative care with primary care providers is highly flawed. Instead, Canada must develop a national policy — similar to other countries, such as Norway {Kassa et al., 2007}, that have used this approach to improve palliative care — explore different models to make the palliative approach to care available to more people earlier in the course of a life-limiting illness as well as in the last days and weeks of life. Whether this is done through specialized palliative care teams or through a shared-care model and more consistent education of practitioners responsible for managing chronic diseases should be the focus of research and evaluation.



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