

The Importance of Palliative Care in Chronic Disease Management

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Palliative care is a subspecialty of various medical specialties with fellowship training and a specialty exam. However, a “palliative approach to care” is an important part of all disciplines dealing with chronic disease management. It is now included in the curricula of all Canadian medical schools, with a choice of different training program lengths for physicians.

CBC Radio One’s program “White Coat Black Art” presented by Dr. Brian Goldman, describes a conversation with a woman living with multiple sclerosis in the episode titled “A Meaningful Life.”¹ The woman with multiple sclerosis told the story about her disease and expressed her fears and hopes very eloquently. She experienced a life of increasing disability, cumulative functional and psychological losses, and the reality that she could die soon due to prolonged seizures. She considered circumstances where she would refuse emergency treatment because that intervention would significantly reduce her quality of life. She also considered medical assistance in dying, but found that her current quality of life was good because of the support she received. In particular, she emphasized the importance of palliative care in her care program, particularly in supporting conversations with her family about her goals of care.

Palliative care is an art as much as a science. The WHO definition of palliative care describes the biopsychosocial and spiritual aspects of palliative care, including care of the patient’s loved ones.² In past years, the practice of palliative care was a combination of physician experience, case histories of off-label prescribing of medications, and interventions based on intuition. As the specialty grows in importance and relevance, more rigorous scientific investigations are being carried out on the interventions used, as well as the range of pharmacological options such as medicinal cannabis and laxatives. Randomized controlled trials such as the Massachusetts General Hospital study in 2010 support the beneficial role of early palliative care consultation in oncology patient care.³ A cohort of patients with newly diagnosed metastatic non-small-cell lung cancer were randomized to receive early palliative care consultation plus standard oncological care or standard oncological care alone, with referral to palliative care by their oncologist if necessary.³ The patients receiving early palliative care consultation had better quality of life, less aggressive care at end of life, and longer survival. This was a key study in promoting the value of palliative care and demonstrating that rigorous scientific investigation can be carried out in patients with advanced diseases.

The ideology of early consultation with palliative care is described in the Bowtie Model of Palliative Care (Figure 1) by Dr. Pippa Hawley, UBC Head of the Division of Palliative Care.⁴ It visualizes how palliative care and disease specialist care intersect. In the beginning, there is a larger involvement of disease management care, with some palliative care involvement. However, as the disease

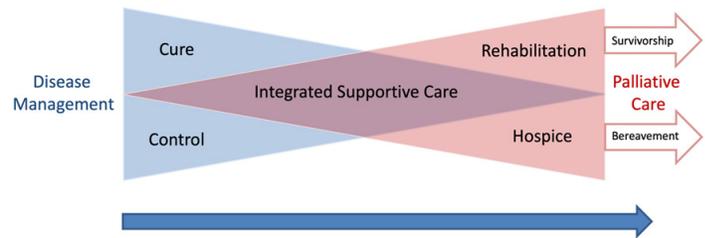


Figure 1 | The Bowtie Model of Palliative Care.

progresses towards end of life, the disease specialist care diminishes and the role of palliative care increases. This model illustrates the evolving role of palliative care in the care of people living with chronic disease, right from the point of diagnosis. Initially, palliative care may focus on symptom management, but it should also involve a “serious illness conversation” with the patient.⁵ This conversation should be a progressive one, in which the meaning of the diagnosis and planned course of treatment are discussed and there is a focus on building a relationship between the physician and patient in the initial phase. This should be followed by further conversations at times of significant change in disease status, or at the request of the patient. These may include discussing the possibility that the patient may die, encouraging patients to express their goals and wishes, involving their loved ones, and naming a substitute decision-maker. In addition, physicians could consider asking themselves the “surprise” question each time they see the patient: “Would I be surprised if this patient died in the next year?” If the answer is no, this should prompt the physician to engage the patient in discussions about the patient’s wishes and goals of care.⁶

As the world’s population ages, physicians recognize that people with chronic diseases, and sometimes multiple comorbidities, often have prolonged suffering and a poor understanding of the nature and natural history of their diseases. As well, conditions such as Type 1 diabetes and certain cancers can now be considered a chronic disease due to advances in pharmacology and surgical techniques. As medicine advances, there is an increasing need for a palliative approach to care throughout hospitals, specialist clinics, family practice, long term care, and community nursing services. Specialist palliative care consultation should only be needed for the most complex cases.

Since the legalization of medical assistance in dying (MAiD), access to palliative care has become even more important. People with chronic diseases whose death is foreseeable are eligible if they have grievous and irremediable suffering. The Canadian Society of Palliative Care Physicians has campaigned in support of Bill C-277, “An Act Providing for the Development of a Framework on Palliative Care in Canada.”⁷ Every patient requesting MAiD should be offered palliation of their suffering. In many cases, palliative care has led to a change in the patients’ quality of life, causing individuals to postpone or withdraw their request for MAiD, as demonstrated by the woman with multiple

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sclerosis interviewed by Dr. Goldman.

Palliative care is not about dying — in fact, it is about supporting people living with a life-threatening illness for as long as is needed. This support involves the management of a person's physical, psychological, emotional, and spiritual suffering. Palliative care is provided by a multidisciplinary care team including nurses, physicians, counsellors, social workers, physiotherapists, and other support services; and can be provided everywhere from the emergency room or hospital bed to the patient's home. Most importantly, palliative care is about supporting patients, their loved ones, and caregivers throughout the illness.

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