

Integration of a palliative approach to care and the role of serious illness conversations in advance care planning

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Introduction

BC is committed to providing a palliative approach to care for persons living with life-limiting illnesses (British Columbia Ministry of Health, 2015). The palliative approach to care aims to reduce suffering and improve quality of life by addressing the physical, psychosocial and spiritual needs for persons and family caregivers. A palliative approach to care is described as a person-centered approach to care guided by the understanding that the person is on a progressive life-limiting illness trajectory (Sawatzky et al., 2017).

The BC Ministry of Health defines person-and family-centred care as “a way of thinking and doing things with persons, families and caregivers as equal partners in health care, rather than doing things to or for them. Persons, families and caregivers become both participants and beneficiaries of a health system that responds to their needs, values and preferences in a respectful, empathetic and holistic way”(British Columbia Ministry of Health, 2017). The BC Health Care system’s valuing of person-and family-centred care is essential to the integration of a palliative approach. Research has shown that to embed a palliative approach, the health care systems’ fundamental values must align with the key principles of a palliative approach (Sawatzky et al., 2017).

This paper describes how the integration of a palliative approach to care is supported by advance care planning, which includes serious illness and goals of care conversations. It is hoped the paper will provide an opportunity for discussion within the communities involved in advance care planning and care of the seriously ill that can lead to a more fulsome understanding of how to embed advance care planning in practice. The BCCPC recognizes the significant amount of work being done by the BC Ministry of Health and the Health Authorities in BC, Alberta and Ontario and community groups in advancing conversations around advance care planning and implementation of the palliative approach to care.

The BCCPC Schema in Figure 1 illustrates the process and components of advance care planning at different periods in a person's life journey and how advance care planning is one component of the palliative approach to care in BC.

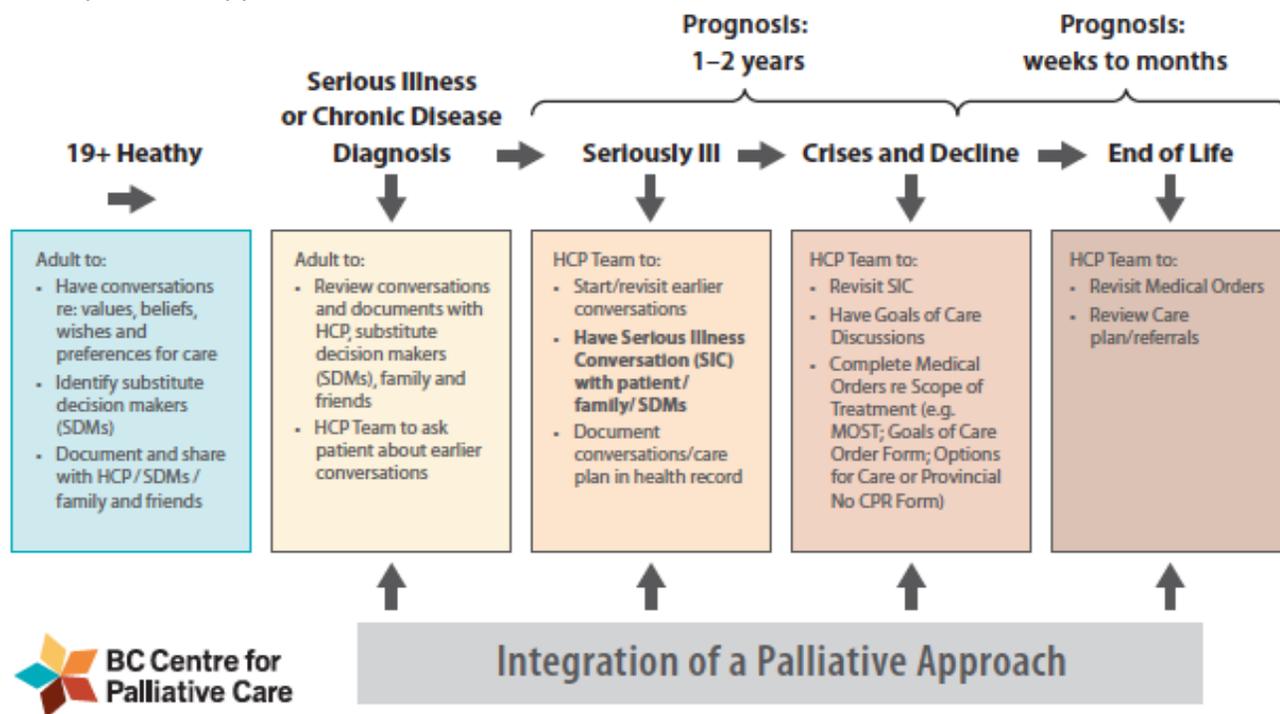


Figure 1- Schema demonstrating BCCPC conceptualization of advance care planning in BC, as an integral part within a palliative approach. Adapted from Ariadne Labs (n.d). 1

Integrating a palliative approach to care

In Canada, the majority of people die as a result of chronic life-limiting conditions (Statistics Canada, 2018). Their illness trajectories involve prolonged time spent accessing primary or acute care while suffering from a steadily increasing symptom burden and loss of independence, often living with an uncertain prognosis. However, despite frequent interactions with the health system, crucial conversations about goals of care or patient values and preferences are not yet routine. This results in a significant burden of non-beneficial and unwanted treatments as an outcome of a lack of conversations that identify person-centred goals and values, as well as options for care, incorporated into an appropriate care plan (Scott, Mitchell, Reymond, & Daly, 2013). Conversations are essential to put the person living with a serious illness at the centre of an ongoing shared decision-making process.

Persons with chronic life-limiting illness are best served by a palliative approach to care which blends palliative care and chronic disease management (Thorne, Roberts, & Sawatzky, 2016). Integrating a palliative approach across care settings ensures that persons with life-limiting conditions and their families are receiving high-quality care according to palliative principles wherever they are being treated (Sawatzky et al., 2016). A palliative approach to care can be integrated early in the illness trajectory by all primary care providers even when potentially

curative treatment is being offered. A palliative approach to care is not tied to formal palliative care services or being on a designated palliative care program although access to specialized palliative care should be available in situations of complexity to provide support to both the primary care provider and the patient and family.

Principles underlying the palliative approach to care include:

- Attention to symptom management and the relief of suffering
- Providing psychosocial and spiritual care
- Focusing on quality of life
- Caring for both the person and chosen family/caregivers, including during bereavement if needed
- Multidisciplinary team approach
- Involvement early in the illness trajectory alongside curative treatment
- Living well until death, accepting death as a natural part of life

(British Columbia Ministry of Health, 2013; Canadian Hospice Palliative Care Association, 2012, 2013).

While not an exhaustive list, these principles are present across palliative care initiatives internationally and are included in the World Health Organization's definition of palliative care (World Health Organisation, 2017). To integrate a palliative approach to care, these principles are adopted early, adapted to meet the needs and wishes of persons and families with any life-limiting illness, and embedded into the settings where a person and family are receiving usual care (Sawatzky et al., 2017). This leads to better agreement between persons and providers on goals of care, a reduction in inappropriate or futile treatments, and support for an open environment where ongoing conversations about illness, decline, and goals become established norms of care (Bernacki & Block, 2014; Sawatzky et al., 2016).

Adopt

Adopting a palliative approach early in the illness trajectory orients care towards what is important for the person and their family through open conversations with the health care providers about the person's goals and priorities as well as prognosis and treatment options. Within a shared decision-making framework, health care providers share information about the illness and what can be expected in the future, and persons and families share their values and preferences for care and together negotiate a plan of care.

Early adoption starts with identification. Health care providers can ask themselves "Would this person benefit from a palliative approach?" (Sawatzky et al., 2017), avoiding the pitfalls of relying on prognostication and linking the delivery of a palliative approach directly to need, not trajectory (Australian Government Department of Health and Ageing, 2011; Shadd et al., 2013).

Adapt

Adapting a palliative approach is about tailoring care to the person and family in the context of their illness. Palliative care was originally developed to treat persons with cancer. Therefore, adaptation is needed to best serve persons with non-malignant life-limiting illnesses that have

different trajectories and symptom profiles to cancer (Sawatzky et al., 2016). Adapting a palliative approach may mean tailoring care to disease-specific needs, delivering care within a person and family's cultural context, or modifying treatment to provide care for persons who are traditionally underserved in BC's healthcare system (Reimer-Kirkham et al., 2016).

Embed

Providing a palliative approach in the setting where the person is being treated ensures that they benefit from the palliative principles as well as illness-specific care. Settings of care where a palliative approach can be embedded include, but are not limited to, long-term care and residential settings, primary care, home care, emergency departments, and acute care units. Embedding a palliative approach in all settings of care involves all health care providers, including health care aides, nurses, physicians, and other multidisciplinary team members (Sawatzky et al., 2017). Support for multidisciplinary team members, as well as communication and coordination within and across teams, are key components of a palliative approach (Sawatzky et al., 2017). Communication related to the persons' and families' evolving understandings of illness, personal preferences, and goals of care is essential in embedding a palliative approach to care (Sawatzky et al., 2017).

Advance care planning in BC

Following legislative changes in 2011, the BC Ministry of Health has been committed to providing resources for the public and health care professionals to engage in advance care planning (Government of British Columbia, n.d.)

Advance care planning is a process that supports capable adults to understand and share their personal values, life goals and preferences regarding future medical care with family and health care providers, and to record and review these preferences if appropriate (Rietjens et al., 2017; Sudore et al., 2017). Advance care planning is a health care decision-making process for adults, which can begin when healthy and continue throughout a person's life.

Serious illness conversations, along with other practices and tools such as goals of care conversations and medical/goals of care orders, are used for care planning and are appropriate at different periods in a person's life journey. All tools are focused on planning for future care and communication that work effectively within a health system to ensure that the care provided is in line with persons goals, values and preferences. Consent for specific treatments is a separate and distinct process that is used as appropriate when treatment decisions need to be made. Recognition by the health care team that the person is seriously ill, triggers advance care planning conversations within the context of his/her illness. This is known as *a serious illness conversation*.

Serious illness conversations

Serious illness conversations are clinician-led discussions between seriously ill persons and health care providers that include person-tailored information about disease understanding, prognosis, goals, fears, worries, strengths, critical abilities and trade-offs within the serious illness context (Bernacki & Block, 2014). Serious illness conversations may or may not result in a

plan for future care, but they do provide a foundation for making future health care decisions and should be revisited over time. They should be initiated early in the illness trajectory, thereby ensuring persons receive care consistent with their goals, values and preferences, even if death is not imminent (Bernacki et al., 2015).

All too often, conversations about goals and values are left until the final months of life, or are put off completely due to prognostic uncertainty (Bernacki & Block, 2014). The timing of the serious illness conversation is important. Conversations are intended to be early enough for the person to have the time, ability and awareness of their illness to be able to enact their personal goals. It is also important that the information gained during a serious illness conversation is made accessible across settings to all team members that are providing care for a person and family.

A team of researchers and clinicians at Harvard University's Ariadne Labs designed the Serious Illness Care Program (Ariadne Labs, n.d.) to address many of the known barriers to early and ongoing conversations (Bernacki et al., 2015). The Ariadne Labs' Serious Illness Care Program is a widely adopted, evidence-based system level approach supporting the use of a structured serious illness conversation guide that has been shown to promote understanding of person-centred goals and priorities for current and future care. This systems-level intervention is built around a Serious Illness Conversation Guide, containing structured questions drawn from best practices in palliative care (Bernacki et al., 2015). Refer to Appendix A for a more detailed description of the Serious Illness Conversation Guide. Using a systems level approach aligns with Sawatzky et al. (2017)'s emphasis on a shift in philosophy supported by systematic interventions to elicit person and family perspectives on care.

Implementation of the Serious Illness Care Program has six-steps:

1. Systematic identification of persons at high risk of death within the next year.
2. Development of triggers to ensure discussions take place at the appropriate time.
3. A 2.5-hour training program for health care providers including role-plays, followed by ongoing coaching and support on how to use the guide effectively (Bernacki et al., 2015).
4. Use of the Serious Illness Conversation Guide; providing a structure to setting up, conducting, closing and documenting the conversation, including prompts with person-tested language (Ariadne Labs, n.d.; Bernacki et al., 2015).
5. Written materials to support persons and families. Firstly, in preparing for conversations by considering and discussing values and goals, identifying their questions, and considering hopes and fears in the face of changing health. Secondly, to support persons in sharing their goals with family members after discussion (Bernacki et al., 2015).
6. A dedicated, structured documentation process in the electronic health record or chart that allows for easy access to information about persons' goals and values for all care team members across settings.

Although on-going evaluation of the overall effectiveness of the program continues, preliminary findings show that when the Serious Illness Conversation Guide is implemented in a practice setting more conversations occur, they are happening earlier during illness, and they are of better quality when the program is used. Persons view the serious illness conversation as

worthwhile, clinicians find the approach effective and feasible, and the value of a multidisciplinary team approach to the conversation was noted (Bernacki et al., 2015; Lakin et al., 2017, Paladino et al., 2015).

Using the above steps for implementation, the BC Centre for Palliative Care (BC CPC) launched the Serious Illness Conversation Initiative to adopt the Ariadne Serious Illness Care Program in 2016, after receiving endorsement from a wide variety of clinicians, educators and decision makers.

Experience in Implementing a Serious Illness Conversation Initiative in BC

The BCCPC project aims to embed the Serious Illness Care Program in care for all persons with serious illness in BC who are estimated to be in the last one year of life. In partnership with Health Authorities and other organizations, over 1300 clinicians, 110 Facilitators and 23 Master Trainers were trained. The role of Master Trainers is to lead the implementation of the Serious Illness Care Program within their communities by training others and developing toolkits for specific needs to facilitate a rollout of the initiative locally. Toolkit development includes adaptations for Substitute Decision Makers (Fraser Health Authority-Dr Charlie Chen), Pediatric Palliative Care (Canuck Place-Camara van Breemen) and for Nurses and Allied Health professionals. Current pilots in BC are in disease-specific groups (e.g. renal) and in various care settings (primary care; residential care; First Nations Communities).

Conclusion

Advance care planning, including practice supports and tools such as serious illness conversations, goals of care conversations, and medical/goals of care orders, plays an essential and important role in the implementation of a palliative approach across care settings. The BCCPC schema (Figure 1) illustrates how each of these tools support advance care planning at a specific period in a person's life journey. All advance care planning practices and tools enable person-and family-centred care, a fundamental principle in the palliative approach, by fostering dialogue between persons, families and health care providers around the person/family goals, values, and preferences and placing them at the centre of care.

About the BC Centre for Palliative Care

The BC Centre for Palliative Care (BCCPC) was established in 2013 with a grant from the BC Ministry of Health to support the implementation of the 2013 Provincial End-of-life Care Action Plan. Working with members of the public, policy makers, regional health authorities, professional bodies and community organizations, the BCCPC facilitates person-centred care by promoting more, better, and earlier conversations between individuals, their families and substitute decision makers, and health care providers and addressing barriers and gaps. These conversations are broadly known as advance care planning (ACP) and BC CPC actively supports the development of ACP resources and strategies to further awareness and understanding of ACP within communities and the health care system.

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Appendix A

Serious Illness Conversation Guide	
CONVERSATION FLOW	PATIENT-TESTED LANGUAGE
1. Set up the conversation <ul style="list-style-type: none"> Introduce purpose Prepare for future decisions Ask permission 	<p>"I'd like to talk about what is ahead with your illness and do some thinking in advance about what is important to you so that I can make sure we provide you with the care you want — is this okay?"</p>
2. Assess understanding and preferences	<p>"What is your understanding now of where you are with your illness?"</p> <p>"How much information about what is likely to be ahead with your illness would you like from me?"</p>
3. Share prognosis <ul style="list-style-type: none"> Share prognosis Frame as a "wish...worry", "hope...worry" statement Allow silence, explore emotion 	<p>"I want to share with you my understanding of where things are with your illness..."</p> <p><i>Uncertain:</i> "It can be difficult to predict what will happen with your illness. I hope you will continue to live well for a long time but I'm worried that you could get sick quickly, and I think it is important to prepare for that possibility."</p> <p>OR</p> <p><i>Time:</i> "I wish we were not in this situation, but I am worried that time may be as short as ____ (express as a range, e.g. days to weeks, weeks to months, months to a year)."</p> <p>OR</p> <p><i>Function:</i> "I hope that this is not the case, but I'm worried that this may be as strong as you will feel, and things are likely to get more difficult."</p>
4. Explore key topics <ul style="list-style-type: none"> Goals Fears and worries Sources of strength Critical abilities Tradeoffs Family 	<p>"What are your most important goals if your health situation worsens?"</p> <p>"What are your biggest fears and worries about the future with your health?"</p> <p>"What gives you strength as you think about the future with your illness?"</p> <p>"What abilities are so critical to your life that you can't imagine living without them?"</p> <p>"If you become sicker, how much are you willing to go through for the possibility of gaining more time?"</p> <p>"How much does your family know about your priorities and wishes?"</p>
5. Close the conversation <ul style="list-style-type: none"> Summarize Make a recommendation Check in with patient Affirm commitment 	<p>"I've heard you say that ____ is really important to you. Keeping that in mind, and what we know about your illness, I recommend that we _____. This will help us make sure that your treatment plans reflect what's important to you."</p> <p>"How does this plan seem to you?"</p> <p>"I will do everything I can to help you through this."</p>
6. Document your conversation	
7. Communicate with key clinicians	



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