

A FRAMEWORK FOR PALLIATIVE CARE IN CANADA

Online Consultation: What We Heard Report

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To obtain additional information, please contact:

Health Canada
Address Locator 0900C2
Ottawa, ON K1A 0K9
Tel.: 613-957-2991
Toll free: 1-866-225-0709
Fax: 613-941-5366
TTY: 1-800-465-7735
E-mail: hc.publications-publications.sc@canada.ca

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A FRAMEWORK FOR PALLIATIVE CARE IN CANADA: ONLINE CONSULTATION "WHAT WE HEARD" REPORT

CONSULTATION APPROACH

On May 7, 2018, Health Canada launched two 70-day online consultations to solicit input from the public and health care providers. For these consultations, a bilingual online engagement platform was used. It allowed participants to discuss topics, share stories and answer quick poll questions.

Throughout the summer of 2018, Health Canada officials held focus groups with representatives of various groups, including underserved populations, caregivers, researchers, data collectors and health care providers, to hear in greater detail the unique challenges facing segments of the population, as well as promising practices.

In September 2018, two more consultation activities were held. On September 12, 2018 a stakeholder meeting was held with over sixty stakeholders (e.g., researchers, health care providers, governmental and non-governmental organizations and caregivers) participating. It was designed to obtain input on how to incorporate what we heard across all of the consultations in a meaningful way into the Framework.

On September 13, 2018, two small roundtable discussions took place to learn more about access to and experiences related to pediatric palliative care and hospice palliative care. At Roger Nielson House, the paediatric palliative care hospice serving Ottawa, Health Canada representatives met with families of former pediatric palliative care patients. At the Maison Mathieu-Froment-Savoie, a Gatineau hospice, discussions were held with health care providers, caregivers, patients and their families to hear about their experiences with palliative care.

This What We Heard Report summarizes the input received through the online consultations, as well as written submissions on a palliative care framework responding to the on-line consultation. The data from this consultation report is based on the opinions, experiences, ideas and feedback submitted by contributors to the online consultations. The data presented here is not reflective of the general public nor should it be seen as representative of the full spectrum of Canadians' views. However, it provides an overview of the information that was provided throughout the on-line engagement process. This Report, as well as input received from the other streams of consultation is reflected in the Framework on Palliative Care.

FORMAT OF THE ONLINE CONSULTATION

The online consultation included two discussion forums: one that was open to the public and another that was closed to accommodate stakeholders and health care providers.

The public consultation had a phased approach and new content was added regularly over the 70 day comment period. The following themes were posted for discussion:

- Definition
- Advanced Care Planning
- National Hospice Palliative Care Week
- Consistent Access to Palliative Care
- Person and Family-Centred Care, People living with life threatening illness, and Caregiver Supports
- Special Populations
- Health Care Provider Education, Training and Supports
- Community Engagement, and Grief and Bereavement

The closed consultation had 10 discussion questions with similar themes as the public consultation.

TYPES OF ENGAGEMENT

Together, the consultations had over 12,000 visits. These visits were made by both those who contributed and those who visited, but did not make a contribution to the consultation. Of those, 1,092 (12%) people registered and contributed to the consultation.

Registered participants could contribute to the consultation multiple times. In total, there were 7,187 contributions to the consultations:

Open Consultation:

- Discussion Forum (14 questions): 5,428 contributions
- Quick Polls (7 polls): 1,087 contributions
- Share Your Story: 47 contributions
- Ideas (7 ideas): 167 contributions

Close Consultation:

- Discussion Forum (10 questions): 458 contributions

Who were the participants?

Those who registered to participate in the consultation provided some basic demographic information. The demographics included:

- region
- gender

REGION

Province/Territory	Open Consultation	Closed Consultation	Total
Ontario	43.7%	41.9%	43.5%
Prairies (AB, MB, SK)	23.0%	23.7%	23.1%
British Columbia	17.0%	16.1%	16.9%
Atlantic (NS, NB, PEI, NFLD)	8.5%	11.8%	8.8%
Quebec	6.5%	3.2%	6.2%
North (YK, NT, NWT)	0.8%	3.2%	1.0%

GENDER

Province/Territory	Open Consultation	Closed Consultation	Total
Female	81%	83%	81%
Male	17%	11%	17%
Other/Prefer not to answer	2%	6%	2%

WRITTEN SUBMISSIONS AND LETTERS FROM ORGANIZATIONS AND INDIVIDUALS

Health Canada also received some written submissions and letters from organizations and individuals who wished to participate in the consultations.

- Total written submissions = 150+
- Total letters from organizations = 29
- Total letters from individuals = 102

What is palliative care?

“Many people confuse end of life care with palliative care and assume palliative care is only offered when someone is actively dying... We need to do a better job at incorporating discussions of palliative care as soon as someone is diagnosed with a life limiting illness.”

Practitioner

A few participants referred to the palliative care definition used by:

- The World Health Organization (WHO);ⁱ and
- The Canadian Hospice Palliative Care Association (CHPCA).ⁱⁱ

Even though these definitions clearly state that palliative care can go hand in hand with other therapies, some participants pointed out that palliative care is still understood as end-of-life care and as a sure sign of imminent death.

Most participants said that public education, training for health care professionals and increased access to palliative care at an earlier stage would help reduce that stigma.

Replacing the term “palliative” with another word was not considered a good option by most participants.

ADVANCE CARE PLANNING (ACP)

“ACP is a gift that you give your family and loved ones that lasts not only when difficult decisions have to be made, but afterwards when a person has died and questions arise about why treatments were either initiated or not.”

Participant

Most participants who have undertaken an ACP process and who have made their wishes known to their loved ones describe the experience as a positive one.

Many participants said that ACP should become a matter-of-fact issue, just like insurance.

Most participants said that they were confident their wishes for care would be respected.

However, some participants said that they feared that their ACP would not be implemented.

Participants identified the following fears around ACP:

- The care team will not be told that I have an ACP;
- The care team will not know where to find my ACP;
- The care team will not listen to my wishes; and
- The resources I need will not be available when I need them (hospice bed, home care).

CONSISTENT ACCESS

"... timely referral. Numerous times clients can remember the person and the shift on when they finally "learned" about palliative care. This needs to be introduced before it's needed so the client can decide and make better choices for themselves."

Nurse

"My mother had to ask about palliative care when she was living with cancer. Her doctor seemed to be resistant to the idea as if it would mean she had given up hope. However, once referred, the relationships formed with the staff were so helpful, both to her and to our family."

Family Member

Participants identified different types of barriers preventing access to palliative care:

- Lack of resources, such as beds, home care services and access to specialists (e.g. doctors, nurses, therapists), especially in remote areas;
- Confusion about what constitutes palliative care and when it should be provided, noting that a very short life expectancy should not be the only criteria;
- For health care professionals, the misconceptions and confusion surrounding curative care, palliative care and end-of-life care fuel fears and denial on the part of patients and foster resistance within medical teams to refer to palliative care services;
- Lack of training and lack of uptake of the palliative approach to care on the part of some health care professionals; and
- Lack of information and resources for patients and caregivers.

Following are some suggestions offered by participants to improve quality of life for patients and their loved ones, including improved access to occupational therapists and making care centres more pleasant, i.e., less clinical.

Three main ideas emerged from this discussion:

1. Making better use of technology, including telemedicine and remote monitoring;
2. Making better use of an interdisciplinary approach to care; and
3. Making home care more accessible.

PERSON AND FAMILY-CENTRED CARE

"Symptom control is everything. Without it, family relationships, and relationships with friends and neighbours suffers. Once symptoms are relieved ... living again can begin."

Palliative Volunteer

“What is important at end of life is whatever the dying person says is important, and this might change from minute to minute or day to day... We ask, ask, and then ask again, “what is important to you right now and what do you need me to do, or want me to do?”

Palliative Practitioner

Most participants mentioned that palliative care is more than just medical care. It also needs to meet one’s psychosocial and spiritual needs. Dignity, compassion and respect were often cited as principles, and were particularly highlighted in testimonies of what worked and what did not during their palliative care experiences.

Overall, personal choice was probably the most important aspect for the participants. People want to express their wishes and establish an end-of-life protocol, or ACP, that will be respected. There were multiple mentions of a holistic approach to palliative care based on communication, access to psychosocial support and “more care” for people living with a life-limiting illness and for caregivers (more time for non-medical dialogue, more continuity, more collaboration, more training, more resources, etc.).

As well, physical comfort, pain and symptom management were among the main concerns of participants.

Recurring challenges faced by caregivers mentioned throughout this theme include:

- Access to supports and services, especially home support for medical care;
- Stress (financial and psychological, including risk of burn-out);
- Communication with health care teams;
- Basic knowledge about care; and
- State of mind: people do not always accept their illness and often resent the loss of control over their own life, which makes caregiving more difficult.

ACCESS TO PALLIATIVE CARE FOR SPECIAL POPULATIONS

“Great examples [of programs for special populations] are the Mission Hospice in Ottawa and the Journey Home hospice in Toronto. People who are homeless or underhoused need a range of services not available in a standard hospice, including flexibility and understanding of their lives.”

Participant

“Implementing a [new] approach... involves community engagement and community capacity development among diverse communities. It also takes time and skilled facilitators who can navigate between cultural communities and the health system.”

Practitioner

Many participants in the consultation said that every Canadian should have access to palliative care when the need arises. Access issues include a general lack of understanding of what palliative care is, and difficulty in obtaining the services from appropriate health care professionals. They also recognized that a lot of work remains to be done so that every Canadian has access to palliative care when the need arises.

This is particularly true for special populations, such as Indigenous individuals, recent immigrants, people experiencing homelessness or who are vulnerably housed, and those living in remote and rural areas.

Some participants also mentioned the need to “walk the talk” by investing in palliative care. They advocated for more hospices, more trained professionals and better public drug and treatment coverage.

HEALTH CARE PROFESSIONALS TRAINING AND SUPPORTS

“There should be more public education and discussion about what happens when we die and our options as to how and when we die. This education is necessary for both individuals and for professionals so that we have a common understanding and language of death.”

Participant

“[End of life discussions] could be improved through the provision of specific training to [teach] health care providers how to handle communicating with patients with life-threatening conditions and discussing palliative care options with them.”

Participant

Providing training to health care professionals on how to talk about death and dying, ACP and palliative care was the most frequent recommendation of participants to the consultation.

Concrete, hands-on training and mentoring were seen as the best approach. A number of participants mentioned role-playing as a great way to learn how to communicate in difficult situations.

Close to half of participants said that appropriate workshops and materials already existed.

The following training programs were most frequently mentioned:

- Learning Essential Approaches to Palliative Care (LEAP Core) developed by Pallium Canada;
- Hospice Palliative Care Nursing Certification (CHPCN);
- The Comprehensive Advanced Palliative Care Education Program (CAPCE); and
- Fundamentals of Hospice Palliative Care.

Some participants said that there needs to be a culture shift in the way we talk about death and dying. This change should be reflected in the priority setting and daily operations of the health care system. For instance, palliative care should be available in long-term care facilities, and health care professionals

should have more time to discuss issues surrounding palliative care with persons living with life-limiting illnesses.

Barriers for health care providers to access training and support identified in the consultation:

- The limited number of training sessions, especially in rural and remote areas;
- The cost of training, which is not always covered employers;
- The lack of support from management (who do not see the value and/or do not make time for it); and
- The lack of time for training while working full-time.

GRIEF AND BEREAVEMENT

“The best time to introduce grief support is some time between when a patient is diagnosed with a life-threatening condition and when death is expected so that those suffering from anticipatory grieving can obtain assistance.”

Participant

“Grief support, in the form of anticipatory grief support, should be offered as early as possible... There are many losses experienced along the journey of an illness and the more support available the better chance that the client, caregivers and loved ones will be prepared to cope with changes.”

Participant

When should grief support be offered?

Most participants believed that grief support should be offered before death. In fact, a large number said that it should be discussed as soon as one is diagnosed with a life-limiting illness.

Among those who believed that it should only be offered after death, half said that it should be offered within the first three months while the other half said that it should be offered whenever necessary.

- From the diagnosis – 61 %
- When it is necessary – 14 %
- Within three months after death – 12 %
- When the patient is referred to palliative care – 6 %
- Before death – 6 %
- In the year following the death – 1 %

How long should grief support last?

Most participants believed that grief is a very personal experience and that it cannot be generalized.

Taking that into account, a third of participants said that grief support should be available as long as it is necessary, sometimes even years after death. Many others said that it should last between six and twelve months.

- As long as necessary – 63 %
- 1 year – 17 %
- 6 months – 13 %
- 3 months – 3 %
- 1 month – 1 %
- 1-2 years – 3 %

Grief support can take several forms, depending on the individual's needs.

The most frequently mentioned types of interventions were:

- Individual counseling;
- Support groups;
- Internet forums; and
- Telephone help lines.

CAREGIVER SUPPORTS AND COMMUNITY ENGAGEMENT

“Without these people [caregivers], what a mess the health care system would be in! We should do everything we can to support them, whatever they need”.

Volunteer

“It is difficult to find appropriate community resources in a timely manner. Some services are actively promoted (hospice volunteers) but sometimes these services are not appropriate for complex needs and families do not know how to access more professionally trained caregivers, or they cannot afford to access them.”

Family Member

More than a third of participants were aware of programs, but a significant number believed that there is room for improvement, both in terms of the variety of services offered and in their availability, especially in rural and remote areas. One fifth of participants said that they were not aware of programs designed to help caregivers or grieving individuals in their region.

The most frequently mentioned types of programs that could be improved were:

- Subsidized free home care services;
- Occasional respite for caregivers; and
- Info lines, websites and documentation about caregiving and bereavement.

A large majority of participants mentioned that community programs would benefit from better funding and from some promotion and advertising.

CONCLUSION

The Consultation Report findings informed the Framework particularly the clear messaging that person- and family-centred care must be the basis of palliative care delivery. The voices we heard through the on-line consultation also inspired and shaped the Guiding Principles developed to accompany the definition of palliative care. These Guiding Principles include:

- Palliative care is person- and family-centred care
- Death, dying, grief and bereavement are a part of life
- Caregivers are both providers and recipients of care
- Palliative care is integrated and holistic
- Access to palliative care is equitable
- Palliative care recognizes and values the diversity of Canada and its peoples
- Palliative care services are valued, understood, and adequately resourced
- Palliative care is high quality and evidence-based
- Palliative care improves quality of life
- Palliative care is a shared responsibility

The Framework will be tabled in Parliament by December 13, 2018 after which an implementation plan will be developed.

FOOTNOTES

ⁱ World Health Organization (WHO). (2018). WHO Definition of Palliative Care:

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 patients 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, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

WHO Definition of Palliative Care for Children

Palliative care for children represents a special, albeit closely related field to adult palliative care. WHO's definition of palliative care appropriate for children and their families is as follows; the principles apply to other paediatric chronic disorders (WHO; 1998a):

- Palliative care for children is the active total care of the child's body, mind and spirit, and also involves giving support to the family.
- It begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease.
- Health providers must evaluate and alleviate a child's physical, psychological, and social distress.
- Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited.
- It can be provided in tertiary care facilities, in community health centres and even in children's homes.

ⁱⁱ Canadian Hospice Palliative Care Association. Definition of Hospice Palliative Care.

Hospice palliative care is aimed at relieving suffering and improving the quality of life for persons who are living with, or dying from, advanced illness or are bereaved.

Palliative care is a special kind of health care for individuals and families who are living with a life-limiting illness that is usually at an advanced stage. The goal of palliative care is to provide comfort and dignity for the person living with the illness as well as the best quality of life for both this person and his or her family. A "family" is whoever the person says his or her family is. It may include relatives, partners and friends.

An important objective of palliative care is relief of pain and other symptoms. Palliative care meets not only physical needs, but also psychological, social, cultural, emotional and spiritual needs of each person and family. Palliative care may be the main focus of care when a cure for the illness is no longer possible. Palliative care services help people in later life who are ill to live out their remaining time in comfort and dignity.

Palliative care services are helpful not only when a person is approaching death but also during the earlier stages of an illness. Palliative care may be combined with other treatments aimed at reducing or curing the illness, such as chemotherapy. Families also benefit from support when their loved one is dying and after his or her death.