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## Understanding Canadians' Views on Palliative Care

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Ce rapport est aussi disponible en français.

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July 2022

This public opinion research report presents the results of an online survey, focus groups and in-depth interviews conducted by Earnscliffe Strategy Group on behalf of Health Canada. The quantitative research was conducted in March 2022 and the qualitative research was conducted from May to June 2022.

Cette publication est aussi disponible en français sous le titre : Comprendre l'opinion des Canadiens sur les soins palliatifs

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## Executive summary

Earnscliffe Strategy Group (Earnscliffe) is pleased to present this report to Health Canada summarizing the results of quantitative and qualitative research undertaken to gain an understanding of people in Canada's views on palliative care to support a public education campaign.

Palliative care can help to improve quality of life for people of all ages living with life-limiting illness by relieving symptoms, helping people continue to be actively engaged in the things they enjoy doing, and when the time comes, enabling a peaceful and dignified death and providing support to the individual and their family throughout the dying and bereavement process. Unfortunately, Canadians do not consistently have access to the palliative care services they require in their preferred setting. Barriers to accessing palliative care are multifactorial and complex and have been exacerbated by the COVID-19 pandemic.

The Government of Canada has committed to improving access to quality palliative care by advancing Health Canada's Action Plan on Palliative Care. A key priority of the Action Plan is to raise awareness and understanding of the importance of palliative care, including public education on grief. Initiatives under this priority area include the development and implementation of a two-phased public awareness campaign:

- i. Phase I - targeting non-palliative care health/social care providers to educate them on the benefits of early intervention of palliative care for patient outcomes and quality of end-of-life;
- ii. Phase II - targeting Canadians to support the gradual normalization of death and dying, and the benefits of palliative care.

Public Opinion Research was required to inform the development of Health Canada's palliative care public education campaign. The overall objective of the study was to gather evidence-based data and key insights on palliative care and on grief literacy. The information gathered will also serve as a baseline to determine key performance indicators to measure the impact of Health Canada's public education efforts.

To meet the research objectives, Earnscliffe conducted a two-phased research project. The first consisted of online surveys of:

- 505 health/social care providers who are not palliative care specialists, including 151 general practitioners, 50 specialists, 151 nurses and 153 other health/social care providers.
- 852 Canadians living with a life-limiting illness, including 261 Black or other persons of colour, 102 Indigenous respondents, and 260 individuals with a physical disability.

The field work with health/social care providers was conducted from February 12 to March 25, 2022. The survey was offered in English and in French. The average length of interview was 12 minutes.

The field work for the survey of individuals with a life-limiting illness was conducted from February 22 to March 13, 2022. The survey was offered in English and in French. The average length of interview was 11 minutes.

Our field work subcontractor for the quantitative portion was Leger. The survey with health/social care providers was hosted by Leger but drew on the MD Analytics’ panel for sample. The survey of individuals with a life-limiting illness was conducted using Leger’s proprietary online panel.

The second phase of the research was qualitative and involved both online focus groups and in-depth interviews. To begin, we conducted three online focus groups with health/social care providers. For each group, six providers were recruited. Two groups were conducted with health/social care providers living in Eastern Canada (Atlantic Canada, Quebec, and Ontario), including one that was conducted in French, and another with health/social care providers in Western Canada (Manitoba, Saskatchewan, Alberta, British Columbia, and the North).

We also conducted 60 in-depth interviews with Canadians with a life-limiting illness, including 20 interviews with Black or other persons of colour and 20 interviews with those with a physical disability. For each target audience, eight interviews were conducted in English with residents of Eastern Canada, five interviews were conducted in French with residents of Eastern Canada and seven were conducted in English with residents of Western Canada. All were offered the opportunity to participate in their official language of choice irrespective of their location in Canada to accommodate those in official language minority communities (OLMCs).

Participants were also provided with incentives in recognition of their time. Appendix B provides greater detail on how the groups were recruited, while Appendices G and H provide the discussion guides used to facilitate the focus group and in-depth interviews and Appendices E and F provide the screeners used for recruiting the focus groups and in-depth interviews.

It is important to note that qualitative research is a form of scientific, social, policy and public opinion research. Focus group research is not designed to help a group reach a consensus or to make decisions, but rather to elicit the full range of ideas, attitudes, experiences, and opinions of a selected sample of participants on a defined topic. Because of the small numbers involved the participants cannot be expected to be thoroughly representative in a statistical sense of the larger population from which they are drawn, and findings cannot reliably be generalized beyond their number.

The key findings of this research are presented below.

## Health/Social care providers

### Familiarity and experience with palliative care

- Most health/social care providers describe themselves as at least somewhat familiar with specialist palliative care, but it varies by type of provider. Almost all general practitioners (GPs) (89%) say they are familiar, followed by 74% of specialists, 64% of nurses and 54% of other providers. Familiarity with a palliative approach to care for each group is similar - 89% of GPs, 72% of specialists, 62% of nurses, and 47% of other providers are very or somewhat familiar with the approach.
  - The qualitative findings demonstrated that familiarity does not necessarily infer understanding. Health/Social care providers’ understanding of the terms was varied with most equating it to end-of-life care.
- Including those who say, “all of the above”, the most commonly identified benefits of a palliative approach to care are improved pain management (91% overall), that the patient receives care aligned with their values (89%), and are connected with practical supports (84%). Results for all provider types follow a similar, if not identical, order.
- The vast majority of health/social care providers understand that palliative care can be delivered by a wide range of professionals (81%) and that it is provided at any point in the trajectory of a life-limiting illness (75%) though it was not as broadly understood among qualitative participants. Of note, fewer GPs, nurses, and specialists understand that palliative care can be provided to patients whose illness is not terminal and that it can be provided alongside treatment to cure or control the disease. Other providers are even less certain of both.
- While daily conversations about palliative care are somewhat rare, 44% of GPs are having these discussions at least once a week and half (50%) do so a few times a month. Very few (5%) never discuss the topic. Just 18% of specialists say they never discuss palliative care with patients. In contrast, 30% of nurses and 40% of other providers say the same.
- Despite high proportions claiming familiarity, only about a third (34%) of providers say they have a good understanding of their role in palliative care. Confidence is highest among GPs (46%) followed by nurses (35%), specialists (28%) and other providers (25%).
- Most providers (79%) believe that they play an important role when they have a patient or client with a life-limiting illness. GPs are the most likely to describe their part as ‘very important’ (60%) while other providers are the least likely to (23%).
- Two-thirds (68%) say that conversations about palliative care are at least somewhat difficult. Specialists are most likely to feel this way (82%) while other providers are more uncertain

(19% don’t know). Comments from specialists in the qualitative discussions suggested that the fact they do not often have longstanding relationships or regular interactions with patients, as compared to a GP, which can make the conversations more difficult. The qualitative and quantitative results illustrated though that comfort increases with tenure and experience.

- Asked whether each of a list of topics should be included in discussions about palliative care, two-thirds or more say each topic should be included. However, of these, the patient’s goals and wishes are most commonly seen as essential (85%). GPs and specialists are more likely than other types of providers to agree that each of the topics should be covered.
- More than half of GPs (56%) and close to half of specialists (48%) say they encounter barriers to implementing a palliative approach to care. A third of nurses (33%) and 29% of other providers agree.
- The most significant barriers, for all types of providers, include a lack of funding for training, additional staff and equipment, lack of time/competing priorities and lack of community-based services. With the exception of GPs, insufficient training or knowledge is also a major barrier, as well as a lack of access to information resources.
  - The qualitative findings suggest that health/social care providers perceive a significant barrier as it relates to the public’s understanding of the term palliative care, and the stigma associated with the term. Findings of the in-depth interviews with Canadians with a life-limiting illness suggest this perception is founded.
- Half or more among each group of providers say they know where to look for information that would help them implement a palliative approach to care. Training modules are for the most part the resources that would be most helpful (68%), followed by webinars and conferences (53%).

## Awareness and understanding of grief

- How often providers support patients dealing with grief mirrors the frequency with which they discuss palliative care. Almost half (44%) of GPs do so at least once a week. Over a third of specialists (36%) and a quarter of nurses (25%) and one-in-five (20%) other providers say the same.
- Three-quarters (77%) of general practitioners say they are prepared to support a patient who is grieving. Over half of nurses (61%) and specialists agree (54%), followed closely by 48% of other providers.

- About half of nurses (48%) and GPs (57%) say they play a major role in helping patients deal with grief. Fewer specialists and other providers feel the same way (22%).
- GPs are more familiar with “complicated grief” or “prolonged grief disorder” (69%) than other providers, followed by specialists (52%), nurses (36%) and other providers (28%).
- For all provider types, lack of time is cited as either the largest or second largest barrier to providing grief support. Overall, half (52%) say it is a major barrier. Lack of expertise is also among the top three major challenges for each provider. Not having an expert to consult and lacking information resources typically round out the top four for each provider type.
- GPs (72%) and specialists (70%) are slightly more comfortable talking with a client expressing their grief overall than nurses (65%). About half of other providers (50%) feel comfortable.
- The vast majority of each provider type agree that it is important to understand a patient’s cultural norms when supporting them with their grief (89% overall strongly agree or agree). However, they are much less certain as to where to direct patients to receive culturally appropriate grief services (36%) or where to find culturally appropriate information on the subject themselves (29%).
- The most helpful resources for discussing grief/bereavement are referral to support groups (67% overall), followed by brochures or facts sheets (55%).
- Over two-thirds (69%) have experienced the death of a patient (highest among GPs at 82% and lowest among other providers at 61%) and one-in-five (20%, though significantly higher among specialists at 46%) have experienced the death of a colleague in the last few years.
- Few (9%) sought help to deal with grief related to these deaths. Colleagues are the most often cited resource (18%) to help them deal with grief, followed by family and friends (12%).
- Over half across each provider type say they have adequate support for dealing with the death of a colleague/patient, but anywhere from one-in-five (19% among GPs) and a third (34% among specialists) say they do not have enough support.

## Communications: preferences and needs

- When it comes to resources that providers currently use to access information, the internet is the most common for GPs (62%), nurses (64%) and other providers (64%). Specialists use it too (60%) but are more likely to rely on academic journals (70%). About half of each group also rely on information from their professional association.

- Training and educational sessions are used by about half of general practitioners, nurses, and other providers as well.
- In fact, training sessions top the list in terms of preferred methods of accessing information for all but the specialists, who still list academic journals as their preferred source.

## Individuals with a life-limiting illness

### Familiarity and experience with palliative care

- About one-in-five (21%) say they are very familiar with palliative care. Over a third (37%) are somewhat familiar. The proportion who say they are familiar (58%) is greater than the percentage who are not familiar (41%).
- Fewer are familiar with the idea of a palliative approach to care; 39% are familiar while over half (59%) are not familiar.
- The qualitative findings suggest interviewees' understanding of palliative care was generally limited to end-of-life care for those who have exhausted all other avenues, and was inconsistent with the definition provided. While interviewees appreciated the aspirational nature of the description, they were surprised to learn that palliative care can be provided at the onset of an illness and alongside curative treatments; that support was also available to family, friends, or caregivers; administered by a variety of health care professionals; and, in a variety of care settings including hospitals, hospices, other facilities and even in the home.
- Presented with a list of potential benefits of a palliative approach to care, a quarter (26%) say they consider all of them to be benefits. The most commonly perceived benefits, factoring in the percentage who said that all the options presented could be benefits, include improved pain/symptom management (68%), the idea that the patient/client receives care that aligns with their values (65%), patients/clients are connected with practical support (63%) and it can result in better patient/client satisfaction (61%).
- Respondents were also presented with a series of statements that outlined facts and myths about palliative care. Responses suggest that some do not clearly understand what a palliative approach to care means. For example, half (50%) say that it is provided at any point in the trajectory of a life-limiting illness. At the same time, about a third say that it is provided only in either a patient's last year of life (28%) or last six months of life (27%). About half believe it is delivered by a wide variety of professionals (48%), but a third (32%) say it is provided by palliative care specialists alone. Almost half (46%) say it is provided when treatment is no longer an option, while one third (32%) say it is provided alongside treatments to cure or control disease.



- After some initial probing to gauge unaided awareness, respondents were provided with a definition of palliative care and a palliative approach to care. One-in-five (20%) say they have had conversations about this kind of care in relation to their illness. A few (7%) already receive palliative care. Another 9% say they have not received it but expect they will. Most either do not know if they will receive this type of care (36%) or do not think they will (31%). Half (53%) say they are prepared to have conversations about palliative care, more than say they are not prepared (40%).
- The most common barriers to accessing palliative care are that they/their family do not think it is needed (26%), they do not know who to consult (21%), it involved difficult emotions (21%) and a lack of resources (19%). A quarter (25%) claim to not experience any barriers to accessing palliative care.
  - Indeed, the qualitative findings uncovered stigma around accessing palliative care. The vast majority of interviewees did not think palliative care was for them, had difficulty thinking of themselves in the context of the interview questions (and often referred to the palliative care experiences of family/loved ones for reference). They also conveyed feelings of pride tied to their perception of the term, and these feelings seemed to inhibit their willingness to discuss or consider how palliative care could be beneficial to them.

## Awareness and understanding of grief

- More than a third (36%) identify every potential source of grief tested as being a cause of grief, however there is certainly not a consensus over all sources tested. Considering those who said, “all of the above”, strong majorities identify the death of a family or friend (83%), a diagnosis of a life-limiting illness (75%), loss of independence (74%), loss of function/mobility (73%), and the end of a relationship (70%) as sources of grief. But on the loss of a job, the proportion drops down to just over half (57%).
- Including 47% who say each emotion or behaviour presented could be a part of grieving, over three-quarters agree depression (81%), disrupted sleep (76%), and lack of interest in usual activities (76%) are parts of grief. Slightly less consensus exists around absence from work or school (62%), nightmares (62%), change in libido (63%), or new aches and pains (63%). These are the most often cited, but over half agree any element tested could be a part of grieving.
- For the most part, respondents agree that listening (84%), comforting (76%) and suggesting that you are available to provide support (74%) are part of supporting people who are grieving. About half also feel that suggesting they consult a professional (54%) and sharing personal experiences (46%) are appropriate.

- Three-quarters (77%) agree it is important to understand a person's cultural context when helping them deal with grief and two-thirds (67%) feel comfortable sharing their experiences with grief.
  - This aligns with the perspective of health/social care providers who, as noted earlier, believe it is important to understand a patients' cultural norms as it relates to the provision of grief support.
- However, over half (57%) feel they would need to know more if they were to support someone who is grieving. Less than half (45%) know where to seek additional help and even fewer know where to find culturally appropriate supports (30%).
- Almost all (92%) have experienced something that could induce grief over the course of the pandemic. Among those who did, 46% say their experience caused grief.
  - They most commonly turn to family and friends for support (65%).

### Communications: preferences and needs

- Asked their preference for receiving information about palliative care and grief, the majority (62%) select their primary care provider, though survey respondents and interviewees indicated they would rely on a variety of sources for information.
- When it comes to supports and resources that would be helpful for people grieving, family and friends are the most important (77%), followed by a licensed counsellor/therapist (70%). Fewer, though still over half, believe social workers (58%), hospice/palliative care team members (58%), primary care providers (57%), online support groups (55%), and community/spiritual groups (54%) would be helpful.
- Additionally, interviewees suggested using traditional communications channels such as radio, television, and newspaper ads, flyers/pamphlets in hospitals or doctors' offices, as well as social media (i.e., Reddit, Facebook, Instagram, Twitter, and Tik Tok) for communicating about palliative care. For sources of information about grief/bereavement, in addition to the sources mentioned above, many interviewees also suggested consulting religious supports, and support groups. Where grief/bereavement are concerned, a few mentioned that they felt that such information is better delivered in person than on paper, or digitally.

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I hereby certify as a representative of Earnscliffe Strategy Group that the final deliverables fully comply with the Government of Canada political neutrality requirements outlined in the Communications Policy of the Government of Canada and Procedures for Planning and Contracting Public Opinion Research. Specifically, the deliverables do not include information on electoral voting intentions, political party preferences, standings with the electorate or ratings of the performance of a political party or its leaders.

Signed:

Date: July 22, 2022

A handwritten signature in black ink, appearing to read "Stephanie Constable". The signature is written in a cursive style with a large initial 'S'.

Stephanie Constable  
Principal, Earnscliffe