Association canadienne de soins palliatifs

Canadian Hospice Palliative Care Association

PALLIATIVE CARE AND MAiD:
CO-EXISTING IN THE NEW ENVIRONMENT

SURVEY REPORT

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MAiD in Canada: A snapshot of year one

The purpose of the survey and eventual report is to share insight into the lived experience of health care workers in Canada who perform or are exposed to Medical Assistance in Dying (MAiD) through their work. The need for this information comes from an absence of data previous and subsequent to the legalization of MAiD in June of 2016. The report also provides a snapshot of the psychosocial supports available within health care organizations where MAiD is administered. A survey was developed by the Canadian Hospice Palliative Care Association (CHPCA) during the summer of 2017 and was distributed to almost 3,000 registered members/associates and affiliates of CHPCA.

Recommendations coming out of the report include:

- Increased education surrounding MAiD and hospice palliative care for both the general public, volunteers in hospice palliative care settings and practitioners;
- Culturally competent training to accommodate diverse religious and ethnic backgrounds to increase the effectiveness of the support being provided;
- Increased funding for hospice palliative care in order to provide individuals with more options for their end-of-life care;
- Increased specialized support for those who administer MAiD;
- Grief and bereavement services for workers following the death of patients who choose MAiD;
- Education on hospice palliative care and MAiD, during the practitioners' initial education and training, subsequent training within health care organizations, and continuing education as MAiD evolves as a practice.

MAiD background

The road to decriminalization in Canada

MAiD in Canada is defined as follows:

Medical assistance in dying as provides patients, who may be experiencing intolerable suffering due to a grievous and irremediable (incurable) medical condition, the option to end their life with the assistance of a doctor or nurse practitioner. Medical assistance in dying is provided only to legally eligible patients.

The discussion of Medical Assistance in Dying (MAiD) dates back to the nineteenth century (Dowbiggen, 2003). Here in Canada, prior to the passing of Bill C-14 in June 2016, Health Canada had only identified 970 medically assisted deaths nationally (Health Canada, 2018). The well-publicized 1993 case of Sue Rodriguez brought the issue to the forefront of Canadians' minds. Rodriguez suffered from amyotrophic lateral sclerosis (ALS). Her request for a physician-assisted death was heard before the Supreme Court of Canada (CHPCA, 2006). More than two decades later in 2015, the Supreme Court of Canada heard the case of Kay Carter, a woman with spinal stenosis requesting physician-assisted death (Butler and Tiedemann, 2015). The

Supreme Court handed down a decision in favour of Mrs. Carter, stipulating that the Federal Government must implement amendments to current laws, making the practice of medical assisted dying legal within one calendar year. The result was Bill C-14, which sought to change elements of the criminal code to decriminalize the practice of hastening death by physicians and nurse practitioners, and others involved in the process, under very specific conditions. The development of the current laws in Canada also drew from the experience of existing international physician-assisted death regimes and consultations in Canada including the Special Joint Parliamentary Committee on Physician-Assisted Dying, the Provincial-Territorial Expert Advisory Group on Physician-Assisted Dying and others (Government Canada, 2016). The decriminalized practice of Medical Assistance in Dying (or MAiD, the term used by Bill C-14) has been legal for over two years. While some information has been gathered, issues around data collection continue to be of concern. Privacy of patients, differing implementation of requirements and practices in each province including among coroners and insurance companies, and no formal legal requirement to collect specific data are among roadblocks to better data collection. All of these issues and more have made a clear picture of the current practice of MAID - and surrounding issues - almost impossible to get.

The current environment, eligibility, and process

There is confusion surrounding the terms "hospice palliative care (HPC)" and "MAiD": many people feel that they are one and the same (Karsoho, Fishman, Wright & Macdonald, 2016). As per the Canadian Society of Palliative Care Physicians (CSPCP) position paper (October 2015) "Implementing hastened death must be a shared responsibility of Canadian society and the whole medical profession, in particular with other health care professional colleagues". MAiD is in fact distinct from, but not necessarily mutually exclusive of, hospice palliative care, which is defined by the World Health Organization as follows:

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, such as chemotherapy or radiation therapy, and includes those*

> *investigations needed to better understand and manage distressing clinical complications.*

However, as a result of Canadians' increasing acceptance of MAiD, the medical environment surrounding death and dying is experiencing shifts (Karsoho, Fishman, Wright, Macdonald, 2016). The introduction of MAiD has changed existing roles within the medical environment. Those who are able to provide MAiD include physicians and nurse practitioners, with assistance from pharmacists and family members (Health Canada, 2018). In a review done by Fujioka et al., among healthcare professionals who can provide MAiD, physicians are typically seen as the first point of consideration, however, psychologists and psychiatrists also play an important role (2018). For those eligible to receive MAiD, they have two options: The first choice is MAiD carried out by a health care professional directly administering a substance that results in death and the second choice is a health care professional providing or prescribing a drug that the patient administers themselves to cause death (Health Canada, 2018).

Under the current laws, those who are eligible for MAiD must meet **all** criteria listed which include being eligible for health services funded by the federal/provincial government, be at least 18 years of age, have a irremediable medical condition, be able to make the request outside of pressure or influence and give informed consent (Health Canada 2018). Furthermore, a irremediable medical condition includes **all** of the following criteria: a serious illness, disease or disability that is in an advanced state of decline and cannot be reversed, unbearable physical or mental suffering that cannot be relieved, and natural death becoming reasonably foreseeable (Health Canada, 2018).

CHPCA's Survey: The Why, the How and the Who

To address the gaps in data following the implementation of MAiD in the year following the passage of the legislation, a survey was conducted by CHPCA and responses analyzed. Its purpose was to better understand the lived experience of health care workers who have experienced MAiD within their place of work, and to analyze the psychosocial supports available for these workers, their patients and patients' families.

Method and analysis

Data was collected from a survey of the CHPCA membership conducted in June of 2017. A total of sixteen questions were asked, (see Appendix B) with several demographic questions (location, setting of care, profession, etc.), one Likert scale question, and three open ended questions. The remaining questions required participants to respond using either Yes, No, or I don't know. The survey was conducted online between June and July 2017 and answers were transferred to Microsoft Excel for analysis. Qualitative data was coded using NVivo 12 for Windows.

Thematic content analysis presents qualitative data for an analysis of the insights offered through open ended questions (Vaismoradi, Turunen, Bondas 2013). Findings of qualitative results can be placed on a continuum in order to analyze the data and interpret themes throughout the results (Vaismoradi, Turunen, Bondas 2013). The primary purpose of data analysis is to describe a phenomenon or patterns in a conceptual form (Elo & Kyngas, 2008). A codebook was developed using NVivo to analyze the open ended response questions (Question 8, Question 16). The codebook was based on recurring themes throughout the research questions. Parent codes included: support offered surrounding MAiD, religion or culture, palliative care, emotions and conscientious objection (see Coding Scheme, Appendix A).

Results: Overview

Overall, almost three quarters of respondents indicated that their program had received requests to perform MAiD, and over a third of respondents reported that MAiD could or had been performed on site and an additional third of respondents reported that MAiD could also be performed offsite. Fewer than half of respondents reported that their organization did not perform MAiD at all, and more than half of respondents were actually unsure if MAiD could be performed at all in the setting of care in which they worked or volunteered.

Many respondents articulated the need for more support and education following the implementation of MAiD procedures in their place of work/setting of care. As well, respondents identified a need for better promotion of - and access to - hospice palliative care services for those at end-of-life, alongside promotion of and access to MAiD. Increased training for grief support for counsellors and chaplaincy teams working within organizations where MAiD is or could be performed were also mentioned. Almost all respondents provided an answer to the open ended last question regarding final thoughts or insights on MAiD from their perspective and experience; an overwhelming number noted confusion between hospice palliative care and MAiD as a major barrier for patients when accessing end-of-life care options.

Results: By the numbers

451 individuals from among CHPCA’s membership responded to the questionnaire. The regional breakdown of respondents include a majority based in Alberta (n=120, 26%), Ontario (n=107, 23.7%) and British Columbia (n=92, 20.3%) (See Table 1). Professions reported by respondents included administrative positions, family caregivers, physicians, nurses, personal support workers, spiritual care providers, social workers, volunteers and others. Among respondents, the most common professions/roles were nurses (n=170, 35.62%), administrative positions (n=79, 17.48%), volunteers (n=76, 16.81%), and physicians (n=56, 12.39%) (See Figure 1). Other than acute care hospital settings, 20.4% of respondents worked in a residential hospice setting, (n=95, 20.4%), home care setting (n=105, 20.2%) or long-term care facility (n=21, 14.9% (See Figure. 2). 320 participants (70.9%) reported that their location had received requests for MAiD from patients and families whereas 76 participants reported that they had not (16.85%). 157 participants reported that MAiD took place on site (34.8%), and 307 participants indicated that their location had developed specific policies around MAiD (68.1%). When participants were asked about additional policies and documents their organization’s respective MAiD policy was developed around (Question 8), 49 participants reported using provincial health documents (10.8%), 64 reported using documents produced by provincial health authorities (14.2%), 50 participants reported using policies from professional colleges (11.0%), 40 participants reported a combination of policies from provincial, federal and professional

colleges (8.8%), 14 participants reported using Hospice Palliative Care Ontario (HPCO) policies (3.1%), and 22 were unsure (4.9%). 182 participants reported that they have not had an opportunity to implement a MAiD policy (40.3%), whereas 195 participants reported that they have done so (43.2%). Of the challenges listed (Question 12) all were rated as significant. 131 participants said that they felt their provincial or territorial ministry of health was providing adequate support around MAiD (29.0%), whereas 175 participants felt there was not adequate support (38.8%). 103 participants also felt that there was adequate support for hospice palliative care (22.8%), whereas 311 participants thought there was not (68.9%).

Table 1.

Responses by Province

Province	#
Alberta	120
Atlantic Provinces	81
British Columbia	92
Manitoba	9
Ontario	107
Quebec	13
Saskatchewan	27
Territories	1
Total:	451

Figure 1.

What is your role - Question 4

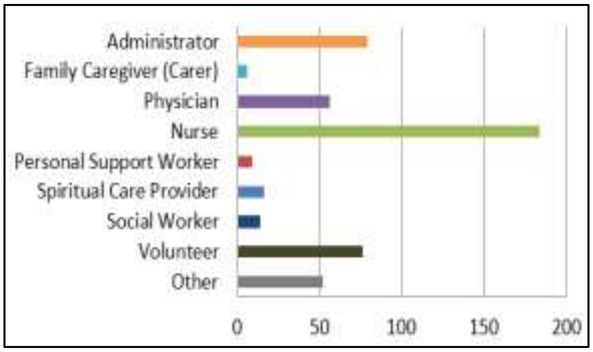


Figure 2.

Place of Work - Question 3

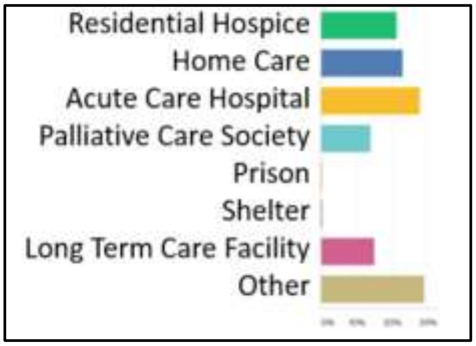
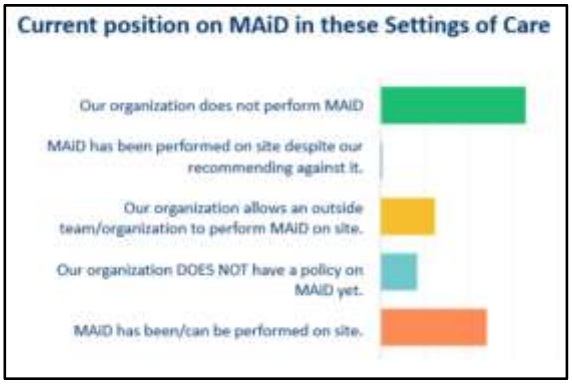


Figure 3.

Current Position on MAiD - Question 11



Responses by Sub-Group/ Profession

Physicians

There were responses from 56 physicians in total (12.4%) with most based in Ontario. Nationally, physicians reported that requests for MAiD came from patients or from families of patients, and that when requested, MAiD did take place on site. 31 physicians indicated that

MAiD could and had been performed in the setting of care in which they worked, and also performed for patients outside of their health care work setting (55.3%). The majority of provinces where requests for MAiD were reported were Ontario (n=16, 28.6%) and the Atlantic provinces (n=15, 26.7%). Of the 31 physicians who reported that MAiD took place on site, the highest concentration were located in Ontario (n=11, 35%) and the Atlantic provinces (n=9, 29%). Furthermore, the organizational policies used to determine how MAiD was to be handled in their place of work were mostly based on provincial documents and policies.

Although a higher percentage of physicians reported being exposed to MAiD within their place of work, the majority of those surveyed (n=26, 46.4%) indicated that they feel the province or territorial health authority is not providing adequate support around MAiD. When further analyzed, many of those reporting this were based in Ontario. In addition, the majority of physicians who responded (n=44, 78.6%) also felt that their provincial or territorial ministry of health was not providing adequate support for or access to hospice palliative care, with most of those responses from physicians in the Atlantic provinces (n=15, 3.3%) and Ontario (n=14, 25%). Furthermore, physicians reported that inadequate information and training has been provided by provincial or territorial health authorities about current policies surrounding MAiD. In a similar vein, when asked, the largest challenge reportedly faced by physicians was the shortage of resources available to deal with psychosocial aspects of care before, during and after MAiD occurred. The lowest identified challenge was public and professional confusion about the difference between hospice palliative care and MAiD by physicians.

Nurses

170 respondents were nurses working primarily in acute care, residential hospice, homecare and long-term care settings. Of these participants, specific policies around MAiD developed by their place of work was widely reported (n=120, 70.5%) with highest numbers based in Ontario (n=18, 10.5%) and the Atlantic provinces (n=16, 9.4%). Canada-wide, of those nurses who reported specific policies had been developed around MAiD in their place of work, 68 respondents indicated that implementation of those policies had occurred (40%). When asked to describe the current practice of MAiD within their program or organization, many nurses reported that MAiD can and has been performed on site (n=29, 17%) and of these respondents, the largest concentration were again (as with physician respondents) were from Ontario (n=11, 6.5%) and the Atlantic provinces (n=16, 9.4%). Policies surrounding MAiD as reported by nurses were based mainly on provincial documents. Also similar to physician respondents, nurses felt that their respective provincial or territorial ministry of health was not providing adequate support around MAiD. Those who reported the highest concern were similarly located in the Atlantic provinces (n=17, 10%) and Ontario (n=21, 12.3%).

Volunteers

There were 76 responses from volunteers, most of whom were based in a residential hospice setting or a palliative care society. The highest responses from volunteers were from Alberta (n=35, 46%). All volunteers indicated that their organizations had developed specific policies around MAiD being performed within their facility. Although volunteers reported that their program did have requests for MAiD from patients and families (n=29, 38%), many (n=27, 35.5%) did not know if their program had received requests for MAiD. Of those who reported that they did receive requests, most were Alberta-based (n=16, 21.0%) as were those who indicated that they did not know if requests had been made (n=12, 15.7%). In addition, many volunteer respondents reported that MAiD did not take place on site (n=45, 59.2%) or were unsure if it did (n=21, 27.6%). Unlike physicians and nurses, volunteers (n=40, 52.6%) did not play a large role in having an opportunity to implement the MAID policy in their volunteer setting of care. As well, there was a lack of responses surrounding whether or not the volunteers knew of any additional policies their organization used when implementing MAiD.

Volunteers also reported and ranked several topics they felt were challenging within their program. They rated public and professional confusion about the difference between hospice palliative care and MAiD as the least challenging, a shortage of resources to deal with psychosocial aspects of care as somewhat challenging, and the emotional toll on healthcare providers and volunteers as the most challenging issue. However, although it was reported that the emotional toll on healthcare workers and volunteers was significant, volunteers reported that they either did not feel that their ministry of health was providing adequate support around MAiD, or that they did not know whether or not their ministry of health was providing adequate support, and that adequate support for access to hospice palliative care was missing, and inadequate information as well as training provided by ministries of health surrounding the current MAiD policies (n=38, 50%).

Administration

79 administrators responded to the survey, many of whom work in residential hospice settings (n=25, 31.6%), with the highest concentration of responses coming from those in Ontario (n=14, 17.7%). The majority of administrators reported that their location/program had received requests for MAiD (n=55, 69.6%) with the majority of requests for MAiD, again based in Ontario (n=23, 29.1%). Nationally, many reported that their location or program had specific policies developed around MAiD (n=62, 78.5%). However, administrators reported that most of the cases where MAiD had been administered, had not taken place on site (n=49, 62%) and most of those from Ontario (n=14, 17.7%) and British Columbia (n=12, 15.2%). Unlike volunteers, many of the respondents in administrative positions reported that they had an opportunity to implement the policy surrounding MAiD in their organization and that their organization’s policy had been based on a variety of different documents such as provincial, faith-based, or professional policies. Although administrators reported that their organization performed MAiD offsite, when asked to describe the current state of the program/site they worked in, many of administrator respondents reported that their organization does not perform MAiD (n=32, 40.5%) with most based, again, in Ontario (n=15). When asked to list the main challenges in the new environment, administrators rated “keeping patient centered care as at the center of focus in hospice palliative care” as the least or somewhat challenging issue and rated “public and professional confusion about MAiD” as the most challenging. Like the other professionals, administrators also felt that their ministries of health were not providing adequate supports around either MAiD or hospice palliative care.

Qualitative Analysis: Insight into responses and emergent themes

Emotions, grief, moral issues

Both families of the patients receiving MAiD and the practitioners involved reported experiencing complex emotions prior to and following MAiD. Of the responses expressed, emotions were coded into two categories ‘Positive or Supportive’ or ‘Negative and Unsupportive’. The majority of responses fell under negative emotions or a general overall lack of support towards MAiD (n=41, 9.1%) and those expressing these feelings were mostly nurses from British Columbia and Alberta: “*As a nurse in active duty for 37 years, I am very uncomfortable with MAiD.”* Participants expressed negative emotions, discomfort with the process and feelings of grief, with one respondent stating *“[they] have not considered the consequences of disenfranchised grief in this matter at all.”* Practitioners reported extreme stress when they had an active role in providing MAiD. Furthermore, a pattern emerged in the data where those respondents whose perception of MAiD was initially supportive and positive towards MAiD, changed once they performed MAiD for a patient. The respondents who expressed support or positive emotions towards MAiD indicated it was because they had experienced or administered a successful MAiD process, resulting in a good death for the patient in their care.

The term “conscientious objection” was specifically used by 3 respondents (nurses and volunteers). This term refers to objecting to a practice or process as a result of one’s morals or principles (Fujioka et al, 2018). One respondent felt that there was a lack of support for practitioners who decided against performing MAiD based on personal beliefs. Another respondent expressed the feeling that there may be an overall hesitation to perform MAiD because of a health practitioner’s obligation to protect and preserve life; however, the lack of support for those who choose not to perform MAiD results in practitioners feeling “forced” to do so. *“Conscientious objection is not supported well enough for doctors/nurses…I feel pressure to support my clients in MAiD despite my religious objections.”*

HPC and MAiD: What do they mean, how are they viewed, what is still needed?

One of the most common topics expressed by participants specifically in Ontario and British Columbia was the role of hospice palliative care in relation to MAiD. Responses were subdivided and coded into four categories: A need for more education and support around hospice palliative care; better funding; more resources for hospice palliative care; and using palliative care alongside MAiD. Of the respondents expressing a need for more hospice palliative care services 10 were nurses (5.3%) and 10 were physicians (2.2%). Of those who were nurses, most were from Alberta and for physicians many were located in the Atlantic Provinces.

The most frequent issue expressed by 24 participants across Canada (5%) was a confusion between HPC and MAiD, and what each method or service offered. Respondents felt that that MAiD is sometimes offered in place of hospice palliative care due to a lack of understanding of what hospice palliative care actually entails. For example, several respondents stated that hospice palliative care was being confused with MAiD, and individual (families and patients) believed that both options would mean assistance in ending the patient's life - sometimes as a desirable outcome, sometimes out of fear of it. Respondents generally believed that better education and provincial or territorial support for effective hospice palliative care would help ensure equitable access to a variety of end-of-life care options, rather than emphasizing one service or method over another.

Respondents felt that there was a lack of resources for hospice palliative care but more resources to support MAiD which is also seen as more accessible and an "easier" end-of life option. Respondents expressed that the lack of funding surrounding hospice palliative care also meant that there were less hospice palliative care beds/services in the community and therefore, fewer options to choose from for those requiring end-of-life care. Furthermore, it was expressed that if funding was put towards advancing hospice palliative care resources and training for hospice palliative care workers, end-of-life care could be improved overall, regardless of the choice made by patients and their families.

Many respondents expressed that with proper education and funding, hospice palliative care could be and should be used alongside MAiD. Respondents expressed that the lack of funding and education surrounding the topic means that physicians do not feel the need to refer to hospice palliative care early on in a diagnosis. However, hospice palliative care is not universally accessible and, as a result, some participants felt that should this change, the demand for MAiD would decrease as individuals would choose hospice palliative care in place of MAiD if available to everyone.

Support

Another important insight expressed by all 451 respondents across professional categories was the support offered before and after MAiD. Support was subdivided into three categories of responses: those who were satisfied with the support, those who were unsatisfied, and those who felt more support was needed. Only one participant when asked for additional insights, stated that they were satisfied with the support being offered for MAiD. The rest of the participants felt unsatisfied with the support and felt there needed to be an increase in the support given. Many of those who identified as unsatisfied were employed as administrators, nurses or volunteers. A common theme that emerged among those who were unsatisfied was the need for better and more supportive debriefing sessions for health care staff following a MAiD procedure. Furthermore, participants felt unsatisfied with the support and training around how to deal with a patient who requests MAiD, and how to deal with the grief or guilt that may follow a MAiD procedure. Another commonality was the lack of support available for the family following the procedure. One participant stated that the grief felt after MAiD was complicated and the support available was not equipped to deal with this type of grief. For example, one participant stated: "*Our support team (social worker /chaplain) was not offered any specialized training on how to deal with the residual effects of MAiD on the remaining family members (grief support)*" as well, another participant expressed *"[They] have not considered the consequences of disenfranchised grief in this matter at all*". Providing anticipatory grief and grief/bereavement support to loved ones and family members of people who have opted for MAiD is still lacking.

Finally, it was expressed that those who were actually providing the support, such as social workers or chaplaincy teams, were not offered specialized training for how to deal with the specific grief following MAiD.

Spirituality and Culture

A final topic mentioned by participants, specifically volunteers, was the role of spirituality and culture and how it may or may not impact a decision to choose MAiD. Those who indicated spirituality and culture posed an issue for MAiD were located in British Columbia, Alberta, the Atlantic provinces and Saskatchewan. Respondents who identified as belonging to a faith community felt that MAiD could be likened to suicide and felt pressure to support clients and/or perform MAiD despite their own personal religious objections

Discussion

The data analysis revealed key themes among the current perspectives on MAiD in Canada. These included issues surrounding psychosocial support, general end-of-life care education, and lack of hospice palliative care services. These themes were particularly evident in responses from health care workers who experienced MAiD directly, such as physicians and nurses. Health Canada has recognized the importance of public reporting on MAiD in order to increase transparency and maintain public trust in such a deeply personal issue (Health Canada, 2017). Some of these improvements in transparency have included the ability for Canadians and key stakeholders to have an opportunity to review regulations being proposed by the federal government on the topic of MAiD and to provide written comments (Health Canada, 2017). Health Canada compiled the findings from the discussions on Medical Assistance in Dying to identify the following issues: similar data would be required from practitioners by both federal, provincial and territorial governments to increase transparency, protection of practitioners', patients' and pharmacists' privacy, complex regulatory requirements, timelines for reporting and proactive communication with impacted professions, and better education/training for practitioners and pharmacists.

Psychosocial supports

It is important for proper support to be available for families and practitioners prior to and following the MAiD process. As noted above, there are complicated emotions and different types of grief surrounding MAiD that may not be experienced if a patient dies in another way. Moreover, lack of support can cause increased levels of stress among practitioners and families which may exacerbate an already complex emotional situation. Those providing support such as social workers, counsellors or chaplaincy teams should receive specialized training in how to cope with emotions felt when someone has chosen to die via MAiD. As stated above, this lack of specialized training has made the currently available supports less effective than they could be. With more specialized support systems, practitioners may feel more comfortable discussing MAiD with patients as well as support for practitioners who may not wish to perform MAiD due to personal beliefs. Furthermore, better support can help loved ones cope before, during and after the death, and engage in a healthy healing process.

Limitations

Although the data presented is from across Canada, a number of factors should be considered when interpreting the findings of this report: 1) The sample size of 451 was a relatively small number and, as a result, may not be representative of the country as a whole; 2) Participants were selected from the membership of a national hospice palliative care advocacy organization (CHPCA) and, as a result, there may be more bias towards support for hospice palliative care in comparison to MAiD; 3) The law decriminalizing MAiD is relatively new and its implementation and impact on the health care system is still largely unknown. As a result, health practitioners and patients may not have enough experience with the procedure to form a full opinion; 4) Not all respondents answered every question and therefore, missing data may have impacted the frequency of certain results and/or responses such as profession or place of work.

Conclusion

The analysis of the data identified important topics of interest surrounding hospice palliative care and MAiD. Psychosocial supports, funding for hospice palliative care, and increased (public) education surrounding MAiD and hospice palliative care were highlighted as key themes. Members of the community and healthcare practitioners need to be provided with more educational tools regarding their local hospice palliative care resources alongside available MAiD resources. Providers are looking to be further educated/trained and supported in providing hospice palliative care services alongside MAiD.

This report aims to provide a better understanding of the current situation - a snapshot - around MAiD in settings of care across Canada. It offers insights into practitioners' and patients' perspectives. With a better understanding of the challenges and the lived experiences within the MAiD environment, evidence can be used to increase education and training for both hospice palliative care and MAiD in tandem with a better support system and follow-up resources after MAiD has been performed. With these tools in place, MAiD and palliative care can co-exist within provincial and territorial health care systems across Canada, to provide a better end-of-life care experience for patients, families, and their health care practitioners alike.

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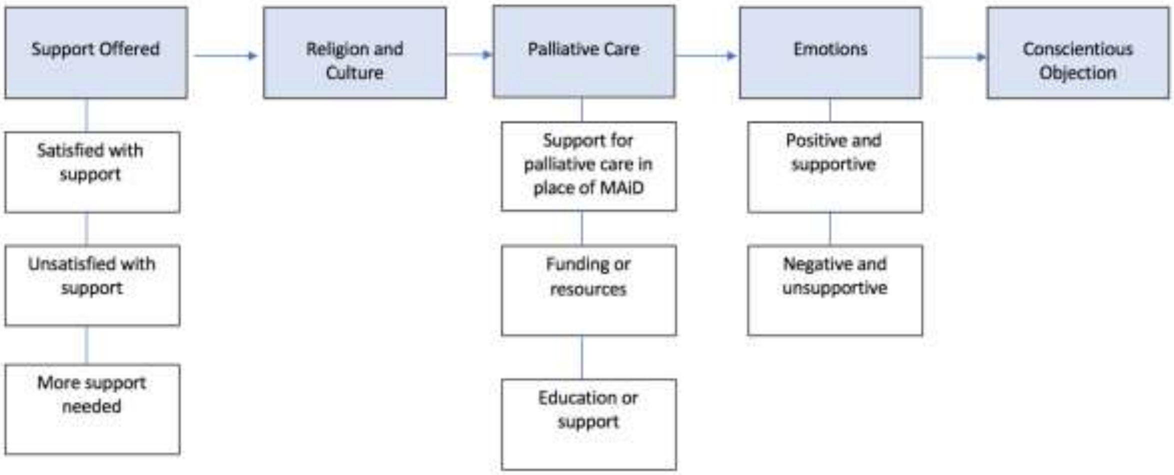
Appendices

Appendix A

Coding Scheme



Appendix B

FINAL Survey Questions for CHPCA Members about Medical Assistance in Dying

Introduction and Process:

Dear CHPCA Associates and Affiliates:

CHPCA would like to survey the membership for their insights and experiences with Medical Assistance in Dying (MAiD) since it passed into law in June of 2016.

The information you provide will be collected, analyzed and presented at the Canadian Hospice Palliative Care Conference's 2017 MAID Challenging Issues Panel on Saturday September 22, 2017 by CHPCA.

All answers are anonymous. You will not be asked to provide your name or that of your organization.

Please consider taking the 5 or so minutes required to fill out the short survey below as your lived experiences and insight would be greatly appreciated as we look ahead to how Person-centered care can remain the center of our focus in the Hospice Palliative Care community across Canada.

Questions

Answers: Yes, No, I don't know.

1. Are you an associate/affiliate or member of the Canadian Hospice Palliative Care Association / your provincial hospice palliative care association?
2. What region of Canada do you work in?

Answers: All PTs & I do not work/volunteer in Canada

3. What type of setting of care do you work in?

Answers: Residential Hospice, Home Care, Acute Care Hospital, Palliative Care Society, Prison, Shelter, Long Term Care Facility, Other (please specify)

4. What is your role in the setting of care?

Answers: Family Caregiver (or Carer), Administrator, Physician, Nurse, Personal Support Worker, Spiritual Care Provider, Volunteer, Other (please specify)

5. Has your location/program had requests for MAiD from patients or their families?
6. Does MAiD take place on site?
7. Has your location/program developed specific policies around MAiD?
8. What other documents/policies was your policy based on?
9. Have you had the opportunity to implement the policy?
10. If possible, please provide further details about your policy**:**
11. Please choose one (1) of the following options that best describes the current practice of your program/site/organization:

Answers:

- Our organization does not perform MAiD.
- MAiD has been performed on site despite our recommending against it.
- Our organization allows an outside team/organization to perform MAiD on site.
- Our organization DOES NOT have a policy on MAiD yet.
- MAiD has been/can be performed on site.
- Other (Please provide details):

1. PLEASE CHOOSE ONLY FIVE (5) OPTIONS: What are the biggest challenges in the new environment of legal Medical Assistance in Dying for your program/organization? - Please rank in order of 1 (least challenging) to 5 (most challenging) <u>for UP TO 5 of the following options</u>
    a. Public and professional confusion about the difference between palliative care and MAiD
    b. Local public backlash against MAiD
    c. Local public backlash against our position not to allow MAiD to be performed
    d. Keeping person or patient-centered care at the center of our focus on Hospice Palliative Care.
    e. Lack of policy and process clarity
    f. Staffing to perform MAiD assessments
    g. Shortage of resources to perform MAiD
    h. Shortage of resources to maintain HPC standards
    i. Shortage of resources to deal with psychosocial aspects of care before during and after MAiD in all settings
    j. Emotional toll on healthcare professionals and volunteers
    k. Other (Provide Details): ___________________________

2. Do you feel your provincial or territorial ministry of health and/or health authority is providing adequate support around MAiD?
3. Do you feel your provincial or territorial ministry of health and/or health authority is providing adequate support for and access to Hospice Palliative Care?
4. Has there been adequate information and training provided by provincial or territorial ministry of health and/or health authority about current policies? Please provide details…..
5. Do you have any additional insights into the first year and a half of Medical Assistance in Dying in Canada that you would like to share?