This is an Accepted Manuscript version of the following article, accepted for publication in Journal of Palliative Care


Published in Journal of Palliative Care, and available online at: https://journals.sagepub.com/doi/abs/10.1177/0825859720951661

We recommend you cite the published version.
The URL for the published version is: https://journals.sagepub.com/doi/abs/10.1177/0825859720951661

Care Considerations in a Patient-and Family-Centered Medical Assistance in Dying Program

Janine Brown, RN, Ph.D(c) (Corresponding Author)
Brown et al., PFCC MAID Page 2

Health Sciences Graduate Program, College of Medicine, University of Saskatchewan and Faculty of Nursing, University of Regina
111-116 Research Drive, Saskatoon, Saskatchewan Canada S7N 3R3
janine.brown@uregina.ca

Donna Goodridge, RN, Ph.D.
Professor, College of Medicine, University of Saskatchewan
donna.goodridge@usask.ca

Averi Harrison, MD Candidate 2020
College of Medicine, University of Saskatchewan
aph784@mail.usask.ca

Jordan Kemp, MD Candidate 2021
College of Medicine, University of Saskatchewan
jkk371@mail.usask.ca

Lilian Thorpe, MD, Ph.D, FRCP
Professor, Departments of Community Health & Epidemiology and Psychiatry, University of Saskatchewan
lilian.thorpe@usask.ca

Robert Weiler, MD
Clinical Professor, Department of Anesthesiology, Perioperative Medicine and Pain Management, University of Saskatchewan; Medical advisor to the Provincial MAID program
robert.weiler@saskhealthauthority.ca

Funding Acknowledgements: The author(s) received no financial support for the research, authorship, and or/publication of this article. This research received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors.

Abstract

Background: Medical Assistance in Dying (MAID) became legal in Canada in June 2016. As part of a project designed to improve end-of-life care for those requesting MAID, qualitative data
from patients, families, and providers were used to assess opportunities to enhance patient-and family-centered care (PFCC) in this program.

**Methods:** Thirty interviews were conducted with patients, families, and healthcare providers. Five patients who requested an assessment for MAID, 11 family members, and 14 healthcare providers were interviewed about their experiences in 2017. Comparative coding and thematic analysis were completed with the support of NVivo12.

**Results:** Emotional PFCC considerations included: exploring and validating the emotional journey, navigating the uncertain, judgmental experiences, and the emotional impact on families and the care team. Physical PFCC considerations included: sensitivity in eligibility assessments, weaving in interdisciplinary care, provision of anticipatory guidance, and death location. Spiritual PFCC considerations included: honoring choice, listening to life stories, supporting spiritual needs, and acknowledging loss. Relational PFCC considerations included: defining the circle of support, supporting the circle, and relational investments.

**Conclusion:** Fundamental to a PFCC MAID program, practitioners must be afforded time to provide holistic care. Program-related suggestions include incorporating interdisciplinary care early, and throughout the illness trajectory, consistency in care providers, appropriate anticipatory guidance, and bereavement supports for family, and dedicate space for MAID provisions. Patients and families must be included in the ongoing development and re-evaluation of MAID programs to ensure continued focus on quality end-of-life care.

**Keywords:** Patient-and-family centered care, Medical assistance in dying, quality improvement, end-of-life care, interdisciplinary care, qualitative research
Introduction

Medical Assistance in Dying (MAID) is an end of life care option in Canada since June 17, 2016, with the passage of Bill C-14. Bill C-14 delineates who may provide and receive MAID, and the legislated safeguards. Little is known about the best practices to provide holistic care in this context. Patient-and family-centered care (PFCC) is recognized as one of the domains of health care quality\(^1\) and is a critical approach for healthcare improvement,\(^2\) for keeping patients and their families as the primary focus of care\(^3\) and for addressing care disparities.\(^4\) The purpose of this project was to explore patient, family, and healthcare provider experiences with MAID to enhance high-quality PFCC MAID care.

Context and Literature Review

Canadians may access MAID if the eligibility criteria in Bill C-14 are met. The patient must (1) be eligible for health services funded by the federal, provincial or territorial government, (2) be at least 18 years or older and mentally competent, (3) have a grievous and irremediable medical condition, (4) make a voluntary request without outside influence, and (5) provide informed consent.\(^5\) Government-mandated safeguards include having two individuals who meet the government definition of independence witness the MAID request form, the ability of the patient to withdraw their request at any time, having two independent assessments to confirm the patient meets eligibility criteria, ensuring that ten clear days elapse between when the consent is signed and MAID is provided (unless both practitioners believe there is imminent death or risk of loss of capacity to confirm consent), and confirming consent immediately before administration. The preamble of Bill C-14 states nothing in the legislation affects freedom of conscience and religion,\(^6\) thus conscientious objection (CO) has been incorporated into various regulatory body position statements.\(^7\)–\(^9\) Some religiously affiliated, or faith-influenced healthcare
facilities object out of conscience to MAID, resulting in discourse surrounding the question if MAID must be provided at every Canadian healthcare facility.\textsuperscript{10} As Bill C-14 was a federal law change and healthcare delivery is under provincial and territorial government jurisdiction, MAID and post-MAID coordination with coroners and/or medical examiners, including completion of cause and manner of death on death certificates, is different across the country.\textsuperscript{11} In July 2018, the federal government devised the national regulations for monitoring and reporting of MAID resulting in standardized reporting timelines.\textsuperscript{12}

Quality improvement (QI) in MAID programs is essential in the development of equitable and sustainable care processes. These care processes must be consistent with federal legislation while meeting the needs of patients, families, and healthcare providers. The patient, family, and provider experiences serve as a launching point to guide program development and as a benchmark to measure future successes. Previously reported family members’ suggestions for MAID QI improvement included: attention to process clarity, challenges regarding scheduling and the 10-day waiting period of reflection, clinician objection to and judgment of patient choice, patient and family privacy, bereavement resources.\textsuperscript{13} Also noted was the challenge of coming to terms with their family member’s MAID choice.\textsuperscript{14} Physicians involved with MAID identified several structural and emotional care provision challenges. These challenged included the refusals of faith-influenced facilities to participate or facilitate MAID care, working with family and friends in grief, the time required for care participation, and challenging conversations with patients deemed ineligible for MAID.\textsuperscript{15} Additional challenges were noted with regards to strained relationships with physicians objecting to MAID, inadequate compensation for supporting a MAID death and an unsustainable workload.\textsuperscript{16} In some
jurisdictions, the requests for assisted dying and rates of completed assisted deaths increased over time,\textsuperscript{17,18} amplifying MAID workload challenges.

It is often assumed that pain and dyspnea are the primary reasons for requesting assisted dying. Cancer, associated with pain, was the most frequently reported underlying health condition for patients requesting MAID\textsuperscript{19} and these patients may benefit from increased access to palliative care. In contrast, neurological conditions, such as amyotrophic lateral sclerosis, may progress more slowly with prolonged loss of autonomy and independence and may be more challenging to palliate adequately. When the reasons for requesting information on MAID are obtained directly from patients, non-physical symptoms such as quality of life, and desire for dignity and control over death are more frequently reported than physical symptoms like dyspnea or pain.\textsuperscript{20,21}

This QI project was conducted one year after MAID legalization, between June – August 2017, within one of the Western Canadian provinces. A local policy was established following provincial guidelines for pharmacists,\textsuperscript{22} nurses,\textsuperscript{23,24} and physicians.\textsuperscript{7} All inquiries and activities related to MAID were tracked regionally. The patient’s most responsible practitioner, or the practitioner who has the “overall responsibility for directing and coordinating the care and management of an individual patient,”\textsuperscript{25} most commonly referred patients for MAID care. During a meeting between the patient and practitioner, extensive discussion regarding end-of-life care goals occurred, and a mental capacity determination was undertaken. If the patient was deemed eligible for MAID, they were provided a formal request form and a second practitioner completed their assessment of eligibility. After a 10-day reflection period (or shorter in the event of declining capacity), the patient was considered eligible to proceed to MAID provision. The patient must retain the mental capacity and provide informed consent right until the time of
MAID administration. At the time of this study, all provisions in the region were completed intravenously by the practitioner. Some facilities expressed a conscientious objection to MAID, and as a result, some patients required transfer to a non-objecting healthcare facility for MAID provisions. Between July 1 and December 21, 2017, our province had 62 requests for MAID; 23 patients were declined as they did not meet the eligibility criteria, “less than 7” patients withdrew their request, and 10 patients died before their assessments were completed.²⁶

This qualitative project was part of a broader MAID QI approach established by the care team. Consent of patients and families to be part of a QI process was routinely obtained. Two medical students completed the interviews under the supervision of the two MAID practitioners and were supported by a multidisciplinary research team.

*Ethical Considerations*

Multiple meetings were held with the healthcare delivery agency’s ethics committee to develop a QI process for the MAID program. The project was considered a QI project by the University of Saskatchewan ethics committees (BEH 17-134).

**Methodology and Methods**

An interpretive description (ID) guided the project in the development of perspectives, patterns, and themes used to inform clinical understanding.²⁷ Within ID, the description of data is insufficient, and the data requires additional interpretation by the research team.²⁸ This methodological approach aligned with the constructivist/interpretivist approach, where the intention was to ascertain the view of those with the lived experiences through a process of collaborative knowledge generation process.²⁹⁻³¹ The core concepts of PFCC ³⁹,⁴⁰ underpinned this project (table 1).
Sampling and Data Collection

Hearing the first-person stories of patient and family care experiences was determined to be critical based on a review of the published literature and the local emphasis on PFCC.\textsuperscript{32,33} These perspectives, as well as those of healthcare providers, had the greatest potential to inform and impact improvements in policy and practice. Key considerations in the sampling were: (1) the desire to keep the perspectives of the patients and families at the forefront, (2) the inclusion of participants who accessed the MAID program at diverse points on their care trajectory, and, (3) sufficient numbers of participants to draw meaningful conclusions.\textsuperscript{34,35} The team aimed to interview six to ten patients who were assessed for MAID, six to ten family members of patients, and ten to fifteen healthcare providers. Data and contextual information were collected through a semi-structured interview (Appendix A). Some of the participants were from the same family unit (i.e., a patient and a spouse, or a spouse and child of a MAID recipient).

Patients, families and healthcare providers who were involved with MAID, and consented to be in contact as part of a QI process, were contacted by the medical practitioner to obtain verbal consent for one of the medical students to make initial contact. When verbal consent was obtained, the student then provided further information about the project and obtained written consent. Interviews conducted by either of two students were audio-recorded and transcribed. Transcripts were anonymized and protected per data storage protocols.

Data Analysis

Data analysis occurred with the support of NVivo12 and was completed by two researchers grounded in qualitative methodologies and end-of-life care. Transcripts were read repeatedly to assist with data familiarity. Data were considered with the core concepts of PFCC,
using an open coding and iterative process. The comparative coding steps\textsuperscript{36} included: (1) code comparison within a single interview, (2) code comparison between interviews of the same participant grouping and (3) final code comparison from groups with alternative perspectives through side by side comparison and contrasting. A codebook supported the data analysis process,\textsuperscript{37} and thematic analysis\textsuperscript{38} guided the development of themes.

**Results**

Thirty interviews were conducted with patients, families, and healthcare providers (Tables 2, 3, and 4) representing 26 unique MAID cases. Participant experiences were identified as care considerations and were conceptualized into emotional, physical, spiritual, and relational categories (Figure 1). These care considerations formed the conceptualization of a PFCC MAID program. The words of the participants are reflected in Table 5.

*Emotional Care Considerations*

**Exploring and Validating the Emotional Journey:** Patients and families required time to discuss and share the impacts of their life-limiting illnesses and the journey that brought them to consider MAID. Desperation, fatigue, and fear were often reported. Providers must understand the patient and family’s emotional pathway that brought them to consider MAID.

**Navigating the Uncertain:** MAID was an unpredictable care terrain for patients and families, and this resulted in emotional uncertainty. Navigating the uncertainty of illness progression and deciding when, and sometimes if, to proceed with MAID while retaining the capacity to consent before provision, required emotional support and care. The consequences of wishing to proceed with MAID, yet being unable to due to loss of capacity, were emotionally devastating.
Judgmental Experiences: Patients and families who were considering MAID or were on the MAID care pathway were exposed to judgments from healthcare providers and others. These statements may not have been intended to be hurtful, yet patients and families were placed in a position where they needed to process and possibly respond to these comments.

Emotional Impact on Families and Care Team: The emotional impact of the request for MAID assessment and MAID death moved beyond the patient and profoundly impacted the family and care team. There was a need to recognize and tend to these unique facets of death and grieving for all involved.

Physical Care Considerations

Sensitivity in Eligibility Assessments: Determination of eligibility, and the communication of eligibility assessment results were processes that often encompassed multiple visits with patients and families. The timing and number of the visits required sensitivity. Further, patients and families needed time to understand and debrief when the outcome of the eligibility assessment was not what they anticipated.

Weaving in Interdisciplinary Care: A team of interdisciplinary practitioners was vital in supporting the patient and family before and during the MAID process. Interdisciplinary care was noted to be a significant care asset for patients, families, and healthcare providers.

 Provision of Anticipatory Guidance: Death day procedures and considerations were unique and often highly unfamiliar in a MAID death. Patients, families, and all members of the healthcare team required anticipatory guidance on these unfamiliar processes.

Location: The importance of choosing a location that was appropriate, comfortable, private, and attentive to the needs of the patient and family could not be underscored enough. There was a
significant need for healthcare delivery agencies to facilitate patient and family choice in the location of death whenever possible. Faith-influenced policies complicated choosing locations.

**Spiritual Care Considerations**

**Honoring Choice:** Honoring choice was a critical validation for patients and their families as they journeyed the evolving care pathway. Patients and families expressed gratitude that their choices were respected and honored by their closest family and by their MAID healthcare team.

**Listening to Life Stories:** It was essential to acknowledge the person and family behind the MAID request and keep the human life as the focus of the assisted death. Listening to stories from the patients and their families was a critical aspect of acknowledging the life lived.

**Supporting Spiritual Needs:** Patients and families had an individualized understanding, appreciation, acknowledgment, and reconciliation of spiritual beliefs and MAID. It was important for health care providers to support the individuals in accordance with the patient’s and family’s wishes.

**Acknowledging Loss:** An essential aspect of keeping the patient and the family at the center of care was acknowledging all forms of loss, including the loss of physical abilities, and the loss of quality of life that precipitated the MAID request.

**Relational Care Considerations**

**Defining the Circle of Support:** Patients and families went through a process that was often not simple nor well-defined when determining with whom they would share the MAID decision. Those who knew of the patient’s desire for MAID (i.e. those within the patient’s circle of
support) were at the discretion of the patient and family. The act of defining who knew about MAID continued after the death had occurred, which influenced the post-death supports.

**Supporting the Circle of Support:** Health care providers were required to support the patient and family unit and facilitate positive relationships and dynamics through the MAID process. All involved in the MAID provision required emotional attendance and care.

**Relational Investments:** The success of the MAID experience rested heavily on the relational approach of the healthcare provider and their intensive investment in the relationship with the patients, families, and other care team members. The relational investment was a demonstration of caring, and, provided the patient and family ample opportunity to connect with MAID team members.

**Discussion**

PFCC recognizes patients and families as allies in QI, research, and policy development.\(^{39,40}\) The importance of quality whole person\(^ {14}\) care has been well-documented, and our findings support the continued evolution of MAID care beyond the application of the legislated eligibility criteria and mandated processes.

Foundational to the provision of many of the identified holistic PFCC MAID care considerations is time, which is also central to the patient-healthcare provider relationship.\(^{41,42}\) Some healthcare providers report an imbalance in the time needed versus the time available for care provision.\(^ {43}\) These time constraints can be magnified in MAID related care, given the reporting timelines per the Regulations for the Monitoring of Medical Assistance in Dying,\(^ {12}\) the remuneration structures,\(^ {16}\) and the pressure of increased demand for assessments, and provisions.\(^ {17,19}\) The workload associated with MAID has been deemed unsustainable.\(^ {16}\)
Exploring issues of sustainability and enhancing the capacity of providers to engage in conversations with patients and families requires urgent intersectoral collaboration between stakeholders. An exploration into the factors underpinning a practitioner’s non-participation in formal MAID provision may also support a better understanding of practitioner participation and sustainability.

Interdisciplinary approaches in end-of-life care improve patient satisfaction, improve organizational aspects of care, and supports personalized care. This resonates with our findings that interdisciplinary care was a significant support to patients and families. Further, we suggest a team of healthcare professionals be commissioned early in the trajectory of a life-limiting illness, well in advance of any formal request and assessment for MAID, to optimize support and care options for the patient and family. Although additional providers may be included to address specific care needs, provider consistency supports the provision of relational care. A team-based approach to MAID care may also offer much-needed collegial support to healthcare providers during and after the care was provided.

Although there is little evidence of increased risk of adverse grief or altered mental health outcomes in individuals bereaved by assisted death, some family members may require additional support through the MAID process and during bereavement. Anticipatory guidance is a proactive intervention to prepare patients and family members for anticipated occurrences. Practitioners can provide anticipatory guidance when working closely with families before a MAID death regarding pre and post-death procedures and support options. Appropriate support through intersectoral collaboration with community agencies is paramount to ensure family members' support continues after death. This may be complicated as the location of MAID
specific bereavement supports may be focused in urban areas and accessing bereavement supports may be complicated by the families’ desire for secrecy.\textsuperscript{13}

Planning for a MAID location that aligns with both the patient’s request and the healthcare provider’s logistical needs requires forethought. Patients and families are already balancing quality of life, MAID timing, the capacity for final consent, and practitioner availability. If a transfer is required to a non-objecting facility, planning must also consider the bed availability within the receiving facility. MAID provision should occur in a space that aligns with the patient and family’s wishes. However, if admission to a healthcare facility is required, a dedicated private, relaxed, and family-accommodating space to facilitate the admission is advisable.

Patient and family perspectives must continue to guide MAID programs and policy development. Government, leadership, administrators, and those involved in MAID programs must be attentive to the needs of those directly impacted by and providing the care. In the sensitive, emotional, and rapidly changing context of MAID, the importance of PFCC cannot be overemphasized. Health delivery agencies should continuously evaluate MAID programs with a PFCC focus and feed the results forward to support successful program development. As there are many MAID delivery models evolving in Canada, further research into PFCC outcomes concerning the different models is required.

\textit{Strengths and Limitations:} A project strength is the inclusion of multiple perspectives, including patients, families, and HCPs. A further strength is the variation within the respondent’s situation within MAID care to explore patients’ experiences along the continuum of MAID care. Limitations to our project are relative to place, time, and sample. Specifically, our project was limited to a single Canadian province, and our care delivery structure may not approximate the
care delivery structure elsewhere. Our findings must also be considered with the timeframe of the data collection, one year after MAID legalization. As the law is further debated, care processes are formalized, and best practices are developed, patients’, families’, and HCPs’ experiences will change. Although we had a robust qualitative sample, we acknowledge variations within or beyond the presented data exist. Lastly, we note a limitation of this project is a significant number of participants from urban areas as well as the significant number of participants who identified as Caucasian and female.

**Conclusion**

PFCC experiences in a MAID program underpin the development of the highest quality care. The care considerations identified assist in conceptualizing the components of a quality PFCC MAID program. Healthcare practitioners must be afforded adequate time to provide holistic, relational, individualized care. Interdisciplinary care must be commissioned early in the life-limiting illness to optimize supports to patients and families before, during, and after the request for MAID assessment. Anticipatory guidance and support must be extended to families before and after the MAID death has occurred. A dedicated healthcare facility space must be appropriate and available for MAID provisions. Including patients and families in the ongoing development and evaluation of MAID programs will ensure the focus on what is most important remains paramount - the quality of care at the end-of-life.

**Acknowledgments:** We are grateful for the willingness of patients and families to share their journeys with MAID with us and for the participation of the healthcare providers in the interviews.

**Disclosure Statement:** The authors do not have conflicts to disclose.
References


Appendix

Flexible semi-structured interview guide, tailored the participant group

1) Are you satisfied with your experience of the MAID process?
2) What went well throughout the process?
3) What did not go well throughout the process?
4) In your opinion, could you comment on the timeliness of the MAID assessment of your experience?
5) Did you experience any barriers to accessing care?
6) If applicable, was the MAID location suitable?
7) Do you have any suggestions to improve the MAID provision in [province/territory]?
8) How has your experience with MAID impacted your life?
9) Would you recommend this process to others? Why or why not?
10) If there any else you would like to share regarding your experience with the MAID process?
11) May we contact you in the future to ask you more questions?

Specific for patients

1) Did the MAID process meet your needs?
2) If MAID was not scheduled to be provided, what was the reason?

Specific for family members

1) What is your relationship to the patient who has requested MAID?
2) Was MAID provided in your experience? If no, what was the reason that MAID was not provided?
3) Did the MAID process meet the needs of you as a support person?

Healthcare Providers

1) What is your relationship to the patient who has requested MAID?
2) Was MAID provided in your experience? If no, what was the reason that MAID was not provided?
3) Are you satisfied with your experience of the MAID process?
Table 1: Core Concepts of PFCC\textsuperscript{46,47}

<table>
<thead>
<tr>
<th>Concept</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dignity and Respect</td>
<td>Listening to patient and family perspectives and choice. Patient and family knowledge, values, beliefs and cultural values are incorporated into planning and delivery of care.</td>
</tr>
<tr>
<td>Information Sharing</td>
<td>Sharing complete and unbiased information in a useful, timely affirming manner to facilitate participate in care and decision-making.</td>
</tr>
<tr>
<td>Participation</td>
<td>Patients and families are encouraged and supported to participate in care and decision-making as they choose.</td>
</tr>
<tr>
<td>Collaboration</td>
<td>In policy and program development, implementation and evaluation, research, facility design, education and the care delivery care.</td>
</tr>
</tbody>
</table>

Table 2: Patient Participant Profiles

<table>
<thead>
<tr>
<th>Gender:</th>
<th>N=5</th>
</tr>
</thead>
<tbody>
<tr>
<td>Female:</td>
<td>3</td>
</tr>
<tr>
<td>Male:</td>
<td>2</td>
</tr>
<tr>
<td>Age Range:</td>
<td></td>
</tr>
<tr>
<td>50-59:</td>
<td>1</td>
</tr>
<tr>
<td>60-69:</td>
<td>2</td>
</tr>
<tr>
<td>70 and older:</td>
<td>2</td>
</tr>
<tr>
<td>Ethnicity:</td>
<td>Caucasian: 5</td>
</tr>
<tr>
<td>-----------</td>
<td>-------------</td>
</tr>
</tbody>
</table>
| Primary residence: * | Large Population Centre: 3  
Medium Population Centre: 0  
Small Population Centre: 2 |
| MAID Involvement: | Assessed and eligible for MAID: 3  
Assessed and not eligible for MAID: 1  
Assessed and eligible for MAID, proceeded to a non-assisted death: 1 |
| Precipitating Medical Circumstance: ** | Cancer Related: 1  
Neurodegenerative: 3  
Circulatory/Respiratory: 0  
Other: 0  
N/A: 1 (patient deemed non-eligible) |
| Location of Eventual Death: | Hospital: 2  
Patient’s Home: 2  
Long-term care facility or nursing home: 0  
Hospice or other: 0  
N/A: 1 (patient deemed non-eligible) |

Table 3: Family Member Participant Profiles (and information regarding their patient family member)

<table>
<thead>
<tr>
<th>N=11</th>
</tr>
</thead>
</table>
| Family Member’s Gender: Female: 9  
Male: 2 |
| Family Member’s Ethnicity: Caucasian: 11 |
| Family Member’s Age Range: 40-49: 2  
50-59: 3  
60-69: 2  
70 and older: 4 |
| Family Member’s relationship to patient: Spouse: 4  
Child: 5  
Sibling: 1  
Friend: 1 |
| Patient’s Gender: Female: 4  
Male: 7 |
| Patient’s Age Range: 50-59: 2  
60-69: 2  
70-79: 2  
80 and older: 5 |
| Patient’s Ethnicity: Caucasian: 11 |
| Patient’s Primary Residence:* Large Population Centre: 10  
Medium Population Centre: 0  
Small Population Centre: 1 |
| Patient’s MAID Involvement: Assessed and eligible for MAID: 1 |
| Patient’s Precipitating Medical Circumstance: ** | Cancer Related: 2  
Neurodegenerative: 4  
Circulatory/Respiratory: 3  
Other: 1  
N/A: 1 (patient deemed non-eligible) |
|---|---|
| Patient’s Location of Death or Eventual Death: | Hospital: 5  
Patients who required transferred from a religiously affiliated facility to a non-religiously affiliated facility: 2  
Patient’s Home: 5  
Long-term care facility or nursing home: 0  
Hospice or other: 0  
N/A: 1 (patient deemed non-eligible) |

---

| Table 4: Healthcare Provider Participant Profiles |
|---|---|
| N-14 | |
| Gender: | Female: 11  
Male: 3 |
| Age Range: | 40-49: 6  
50-59: 5  
60 and older: 3 |
| Professional Group: | Medicine: 3  
• Family medicine practitioners: 2  
• Medical specialist practitioner: 1  
Social Work: 4  
• Acute care social worker: 3  
• Community based social worker: 1  
Hospital Nurses: 7  
• Registered Nurse: 6  
• Licensed Practical Nurse: 1 |
| Involvement with MAID: | Provided care to patient/families the day of MAID: 5  
• Provided MAID: 1  
• Provided Supportive Care: 4  
Provided care to patient/families in advance of MAID: 6  
Policy Development & Staff Support: 3 |
| Geographic Location: * | Large Population Centre: 13  
Medium Population Centre: 0 |
**Notes:**

*According to Statistics Canada, a large urban centre consists of a population of 100,000 or more, a medium population centre consists of a population of 30,000-99,000, a small population centre consists of 1,000-29,000.

**Precipitating medical circumstance groupings are in alignment with the Reporting in the Government of Canada reports on MAID.

Table 5: Exemplar Quotes by Theme

<table>
<thead>
<tr>
<th>Emotional Care Considerations:</th>
<th><em>Exploring and Validating</em> the Emotional Journey</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>* PFCC concept of dignity and respect</td>
</tr>
<tr>
<td></td>
<td>“I tried [suicide] twice. And it didn’t work. I mean, you can see the size of me, I can go into very low sugar fast. I took 250 units of insulin and it didn’t work. I took something like a month’s worth of pills. One pill could make me go to sleep for days. I took the whole bottle, and it didn’t work. And the thing about MAID, is, I know it is going to work.” (Patient. Assessed and eligible for MAID. Interview 1)</td>
</tr>
<tr>
<td></td>
<td>“I guess he [the physician] asked her why. Why do you want to do this? And she just looked at him and said, “don’t I have the right to quit?” (Family member. Sibling received MAID. Interview 11)</td>
</tr>
<tr>
<td></td>
<td>“What I’m struggling with right now is. You know, because she was pushing, pushing, pushing, I was fighting, fighting, fighting. And so. And so in her last 24 hours I was angry at her. Instead of preparing myself to lose her. So I feel guilty for that.” (Family member. Parent received MAID. Interview 16)</td>
</tr>
<tr>
<td></td>
<td>“We had prepared ourselves, and dad, and um at two o’clock that day it [MAID provision] was supposed to be done. And they [providers] come in to obtain final consent and whatever…he couldn’t answer the questions and so everybody was prepared for it all to happen and they just couldn’t go through. It was horrific.” (Family member. Parent eligible for MAID, but did not receive MAID. Interview 10)</td>
</tr>
<tr>
<td></td>
<td>“He [the patient] was so afraid that his mind might not stay that bright, that’s why he really wanted to get the wheels put in motion [and access MAID].” (Family member. Spouse received MAID. Interview 14)</td>
</tr>
<tr>
<td></td>
<td>“People say to me ‘how good you look.’ The point is, I don’t feel that good.” (Patient. Assessed and eligible for MAID. Interview 3).</td>
</tr>
<tr>
<td></td>
<td>“The [patient] had a conversation with his [family doctor] and [the family doctor] was sorted of giving him the gears about how he should fight the good fight, and how he needed to eat more and drink more and whatever. And he looked at her and said “but I’m dying, I’m not recovering from this. This is ridiculous.” (Healthcare provider. Interview 16)</td>
</tr>
<tr>
<td></td>
<td>“With (sister), one minute she’s sitting there talking to you and then next minute, she’s dead. And you watch that happen. I think that’s the part that I wasn’t ready for… I see it at night, I see it in the morning. Every time I think about her, I see...”</td>
</tr>
</tbody>
</table>
### Families and Care Team

* PFCC concept of dignity and respect

| that. And I guess that’s the part that I wasn’t prepared for.” (Family member. Sibling received MAID. Interview 11) |

| “I’d been present for a lot of natural deaths but this was different. I felt shock initially, and then having to put that aside and help the family, which I could do it was just hard. And then when I left, I kept thinking “How do I deal with this” or struggling with “I don’t really know how I feel about this.” (Healthcare provider. Interview 11) |

### Physical Care Considerations:

#### Sensitivity in “Eligibility Assessments”

| “the [family doctor] …gave us [the family] a letter and gave us 30 seconds to look at it. That’s all the information we received that she was denied. So we don’t know at what point she was denied, if it was months before or whether it was the day we received the letter.” (Family member. Parent was not approved for MAID. Interview 15) |

| “[the doctor] would say, “I’m in the neighbourhood, so I thought I would just pull up in [to visit]”,…it was hard on dad because he was like, what if I’m just in this ‘lala land’ [and then be deemed to have lost capacity].” (Family member. Parent received MAID. Interview 13) |

| “There should be two doctors that go into interview...right? If he [patient] can answer the questions once, he shouldn’t have to wait and wait and wait and then have to redo it.” (Family member. Parent eligible for MAID, but did not receive MAID. Interview 10). |

#### Weaving in “Interdisciplinary Care”

| “The medical support we’ve had has been terrific. So, doctors, palliative care nurse, un occupational therapists, physiotherapists, speech therapists, so we have a really good group of services that have wrapped, you know, the medical services around us.” (Family member. Spouse approved for MAID. Interview 4) |

| “A few family members were struggling with it [the death], but the social worker on the floor and a few of the team members helped. And we had a team meeting ...prior to this to deal with the emotional aspects of what was going on.” (Healthcare Provider 10) |

#### Provision of Anticipatory Guidance

| “My sister had to explain it to me. Is that when, when, when they pass, they expunge air from their lungs. And it’s like a gasping sound. I wasn’t prepared for it and thought she was in pain. So, um she wasn’t. Had I known that that was going to happen, it wouldn’t have been so hard for me at that time. Just to say that, you know this is the process...The sedative goes in. It relaxes them and it relaxes their lungs and she’s going to release air at the end. It’s just so that, you know when it happens, you don’t, you’re not thinking, “oh my god she’s struggling, she’s fighting or she’s hurting.” (Family Member. Parent received MAID. Interview 16) |

#### Location

| “This patient had spent a long time in the [redacted] unit at [faith-influenced facility]. So, she was leaving a place she was at for a long time, the staff and an area that she was comfortable with. Then she came here [non-faith-influenced facility] and she lost that support and familiarity. They lost all the rapport and support that had been built, which is huge in this process. I think it was upsetting for them [patient and family] to have to go through that.” (Healthcare Provider. Interview 11) |
“She [patient] originally thought she would like to have it done in the hospital, um, just because, she was worried that I would be, uh, uncomfortable with it in the home. But I knew she wanted it in the home. And I completely agreed that it should be in the home. That was her nest and comfort. Her area of comfort for 50 years. For me it was appropriate.” (Family member. Parent received MAID. Interview 16).

<table>
<thead>
<tr>
<th>Spiritual Care Considerations:</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Honoring Choice</strong></td>
</tr>
<tr>
<td>* PFCC concept of dignity and respect</td>
</tr>
<tr>
<td>“It does help you emotionally to know that you, your belief systems and your loved one’s belief systems are not evil.” (Family member. Parent received MAID. Interview 16).</td>
</tr>
<tr>
<td>“I think you were put into this world without asking, you’re entitled to leave it when you want and how, without pain or legal problems…. Palliative care. If you prefer that, then have it! But it should not be forced upon you. You should have the choice. Availability and the choice of alternatives. Freely available, commonly practiced.” (Patient. Assessed and eligible for MAID. Interview 3).</td>
</tr>
<tr>
<td><strong>Listening to Life Stories</strong></td>
</tr>
<tr>
<td>* PFCC concept of dignity and respect</td>
</tr>
<tr>
<td>“She fought for a lot of things [and] she did a lot of things. I don’t know if she told you. She was in a propelled parachute. She was in a hot air balloon. She jumped out of an airplane. She’d been on cruises. She’d been to Vegas, Tofino, BC. Alaska four times with [her husband] on a cruise.” (Family member. Sibling Parent received MAID. Interview 11).</td>
</tr>
<tr>
<td><strong>Supporting Spiritual Needs</strong></td>
</tr>
<tr>
<td>* PFCC concept of dignity and respect</td>
</tr>
<tr>
<td>“Guess the other thing that forms my mind is I’ve been a spiritual seeker all my life so I guess I could call myself a, oh how do I put them? In order of occurrence, or what’s most important to me? I guess, I was raised a Lutheran, that didn’t take. Looked at other Christian religions, didn’t take. Buddhism is most practical of what you can do with your mind and function. Hinduism is a more recent interest of mine. I took a look at Islam…So I’m kind of a dabbler. I’ve taken what I felt was best, what resonated in different things. So I have no real fear of death. It’s getting there that’s hard. If I could just sit down and meditate and be gone, it would be great.” (Patient. Assessed and not eligible for MAID. Interview 2).</td>
</tr>
<tr>
<td>“We are Catholic, dad wasn’t you know. So, a little bit of that belief came into play, but towards the end we were all right with him. We knew what he wanted and we respected that.” (Family member. Parent received MAID. Interview 13).</td>
</tr>
<tr>
<td><strong>Acknowledging Loss</strong></td>
</tr>
<tr>
<td>* PFCC concept of dignity and respect</td>
</tr>
<tr>
<td>“You give up so much and I’m not talking material things. I’m talking independence. The fact that, I mean, I have to plan when I go pee and I plan, like, it’s just. And everybody says oh you know it’s just little things. But you add up those little things and they become big things.” (Patient. Assessed and eligible for MAID. Interview 1).</td>
</tr>
<tr>
<td>“He [family member] was in and out of the hospital all the time and was having a hard time getting around and then what really topped it off for him was he lost the use of his hands, so meant that he couldn’t uh um be mobile anymore or text or even talk on the phone or even whatever do what he wanted to do you know work on the computer and stuff like that.” (Family member. Parent received MAID. Interview 10).</td>
</tr>
<tr>
<td><strong>Relational Care Considerations:</strong></td>
</tr>
<tr>
<td><strong>Defining the Circle of Support</strong></td>
</tr>
</tbody>
</table>
| “We let, his grandchildren know, my kids [and] his children and grandchildren knew, but we really didn’t want anyone else in on this because he didn’t want
<table>
<thead>
<tr>
<th>Supporting the Circle of Support</th>
<th>anyone trying to talk him out of it.” (Family member. Spouse received MAID. Interview 12).</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>“My problem right now is I don’t share with people. I share very limited with people that mom’s passing was done through MAID. And my, it’s not because I don’t 100% believe it.” (Family member. Parent received. Interview 16.).</td>
</tr>
<tr>
<td></td>
<td>“They [children] had time to write him notes and say their goodbyes in [hospital name]. They wrote really nice notes which was lovely.” (Family member. Spouse received MAID. Interview 14).</td>
</tr>
<tr>
<td></td>
<td>“Everybody was there, having coffee and whatever. Then in the afternoon, they went to the bedroom and everybody stayed. All the right people were there and they visited which is good and that’s what he would have wanted. He was at home as he requested. She [his wife] was able to lay beside him, all the things he wanted. It was all good- as good as it can be.” (Healthcare Provider. Interview 13).</td>
</tr>
<tr>
<td></td>
<td>“The patient had a great support. Initially the granddaughter was continuously coming and I was more involved with her. And then there were other family members and I could offer them chairs and things to drink- tending to them that way and it was nice we were able to do that for them.” (Healthcare Provider. Interview 6).</td>
</tr>
<tr>
<td>Relational Investments</td>
<td>“We met with him [MAID provider] every week. Every Wednesday at 2 o’clock, he was down at [care home] to meet us. It was incredible. I mean that he would take his time out of his busy, I’m sure it’s very busy, schedule to come and meet with us, it was incredible.” (Family member. Parent received MAID. Interview 13).</td>
</tr>
<tr>
<td></td>
<td>“It’s [the caring] not something that they, it’s not like, “here’s my resume”. You can just feel it from them. And I think that’s, being able to feel that, um, helps the family. It reassures the family.” (Family Member. Friend received MAID. Interview 6).</td>
</tr>
</tbody>
</table>