

Anticipating nursing practice implications of medical assistance in dying for minors in
Canada: An environmental scan and policy analysis

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Introduction

In June of 2016, Canada became the fourth country to legalize medical assistance in dying (MAiD). Now, Canadians over the age of 18 can apply for MAiD if they are in an “advanced stage of irreversible decline and will die in the foreseeable future” and are experiencing “grievous and irremediable suffering” unrelenting pain and suffering (Criminal Code of Canada, 2016). This change in legislation was as a result of a decision of the Supreme Court of Canada, which overturned a previous ruling that barred Sue Rodríguez access to physician assisted dying. In the most recent federal case of Carter vs. Canada, the final decision suggested physician assisted death was a right Canadians should be permitted and should be made available within Canada (Butler & Tiedemann, 2015). In response, The Criminal Code of Canada was amended to permit physicians and nurse practitioners to prescribe and provide a lethal medication to patients with a grievous and irremediable medical condition (Ministry of Justice, 2016). The law, however, has an age restriction of 18 years, which can be argued is in direct violation of Section 15-1 of the Canadian Charter of Rights and Freedoms (McCrudden, 2008). Section 15-1 of the Charter states that “Every individual is equal before and under the law and has the right to the equal protection and equal benefit of the law without discrimination and, in particular, without discrimination based on race, national or ethnic origin, colour, religion, sex, age or mental or physical disability” (Department of Justice, 1981, page 4). By purposefully excluding children based on their age, it could be argued that the Canadian Government is facilitating inequitable access to the full range of health care that is provided within Canada (McCrudden, 2008). There are advocates on both sides of the argument, many of which presented their thoughts to the Special Joint

Committee on physician-assisted death, whose summary informed the creation of Bill C-14, the new MAiD legalization (Ministry of Justice, 2016). Although the resulting Bill C-14 (Cummings & Mercurio, 2010) and subsequent change to the Criminal Code did not include minors, the suggestion from the committee was to revisit this topic, along with other vulnerable groups that were directly excluded from this bill. The law stipulates timelines and revision dates that will consider the inclusion of these groups, but only after there is an independent review of the desire and possible implementation for minors.

Another area in which the Committee advised revision was the inclusion of, and coverage for, nurses to participate in medical assisted dying. The main thrust of the bill is directed at creating safeguards for physicians and nurse practitioners (Bill C-14, 2016). However, historically the majority of patients receive most of their information and support surrounding end-of-life (EOL) issues from their bedside nurses (Heinze & Nolan, 2012; Hinds & Kelly, 2010). Nursing practice and nurses' experiences of providing end-of-life care will also be altered by this bill, therefore, it is imperative that their role within MAiD be understood. In addition to creating space for MAiD within the criminal code of Canada, the new legislation outlined timelines for the review of the present safeguards, one of which is mature minors. The possible inclusion of pediatric patients within MAiD necessitates an examination of pediatric palliative care (PPC) and the related nursing roles. Considering that some Canadian citizens have reported difficulty gaining access to MAiD since June 17th (Lamoureux & Muncar, 2016), nurses could potentially help address issues of accessibility. Therefore, a comprehensive understanding of nurses' abilities, perspectives and reach could facilitate more Canadians ending their life in a manner of their choosing.

This SPAR project investigates both the inclusion of minors and the role and considerations for nurses as they assist their patients with this new aspect of care. A literature review of MAiD and associated topics will be performed to understand the depth and breadth of the complexities that arise in the context of minors and MAiD. An environmental scan will examine other countries with MAiD regulation in relation to pediatric patients, the attitude and perceptions of physicians and nurses surrounding the concept of MAiD for minors, and the scope of nursing in relation to MAiD. The policies that pertain to MAiD in nursing and physician governing bodies as well as BC Health Authorities will be examined to understand the ideal scope of practice, and outline any potential gaps. Nursing considerations with respect to potential practice issues regarding the inclusion of minors in the Canadian law will be discussed.

Significance of the issue

Presently, Belgium and the Netherlands are the only countries that permit children to be included in MAiD, and both have similar rates of children diagnosed with life-limiting illnesses, to Canada (Giglio & Spagnolo, 2014; Landry, Foreman, & Kekewich, 2015). The inclusion of children in their MAiD legislation stimulated tremendous debate in both countries. The common criticism by advocacy groups was that the exclusion from MAiD on the sole basis of a child's age was discriminatory (Raus, 2016). The main objection to pediatric inclusion is related to ideas about a child's capacity for self-determination and critical decision-making (Cummings & Mercurio, 2010; Giglio & Spagnolo, 2014). Debate related to individual autonomy surrounding decision-making is not new in pediatric care (Heinze & Nolan, 2012), nor is there consensus among health care providers (HCP) (Cummings & Mercurio, 2010). Growing numbers of children are

living with life-limiting illnesses that are both chronic and complex (Dewan & Cohen, 2013) because of medical advancements in pharmacology and treatment options. With the popularization of family-centred care and patient assent, children are increasingly encouraged to be involved in decision-making related to their health care. Children are being encouraged to assert their autonomy and advocate for their preferred treatment options and trajectory of care (Shields et al., 2012). This should not be any different when it comes to the time-line and experience at the end of their lives. Pediatric palliative care nurses understand the importance of supporting patients throughout the dying process and have endorsed pediatric advance directives (Doorenbos et al., 2012; Hammes, Klevan, Kempf, & Williams, 2005; Lotz, Jox, Borasio, & Fuhrer, 2013). Were MAiD to become an option for pediatric patients, nursing could play a major role.

Historically, and in numerous studies, family members have identified the nurse as the health care team member who is their primary source of information and support (Lotz et al., 2013); this is no different in PPC. Nurses routinely spend more time with their patients than any other health provider, and they advocate on behalf of the patient and family (Albers, Francke, de Veer, Bilsen, & Onwuteake-Philipsen, 2014). They are often considered by patients to be the most trusted member of the health care team (Shields et al., 2012). The inclusion of MAiD into a pediatric patient's health care options will impact a nurse's scope of practice and care delivered (College of Licenced Practical Nurses of British Columbia, 2016; College of Registered Nurses of British Columbia, 2016; College of Registered Psychiatric Nurses of British Columbia; 2016). Policies set out by employers as well as nursing regulatory bodies will outline nurses' roles in relation to MAiD. More importantly, nurses will potentially have a tremendous influence

on the end-of-life experiences of children and their family members. In this context, nurses might be challenged with issues related to the level of involvement surrounding information sharing, family-centred care, and patient advocacy, as well as delineating nursing scope of practice. Nurses might also have a moral or religious conscientious objection to the provision of MAiD, which would in turn affect their fellow nurses and possibly their patient assignments. Given the potential implications for nursing practice in the provision of MAiD for their patients, it is essential to explore the current barriers experienced in PPC, gain insight from other countries, and examine policies and guidelines created by governing bodies to identify challenges and possible areas of study to be fully prepared in the event that pediatric patients become eligible for MAiD in Canada.

Methods

To address these issues, the aim of my SPAR project is to explore the topic of minors being included in future iterations of the MAiD legislation and the ways in which the inclusion of minors in MAiD legislation might impact the nursing profession. First, I define terms and concepts that are used throughout this document, including medical assistance in dying, palliative care, end-of-life care, euthanasia, assisted death, and assisted suicide. Any link between these concepts will be explained to ensure clarity within the project. After the terminology is clear, I will focus on a series of steps to create a complete picture: 1) a literature review, 2) an environmental scan, 3) a policy analysis and 4) stakeholder interviews. This SPAR project will use the Canadian Nurses Association Code of Ethics guiding principle throughout the analysis (Canadian Nurses Association, 2008).

Canada is the only country that permits both nurse practitioners and physicians to provide a prescription for ending a patients' life at the patient's request. All other countries with government-sanctioned assisted death provide options that can be administered or prescribed by a physician only and, therefore, it is known as physician assisted death. Because of this distinction, Canadians are privy to medical assistance in death or dying (MAiD) as opposed to physician assisted dying or death (PAD). In this discussion, these terms will not be used interchangeably, as PAD does not include the actions of any other health professionals involved in the process. As mentioned by the CNA representative to the Special Joint Session on Physician Assisted Death, nurses are regularly identified as the greatest source of information by patients, therefore the Canadian law was crafted to pertain to all health professionals that might potentially eventually be involved in the process of assisted death (Canadian Nurses Association, 2016). Additionally, the permitted Nurse Practitioners' (NP) assessing and prescribing rights increases the access of MAiD for Canadians, as NPs are often the only health professional available in rural or Northern Canada.

Definitions

Assisted death – providing a prescription for medication that, once consumed by the patient, will directly lead to their death. [Two terms are used within the literature to describe the same process of assisted death: assisted death and assisted suicide. I have found that those using the term “assisted suicide” tend to be those that are opposed to the concept or that the papers including that term were written prior to any laws being in place when assisting a death was legal. The concept of suicide has a negative

connotation within society and therefore this paper will be using the more neutral term of assisted death.]

Assessor – A physician or nurse practitioner who assesses a patient for their eligibility for MAiD.

Child – a person who is below the age of majority. [Within Canada the age of majority is 18 years, however in BC it is 19 years. Due to the federal reach of the Criminal Code of Canada, within BC, children 18 to 19 years of age are eligible to receive MAiD.]

End-of-life care – the care provided to a patient when they are in the end-stage of their illness and death is imminent.

Medical assistance in dying (MAiD) – the act of enabling a patient to receive a medication that will lead to their death. [Canada has identified this as the preferred term because this act protects all health professions aiding in the assessment and provision of MAiD (Wilson-Raybould, 2016). Canada is the first country to permit NPs to prescribe and/or administer medications to end the life of an eligible patient who has requested MAiD.]

Palliative care – the care provided to a patient that is dedicated to relieving symptoms and increasing quality of life instead of providing treatment that is aiming to cure the patient.

Pediatric physician assisted death (PPAD) – a physician administering or prescribing a medication that will lead to the death of a person aged less than 18 years.

Provider – A physician or nurse practitioner who assesses a patient for their eligibility for MAiD and either administers or prescribes the medication with the intention of ending the patient's life.

Physician assisted death (PAD) – a physician administering or prescribing a medication that will lead to their death.

Voluntary Euthanasia – the act of administering a substance to a patient with the intent that it will directly lead to the patient’s death with the patient’s consent.

Literature Review

This literature review has three main exploratory aims: (1) to gain a broad understanding of PPC within Canada, (2) to determine barriers that prevent children from receiving palliative care within Canada, including an exploration of autonomy and consent, and (3) to anticipate the potential nursing role if pediatric patients become eligible to apply for MAiD. The description of the current PPC climate will create context in which the pediatric MAiD discussion will take place as well as identify barriers to MAiD. One key reason for the exclusion of minors from the initial MAiD legislation is their perceived inability to provide informed consent. Therefore, I will examine the concepts of children’s autonomy within decision-making and the sliding scale by which HCPs assess competency, as well as parental decision-making and the involvement of health professionals. The experiences and perceptions of nurses providing PPC will be examined in order to anticipate potential problems with the MAiD legislation and its functionality with the pediatric patient and their family. A patient does not need to be receiving palliative care in order to receive MAiD, but given the inclusion criteria for MAiD that a patient must be in an advanced state of decline, it would be a reasonable assumption that many of these patients will have palliative services involvement. I will also examine the issue of conscientious objectors and how refusing to care for these patients could play out within nursing practice. All of these issues could be

potential barriers for children not gaining access to MAiD in the future. It is important to understand the climate in which this change in legislation will occur in order to anticipate potential barriers.

Pediatric Palliative Care Summary

Canadians of all ages have been experiencing problems accessing palliative care services. This has been identified as an issue for quite some time, and one can assume that difficulties will only increase (Butler & Tiedemann, 2015). Widger et al. (2007) found that the referral rate to palliative care services within Canada only reached 5% of the children for whom MAiD might have been applicable, were it legal within Canada. This is compared to the 16-30% of adult patients eligible for MAiD that had received palliative care services within Canada (Butler & Tiedemann, 2015). There are only five PPC hospices within Canada, and PPC services are only offered within pediatric hospitals, all of which are in urban settings. This creates a geographic barrier for those who do not live in one of the five urban centers, or those who want to return home for their child's palliative care services (Chavoshi, Miller, & Siden, 2013). Some family physicians and pediatricians in smaller communities offer palliative care services, but these are few and far between (Butler & Tiedemann, 2015). This greatly limits access to palliative care for children throughout Canada. These barriers to palliative care services will inevitably become an important consideration in ongoing deliberations around access to MAiD for children and their families.

Not only are children and their families encountering difficulty accessing palliative services, their time to referral for the service is quite variable (Widger et al., 2007). Parents who have had a child die while using palliative care services have

identified that timelier referral to palliative care services would have been beneficial. The parents' reasoning included wanting more time with their child, and posthumously regretting not shifting treatment from curative to palliative sooner to have more symptom free days (Lipstein, Brinkman, & Britto, 2012; Stewart, Pyke-Grimm, & Kelly, 2012). This time lag can partly be explained by the parents not understanding the child's prognosis or the aim of palliative care, and therefore not accepting the referral, but could also be related to palliative care not being discussed by health care professionals (Knapp & Thompson, 2011; Williams-Reade et al., 2015). The time of referral to the palliative care service ranged within studies, but those with a short referral time did not provide parents the sufficient processing time to understand the implications of a change in goals of care, let alone the likelihood of their child's death (American Academy of Pediatrics, 2000; Widger et al., 2007). Discussion regarding a child's diagnosis, prognosis and care options often occur with a physician, parent and when appropriate, the child as well. Communication breakdown during these meetings is common, either from the physician's poor communication skills, or the parents not being in a place where they are able receive the information. This can leave parents not fully comprehending the care options and the potential side effects should they choice one over another, but are still asked to make a choice. This lack of mutual understanding can lead to physicians to provide less effective patient care as well as a decline in effective communication within the team and family unit (Doorenbos et al., 2012; Williams-Reade et al., 2015).

The process of acknowledging and understanding their child's diagnosis and prognosis, as well as comprehending the implications of those facts, will be different for every parent, and can take a varied amount of time. Some parents are never able to accept

their child's palliative prognosis. However, there are various ways that HCPs may be able to help parents move toward a level of comprehension that will help the parents make informed decisions. The early introduction of palliative care can decrease the stigma of palliative care when presented as a possible care option, rather than exploring this avenue as a last resort. Studies suggest that the introduction of the palliative care concept early on could increase the uptake of that service as the patient's disease progresses (Knapp et al., 2011; Linton & Feudtner, 2008). To summarize, very few children who could benefit from PPC are receiving it, and when they do it can come too late for the family and patient to receive the full benefit. The palliative approach to care is aimed at increasing the patient's quality of life by treating the patient's symptoms rather than aiming for curative treatment (De Lima et al., 2017). The adult and pediatric palliative care international associations do not consider MAiD as part of their clinical specialty, so thoughtful consideration regarding how to ensure this care option is provided for patients, and who ought to have that conversation is essential to ensuring equitable patient access. Through further exploration into the parental perception of PPC we might be able to gain understanding of perceived barriers. Nurses are ideally placed to connect with families and discuss their impression of palliative care to identify any false perceptions of the service. This nursing initiative could enable more equitable access to palliative care discussions within pediatrics, and by extension, pediatric MAiD.

Proximity to, and false perception of PPC services are not the only barriers experienced by patients and families. Some research has examined physicians' perspectives regarding children receiving palliative care. In an effort to understand the PPC needs within Canada, the Canadian Pediatric Surveillance Program surveyed the

nation's pediatricians in 2015 (Cyr & Maissonneuve, 2015). It underlined the gap in care discussed above, but also identified physicians discomfort regarding discussing PPC, suggesting an increase in education for pediatricians surrounding PPC would be beneficial. One in five respondents identified this specialty as a knowledge gap. This sentiment is echoed in other research (American Academy of Pediatrics, 2000; Atwood, Hoffmann, Yan, & Lee, 2014). Many physicians and nurses have felt uncomfortable introducing or discussing PPC, which decreases a child's access to the referral. Some factors contributing to these feelings are previous personal and professional experience, and educational history, and cultural background, all of which contribute to the comfort level when discussing palliative care (Deep, Green, Griffith, & Wilson, 2007; Westphal & McKee, 2009). Professional or personal experiences may have negatively influenced a HCPs experience with palliative care. These informative experiences could result in a HCP not discussing this option with their patient. HCPs have also said that an uncertainty of prognosis, language barriers and time constraints are three major reasons for delayed referral to PPC (Howell, 2012; Lotz, Jox, Borasio, & Fuhrer, 2013; Youngblut & Brooten, 2012). A physician's comfort level with discussing palliative care is linked to their education on the topic as well as their personal beliefs on the subject; those that have less exposure to palliative care feel less comfortable discussing palliative care (Deep et al., 2007). Given how few children receive palliative care, it would make sense that physicians have an even lower comfort level discussing palliative care for children, leading to fewer children receiving a PPC referral.

To summarize, gaining access to PPC is currently an issue for Canadian families. While MAiD and PPC are not mutually exclusive programs, I anticipate that families

may experience comparable barriers when trying to access either service. And given MAiD is such a new care option for Canadians, the potential for health providers to be unfamiliar, and therefore, unable to discuss this topic with their patients, is a distinct possibility. To combat that challenge, nurses and community stakeholders will play a large role in educating institutions, HCPs, and patients about this care option.

Autonomy and Consent

Apart from the lack of referral to palliative services and resources, I anticipate other barriers will exist if children are able to apply for MAiD. Barriers for pediatric patients to MAiD have not been described within the literature, apart from practitioners objecting to the practice for either moral or religious reasons. As of yet, no research has explored contentious objections in any great depth. This points to another way of exploring barriers to pediatric MAiD, which is to examine common debates within pediatrics linked to the eligibility criteria for MAiD, including capacity to consent.

Determining capacity for informed consent has proven contentious in pediatrics, and is directly linked to the concepts of non-maleficence and beneficence (Harrison, 2004; Pretzlaff, 2005). Part of the ethical code that HCPs work to uphold is to “do no harm”, also known as non-maleficence. HCPs must also practice beneficence, which means actions that help prevent or remove harms (Canadian Nurses Association, 2008). These two ethical ideas can occasionally be at odds based on a person’s individual perspective. Such ethical dilemmas explain why patient consent is necessary within health care (Birchley, 2010; Drake, 2001; Weir & Peters, 1997). Within pediatrics practice, there is the assumption that children are not capable to provide informed consent (Hein et al., 2015). This assumption stands until a parent or HCP makes an assessment,

but that determination may only stand for one instance of decision-making. This practice means that children are not able to regularly have autonomy over their care. It is imperative that a continual assessment of a child's capability competence occurs, but also that more attention is paid to this topic in general (Harrison, 2004). An assessment tool to determine a child's capability to consent could be created to avoid children not having autonomy over their medical choices simply because their HCPs did not feel they were able.

For children, parents are legally and socially bound to make most decisions (Queen's Printer, 1997). For example, the surgery needed to save a child's life might also result in the loss of a limb. With some previous consultation and education, the medical treatment decision is left with the parents to determine what is in the best interest of their child, taking into consideration all aspects of the child's life (Hinds & Kelly, 2010; Royal College of Paediatrician and Child Health, 2004). For some children that decision might be to stop treatment and initiate palliative care, while other parents might opt for the surgery. Parents are legally obligated to make decisions that are in the best interest of the child. Because they are under no legal obligation to include the child in that decision-making, the level of involvement of the child is determined by the parents (Queen's Printer, 1997). When the child reaches age of majority, consent is sought from the child themselves.

A 1995 policy statement from the American Academy of Pediatrics stated that children should be involved in their medical decision-making as well as provide assent for procedures and plans of care in line with their developmental abilities. This statement is echoed in the most recent position statement from the Canadian Paediatric Society

(AAP Committee on Bioethics, 2016; Harrison, 2004). Since there is no standardized tool selected by these childcare advocacy bodies, the enactment of this statement will be carried out by parents and practitioners in their own way. Some researchers describe pediatric consent as an incidental process, while others insist that the patient can demonstrate multiple attributes without advancement; but there is no definitive description of competence or consent (Hein et al., 2015). The decision of competence lies with the HCP. Childcare advocacy bodies have stated that children should be included in the health care discussions to assess and improve their level of capacity, which can be achieved through following the levels of participation, but this is not enforced globally by policy. Levels of participation have been identified by the Royal College of Paediatricians and Child Health as follows: 1) informing children; 2) listening to them; 3) taking account of their views so that they can influence decisions; and 4) respecting the competent child as the main decider about the proposed health care interventions (Royal College of Paediatrician and Child Health, 2004). HCPs view the levels of competence as the ability to 1) understand the information; 2) make a decision by choosing from the different options; 3) reason about the way in which the decision has been reached and; 4) be able to appreciate the consequences of the resulting decisions (Koocher & De Maso, 1990). Many different models of assessing competency and capacity to increase the ability to engage in decision-making have been created (Hein et al., 2015). As of yet, there has been no definitive investigation into what should be used to establish pediatric capacity for decision making.

The majority of debates surrounding consent and pediatric decision-making have to do with how to determine where children are on these scales as well as how to create a

subjective method of assessing a pediatric patient's competency. As early as 1982, studies identified that nine year olds made the same treatment decisions as adolescents and adults, indicating children could be competent to make medical decisions without parental guidance (Weithorn & Campbell, 1982). Presently, children are still relying on their physicians' and parents' opinions of their capacity to determine their involvement in their health care decisions, creating a large equity gap within pediatrics. Some HCPs are comfortable with a sliding scale of competence or capacity, while others are rigid in their understanding of informed consent. Some take the child's developmental age into account, while others impose the same requirements for children and adults. Currently, there is no standard assessment tool, but decided by the values, judgment and past experiences of the health provider (Drake, 2000). There is the potential for two HCPs to disagree about a child's capacity to consent, leaving the level of a child's involvement up for debate. This ought not to happen, because it could lead to further inequity for children, keeping them from potentially appealing health care options. When considering the inclusion criteria for MAiD within Canada, the ability to provide consent is essential. In order for children to be able to gain equitable access to MAiD, the details surrounding HCP's objective assessments of capacity will need to be clarified.

Parental Decision Making

HCPs are not the only adults potentially preventing children from gaining access to health care options; a child's parents could also be a barrier. I anticipate scenarios where a child and their parents do not agree about the use of MAiD. Parents are given the right and obligation to be the surrogate decision-maker for children within BC through the Infant Act (Eggman & Alejo, 2016). Capacity to consent is one of the

eligibility criteria for MAiD, and if children were given access to the same health care options as adult Canadians, this criterion will be of great importance. Therefore, an analysis of parental decision-making would enhance understanding of the potential issues for pediatric patients seeking MAiD in the future.

Parental decision-making is a complex concept influenced by a variety of factors that impact the choice of the child's health care trajectory. A parent's decision-making process is informed by many factors: their personal and cultural background, socio-economic status, their relationship and experience with the health care team and the clinical situation of their child (Heinze & Nolan, 2012; Hinds & Kelly, 2010). The inclusion of the child in the decision-making process is dictated by the parent as well as the HCP's level of advocacy for that child. If neither adult feels that the child should be involved, the child has limited mechanisms to request inclusion. In addition, parents acting as surrogate decision makers often have limited experience with medical decision making, and might have differing views on ideal health outcomes from the health care team or their own child (Carnevale, 2005; Claassen, 2000). Parental decision making regarding medical decisions is a skill with which most parents have limited experience. A parent's decision is not only regarding the health care issue, but also the child's level of autonomy to be involved in these decisions based on their impression of their child's capacity as well as their style of parenting (Drake, 2001; Eggly & Meert, 2011). Their own personal blueprint for what it means to be a parent can influence the health care choices they make for their child. These factors all influence the medical decision making that shapes health care decisions (Heinze & Nolan, 2012; Kuntaros, Wichiencharoen, Prasopkittikun, & Staworn, 2007; Lipstein, Brinkman, & Britto, 2012).

For example, if a parent is religiously opposed to MAiD, but the child does not share the same values, that child is potentially barred from access. If a parent does not have a good relationship with HCPs, leading them to ignore the potential health care option presented for their child, that child may similarly be deprived of options. Therefore, parents are directly involved in determining the child's level of involvement in their own health care decision making. This will vary based on the parent, leading to minors not having equitable access to their health care decisions.

Literature Review Summary

There are a variety of ways that children are vulnerable to being excluded from access to MAiD: through lack of access to palliative care services, through denial of care options from parents, as well as HCPs objectively assessing the child's capacity to consent. When caring for pediatric patients that might want MAiD, nurses must be mindful of these professional and personal barriers. Nurses often act as advocates when they feel their patients' wishes did not receive the attention deserved. Pediatric nurses are experienced in listening to the health care team, the parents' and the child's point of view, and then identifying which member is not receiving equal amount of attention paid to their care ideas. Nurses do not formally assess patients for their eligibility but they are able to inform and initiate referrals for MAiD, therefore understanding the complexities of this situation will be essential. While understanding the issues within a team are important, it is equally as important for nurses to understand the inclusion criteria for MAiD.

Summary of Canadian Law

The relevant Canadian legislation passed into being on June 17th, 2016. Here is a summary of the inclusion and exclusion criteria for MAiD in Canada. There are many terms within this legislation that have not been defined by the lawmakers, terms such as “reasonably foreseeable”, “advanced state of decline” and “grievous and irremediable” (Ministry of Justice, 2016). This leaves the interpretation of those terms up to the practitioner assessing a patient’s MAiD request as well as a patient’s opinion about the state of their suffering. To gain access to MAiD, a patient must meet numerous eligibility criteria, which are as follows:

- The patient must be eligible for health care within Canada and must be at least 18 years of age and able to make health care decisions.
- The patient must have a grievous and irremediable medical condition in an advanced state of decline with death being reasonably foreseeable.
- This disease causes them enduring physical or psychological suffering that is intolerable to them and that cannot be relieved in a manner that the person considers acceptable.
- The patient making the request for MAiD must do so voluntarily and put it in writing; this document must be witnessed by two individuals who will not be providing care.
- The patient must provide additional consent directly prior to administration of the medication and be aware of their option to withdraw from the treatment.

- In order for MAiD to proceed, each patient must have at least two independent assessors for competency and legitimacy of request, one of which will prescribe or provide the lethal medication.
- Physicians and nurse practitioners are both eligible to provide this service. The patient can choose between either voluntary euthanasia or assisted death, helped by either a physician or a nurse practitioner who is able to administer the medication or provide a prescription.

In addition to the inclusion criteria, there are some exclusion criteria that were created with the explicit purpose of ensuring the safety of vulnerable populations, such as minors, and those suffering from a mental illness (Ministry of Justice, 2016). Safeguards were created to exclude some vulnerable groups from achieving death through the provision of MAiD. These exclusion criteria include being under the age of 18 years, or experiencing intolerable suffering related to a mental illness. Another safeguard inhibits patients from stipulating circumstances in which they would like to receive MAiD within their advance directive. However, the final section of the Criminal Code mandates that these safeguards be evaluated. Section 9.1 states that “the Ministry of Justice and Ministry of Health *must* initiate independent reviews of these issues related to requests from mature minors, advance requests and mental illness within 180 days after the initial law has been passed” (Criminal Code of Canada, 2016, section 9.1). A summary of the review must be submitted to the House of Parliament for review two years after the review was initiated. Therefore, a review committee of the Senate and House of Commons is to investigate the present bill and propose any potential changes by January of 2021.

The exploration of the pediatric palliative care experience has exposed some predictable barriers to equitable care, mostly surrounding historically present issues with consent of minors and pediatric palliative care access. Since the amendments to the criminal code indicate the co-appointment from the Ministry of Health and Ministry of Justice as examiners of the inclusion of mature minors as eligible for MAiD; it would behoove the nursing community to be prepared for this eventuality.

Environmental Scan

Canada is not the only country to have legalized MAiD in some form or another. The following is an environmental scan of countries and states that have legalized MAiD. This scan will help develop a better understanding of the social and political trends around the world, as well as the cultural influences of change. Each law has different inclusion and exclusion criteria that inform who is eligible for, and who can assist with, MAiD. Where possible, a brief description of the perceptions of the practice for physicians, nurses and patients will be provided. Not only will this provide a greater understanding of issue of MAiD globally, but it will also highlight the potential issues that are likely to arise in the future for Canadian patients, families and nurses.

Presently, there are two ways to gain access to medical assistance in dying throughout the world: through changes to a country's laws, or through a court ruling. This environmental scan will focus on countries and states that have changed their laws to include medical assistance in death within health professionals' scope of practice. That includes Canada, the Netherlands, Belgium, Luxembourg, and five states in the US: Oregon, Washington, Vermont, California and Colorado. For the countries and states that have legalized access to MAiD, their inclusion and exclusion criteria will be

reviewed, as well as any relevant attitudes or perceptions of health professionals or citizens of those countries that may contextualize those criteria. This environmental scan will also briefly discuss countries and states that have potential access to MAiD through court rulings or a vague criminal or penal code. These nations have not changed their laws to include the practice, but rather a court ruling has indicated the practice is constitutional or a present law has a loophole through which patients have sought MAiD. Canada was the fourth country to create a national law. The statewide laws in Colorado, California, Oregon, Washington and Vermont will be analyzed individually and not federally. While the inclusion and exclusion criteria of these countries and states will not be discussed, an understanding of their situation is important to comprehend the circuitous path some patients have to take in other countries in order to access a service that is now supported by the Canadian Government.

Access to MAiD through Court Ruling or Legislative Ambiguity

At present, there are three countries and one state in the world where MAiD is not legal but physicians are providing the service and not being prosecuted. In Colombia, Switzerland the United Kingdom (UK) and Montana, there have been court rulings identifying the ambiguity in the present laws and creating precedence for not prosecuting those who provide PAD. In Switzerland and Colombia the laws do not state that medically assisted death is illegal, nor is it legal. And in Montana and the UK, the courts have identified ways for medical practitioners who provide assistance in death to evade prosecution. The issues being discussed within these countries are of a far different nature than those with legalized MAiD.

An example of legal evasion is in Switzerland; article 114 of the Swiss criminal

code that identifies an individual who kills a person for compassionate reasons on the basis of the serious request will be fined or sentenced to a jail time (Nicol & Tiedemann, 2015; van der Heide et al., 2003). This would imply that assisted death is illegal; however, article 115 of the criminal code then states that any person that provides assistance to a person trying to commit suicide is only considered to have committed a criminal act if they do so for selfish reasons. Health providers within Switzerland have taken that as permission to assist suicide by anyone as long as their reasons are not selfish (Hurst & Mauron, 2003). These laws have created “suicide tourism” in Switzerland, which has long been considered a destination where those who can pay may obtain an assisted death (Emanuel, Onwuteake-Philipsen, Urwin, & Cohen, 2016; Hurst & Mauron, 2003). In an effort to clarify the issue, the Swiss government asked the Federal Department of Justice and Police to debate this issue in 2009 and 2010, but they have still not reached a consensus (Nicol & Tiedemann, 2015).

The UK, Germany, Alaska, Colorado, New Mexico, Montana, and Minnesota have all had court rulings where physicians who performed PAD were not prosecuted. For example, in Montana, two terminally-ill patients and a group of sympathetic doctors brought a case against the District Court. The court ruled that patients with terminal illnesses should be able to die with dignity, and therefore, found that physicians who helped patients die would be protected under this ruling (Nicol & Tiedemann, 2015). Unlike in the ruling of *Carter v Canada*, the court did not request that Montana should change the law regarding PAD, and therefore, the practice is still illegal. The process for Canadian children and their families, as well as for the health providers delivering the service, will be very different from that which might occur for those in unregulated

countries. Due to the lack of information and clarity surrounding nursing roles as well as lack of definition surrounding the possibility for PAD for children in these states and countries, they will not be included in this analysis. Only countries and states with defined and lawful MAiD practices will be discussed in detail here.

US States

Within the US there are presently five states (Oregon, Washington, Vermont, California and Colorado) that have legalized PAD, all of which have very similar inclusion and exclusion criteria. Oregon was the first place in the world where physician assisted euthanasia was brought into law in 1997. Due to the ground-breaking nature of the legislation, all future states modeled their laws upon the Oregon ‘Death with Dignity’ Act (Nicol & Tiedemann, 2015) California, Washington, Vermont, and most recently Colorado all have similar laws permitting PAD. All states require a diagnosis of a terminal illness, and the patient must be deemed competent or capable of making their own medical decisions (Eggman & Alejo, 2016; Oregon Public Health Division, 2015; Shumlin, 2013; Washington State Department of Health, 2016). The applicant must provide both verbal and written consent and must be over the age of 18 years. Witnesses to the request are not permitted to be a health professional from the institution providing care to the patient (Rose, 2007). Additionally, the death of the individual should be expected within six months in Vermont, Oregon, Colorado and Washington and within one year in California. All states require waiting periods as well as a minimum of two physicians to approve the process and only a physician can provide euthanasia.

Despite these narrow inclusion criteria, annual reports from Washington and Oregon report a slow but steady increase in the number of patients who receive PAD,

equalling 0.3% of total deaths (Oregon Public Health Division, 2015; Washington State Department of Health, 2016). These annual reports also show an increase over time in the number of deaths due to PAD. Another indication that PAD is desired throughout the US is the growing number of grievances since 2007. In 21 of the 50 US states, there have been 54 lawsuits surrounding an American citizen's right to end their life with medical assistance, all of which were "either tabled or defeated" (Rose, 2007).

Another indicator of the desire for PAD is found in what is known about the attitudes and perceptions of physicians and potential patients. There has been very little academic literature to explore the attitudes and perceptions of this practice for the medical or nursing practitioners in these states, let alone the inclusion of minors or the role that nurses play within the practice. The perceptions of physicians and nurses are hard to find in the literature, and public opinion on the subject has not been captured regularly. What little literature does exist centres on health professional opinions, and will be explained below.

Prior to the legalization of PAD in Oregon, 2,761 Oregon physicians completed a survey that explored their perceptions of providing PAD to their patients or those of their colleagues (Lee et al., 1996). 33% said it was immoral and 34% said that it was against their religious belief. There was no analysis provided to indicate if there was a correlation between the respondents of the two questions. 60% of the physicians surveyed believed that terminally ill patients had the right to commit suicide, but only half of the participants would be willing to provide PAD (Lee et al., 1996). The practical concerns were mostly regarding the potential for litigation from family members, their regulatory college or federal prosecutors, as well as the potential dangers of administering the

medication (Lee et al., 1996). The physicians were unsure if they would be able to identify depression or predict life expectancy. They saw these as potential barriers for physicians if those criteria were part of the safeguards. As predicted, religious belief greatly impacted physicians' opinions towards assisted dying. This study did not explore the concept of PAD for minors, nor did it discuss interdisciplinary issues. Lee et al. described a diverse group of physicians whose opinions were varied, but only one third of them were willing to provide PAD once the practice was legal (Lee et al., 1997).

Much like physicians, there is a lack of robust literature exploring the perceptions of nurses within the states where PAD is legal. In a 2004 survey of 531 hospice nurses and social workers in Oregon, 95% of the participants were in favour of health care centers providing PAD as an option for patients. Only 22% of the participants indicated that they would not feel comfortable discussing the option, but would still support their co-workers to facilitate access (Miller, Ganini, Goy, Delorit, & Jackson, 2004). Although some nurses and physicians might have beliefs that would prevent them from providing this service, there are evidently others who are eager to support the provision of PAD to the American public.

Civic support for PAD has been assessed in the Gallup survey since 1947. Support for the practice has risen from 37% to the present level of 67%, but peaked in 2005 with an acceptance rate of 75%. This is the only continual assessment of public perception of the topic available. Much like HCPs perceptions of the topic, Americans would like to have access to the service, but reserve the right to not be involved, mostly based on religious grounds (Emanuel et al., 2016). In the future as most states legalize the practice, I hope that the interest in research surrounding this topic will also increase.

Despite the show of increased interest in PAD, there has been no indication of attitudinal change or a legal precedent looking to include minors in the legislation.

Physicians, nurses and the US public have varying opinions about the practice of PAD with all groups having both critics and supporters. Within the US, there has been a steady increase of patients dying by PAD (Nicol & Tiedemann, 2015). This trend should be considered when anticipating the needs of Canadian patients as well as anticipated support for health professionals.

Benelux Region

The Benelux region comprises the Netherlands, Belgium and Luxembourg, all of which have passed MAiD legislation. The health professionals within this region have been discussing PAD for upwards of 20 years. These countries' laws are considered the most progressive, because they permit access for minors and people suffering from mental illness to PAD, as well as allow the use of advance directives to act as consent for PAD (Emanuel et al., 2016; Nicol & Tiedemann, 2015). An anonymous survey of European neonatologists revealed that, despite euthanasia not being legal in their countries at the time of survey completion, more than 30% have euthanized children and none were prosecuted legally. This indicates that the practice of neonatal euthanasia is considered acceptable by a substantial sub-group of HCPs and families (Emanuel et al., 2016). Unlike the states within the US whose laws are quite homogeneous, the eligibility criteria within these countries' PAD laws are disparate. Each country's inclusion and exclusion criteria will be reviewed along with any pertinent research surrounding the perceptions and attitudes of health professionals towards PAD. Where possible, specifics surrounding minors and nurses will be highlighted.

Luxembourg.

As of 2008, citizens of Luxembourg are able to request PAD, both assisted death and euthanasia. As in Belgium, the patient does not need to have residency in the country to qualify, but there is an understanding that the physician and the patient have had a long-standing relationship. The patient that is applying must be over the age of 18 and have a terminal medical condition that gives the patient relentless and insufferable physical or mental grief without the prospect of improvement (Emanuel et al., 2016). No waiting period is needed and advance directives can be used to indicate the wishes of the patient with no time restriction (Nicol & Tiedemann, 2015). No specific nursing research or investigation into the inclusion of minors in this law has been collected from this region.

The Netherlands.

The Netherlands was the first country in the world to legalize PAD, both assisted death and euthanasia, in 2002. Only physicians are able to prescribe or administer the lethal medications. There is no required diagnosis, but the applicant must be experiencing intolerable suffering with no possibility of alleviation. Patients may apply for PAD through their advance directive. The patient must receive two sets of approval from two independent physicians, but there is no waiting period. Controversially, the age restriction on PAD was set at 12 years and older. Children from age 12 to 15 years can request PAD, but medical staff requires parental consent to proceed with processing the request; patients in this age group are excluded if they are suffering from a mental illness (Pousset, Mortier, Bilsen, Cohen, & Deliens, 2011). Youth aged 16 and 17 years can apply for themselves and parental consent is not required if the youth is deemed

competent by two physicians; however, parents must be aware of the PAD request. The Netherlands was the first country to legalize PPAD, which is a practice that is accepted by more than half of Dutch physicians.

In three studies of Dutch physicians who specialized in treating children and infants, it was found that roughly 60% of all participants thought that the Dutch legislation should have no age restriction, or would be willing to provide PAD to the pediatric population (Bolt, Pasman, Willems, & Onwuteake-Philipsen, 2016; Vrakking et al., 2005; Vrakking, van der Heide, Onwuteake-Philipsen, van der Mass, & van der Wal, 2007). Vrakking et al. (2005) provided hypothetical examples and asked for the physician's opinions. Both Bolt et al (2016) and Vrakking et al. (2007) asked for the physician's opinion and experience with respect to children aged one to seventeen. Their findings confirmed that the issue of neonatal PAD has been a contentious one within the Netherlands, but has been addressed and has been a debate within the Dutch context¹.

¹ The Groningen Protocol is a guideline created by two neonatologists to address the issue of neonatal euthanasia with parental consent when they felt it was acceptable to medically end the life of an infant (Verhagen & Sauer, 2005). Advancements in technology, surgeries and treatments have increased the number of infants living through childbirth with multiple comorbidities. These treatments are not always fool-proof and might render the infant severely incapacitated, care dependent or unable to communicate or move for the rest of their life. These advancements have created more grey areas for health professional and parents. The protocol, which was created in collaboration with lawyers, delineates a clear decision-making process for parents and expedites reporting of life-ending procedures for neonates (Verhagen & Sauer, 2005). There has been much debate within the Netherlands about the ethics surrounding this protocol, mostly hinged on the issue of lack of consent from the patient.

From their perspective, this history might have normalized the issue of PAD for children that are less able to provide consent, shifting the perception of Dutch physicians to create an atmosphere where PPAD is a more accepted practice. The participants in the Vrakking et al. 2007 study were mostly pediatricians, who felt that having an age limit on the present bill was arbitrary and that each request for PPAD from a child or parent should be considered on an individual basis. As seen in other studies, if a physician reported a religious background, their level of acceptance of the practice was lower than those who were non-religious. Vrakking et al. (2005) uncovered that almost three quarters of physicians were willing to increase pain medication for the intention of relieving patient pain, but also with the potential implication of ending the child's life. From this brief review of this set of studies, we can see that the issue of the practice itself is quite polarizing; so too is the issue of parental involvement and consent in PPAD.

The issue of parental consent has been quite contentious among Dutch physicians, and this was demonstrated in similar findings in all three studies. Among physicians open to PAD, 55-60% would want to have parental consent prior to providing the lethal medication (Bolt et al., 2016; Vrakking et al., 2007). For children aged 1-11 years, some believed that pediatric patient assent would be beneficial, but not essential provided that there was parental consent (Bolt et al., 2016). If a parent makes a request on behalf of their unconscious child 37% to 42% of pediatricians would be willing to provide assistance (Vrakking et al., 2005). As the age of the child increased, the consent of the child began to supersede the importance of the parental consent in all three studies, but only one in ten physicians were willing to provide PAD without parental consent (Vrakking et al., 2005). At the time Vrakking et al. (2005) gathered data, PAD had not

yet been legalized in the Netherlands; however, they followed up with another study to gain real experiences of physicians working with PAD.

In that subsequent study, Vrakking et al. (2007) continued to gather data about PPAD by surveying physicians who provide access to or discuss PPAD from Pediatricians in the Netherlands. Eight out of ten pediatricians had already been asked to provide PPAD prior to the law being created (Bolt et al., 2016; Vrakking et al., 2007). Bolt et al. (2016) found that 13% of the requests were from children and their parents aged 1 to 11 years, and the number was doubled for children aged 12 years and above. These experiences highlight a need and desire for PPAD, not just for those that are permitted access through the Dutch law, but for equitable access for all children in the Netherlands. There have not been any investigations surrounding parent or pediatric patients' perspectives or desires for PPAD in the Netherlands, nor has there been an investigation into nurses' perceptions and experience. These research gaps should be addressed in order to comprehend the full breadth of perception associated with this practice in the Netherlands.

The Netherlands was the first place in the world to permit PAD for the pediatric population. Although children aged 12 and older have slightly different inclusion and exclusion criteria for PAD, the majority of studied Dutch pediatricians and neonatologists accept the practice and are willing or have already provided PAD to patients, either before or after the practice was legal. As outlined in the literature review, the issue of parental involvement and consent are highly contentious issues, and these remain divisive within the profession. Despite the breadth of perceptions, these studies provide a point of reference for understanding potential attitudes among health professionals in other

countries that are receiving or will experience requests for PPAD. Research regarding the perceptions and practices of nurses are also necessary to understand the ethos of the PAD culture in the Netherlands. Surveys of Dutch nurses, parents and pediatric patients also shed light on the experiences and potential barriers for children and their families to gain access to PAD.

Belgium.

Much like the Netherlands, Belgium signed euthanasia and assisted dying into law in 2002. As in all other countries, the applicant must be in consistent and irreversible mental or physical pain, with no hope of relief. Similar to the Netherlands, Canada and Luxembourg, but unlike the US states, the patient does not need to have a terminal diagnosis. For any patient that applies with a terminal illness, they do not have to observe a waiting period prior to carrying out the euthanasia or assisted suicide. If the applicant does not have a terminal illness (for example, depression) they would have to wait a month prior to completing their request. If a patient has a mental illness causing insufferable pain, they can still apply for PAD, but they must have two independent physicians as well as a psychiatrist assess their request (Emanuel et al., 2016). If there is no psychiatric diagnosis for the patient, only two physicians have to provide approval. As in Luxembourg and the Netherlands, an advance directive can indicate and provide consent for PAD, but that only applies to applicants over the age of 18 years. Initially, there was an age restriction on applicants. In 2014 the inclusion criteria was changed to include anyone who has the capacity for carrying out objective judgment about their medical issue. This makes Belgium the only country where anyone can apply for PAD, regardless of their age.

The initial law in 2002 only permitted those over the age of 18 years or emancipated minors to apply for relief. Because the issue of capacity initially excluded children, when the Belgium lawmakers removed the age restriction in 2014, they added some additional safeguards for this vulnerable group (Nicol & Tiedemann, 2015). These now include the following: 1) the child must be in unceasing physical pain from a terminal illness and the parents must consent to the application, and 2) the child must be determined competent by a child psychiatrist or psychologist as well as gain two additional physicians' assessments. For some practitioners, the idea of a child requesting PAD was unacceptable. However, many Belgians did approve of the removal of the age restriction for PAD, and considered that providing children euthanasia, in conjunction with the consent of the parent and taking the child's opinions into consideration, could be of benefit to some families (Provoost et al.; 2005, Pousset et al.; 2011). When the age restriction was ultimately lifted in 2012, newborns and children were not granted access to the law solely based on their age. In practice, the majority of children will not be able to meet the initial inclusion criteria of capacity for discernment. Health professionals are greatly involved in the decision making that takes place with pediatric patients and their families (Sheilds et al., 2012). It is important to explore perceptions of those gateway professionals in order to understand the issues patients might have with PAD access or education. Only three studies have been published that explore the perceptions and attitudes of Belgian nurses and doctors. The data collected concerning nurses' involvement in PAD took place in 1994, prior to the legalization change in Belgium. Studies exploring physician attitudes related to including minors in the PAD law and their involvement will be discussed below.

Two studies were conducted before the most recent changes in Belgian law that examined physician perceptions and practices with respect to end-of-life decisions for children and neonates. The first study surveyed pediatricians who signed death certificates of children who died in Flanders, Belgium. This study uncovered two distinct groups: one that accepted the idea of children having access to PAD identified as the acceptant cluster (67.7%) and the other group (32.3%), which was more reluctant to participate in the practice (Pousset et al., 2011). Physicians in the acceptant group were more likely to have provided PAD to a patient in the past and were more willing to do so in the future. The reluctant group was less willing to consider the wishes of the minor and thought that adequate pain control should be all that is needed for minors at EOL. There were some commonalities between the groups. 69% of the participants thought that it was acceptable to administer a lethal dose of medication if the request came from the parent without the child's consent, and 85.5% of participants thought that treatment aimed at prolonging life is not always the best option for some of their patients. Roughly the same amount of all participants thought that teenagers' perceptions of their treatment should be taken into consideration. 71% of the physicians thought that a request for life termination from a minor should be recognized if they are capable of making a rational assessment of their interest.

The second study also based out of Flanders, Belgium, sent questionnaires to physicians who had signed death certificates of neonates prior to 2015. Although this study asked questions about what happened to real patients, the results were similar to the prior hypothetical study. The study uncovered a similar number of neonatologists have also withdrawn treatment or provided enough narcotic to act as a PAD medication

(Provoost et al., 2005). Of all pediatric deaths reported in Flanders, Belgium, neonatologists had to make an end-of-life treatment decision for 91% of their patients who were less than seven days old prior to their death, and for 61% of the deaths of children between one week and one year. Given the high number of patients suffering at the end of their short life, MAiD is a possible treatment option a physician could offer families to alleviate unnecessary pain associated with potentially futile treatment. Similar to the above mentioned study (Pousset et al., 2011), almost 50% of the time medications were administered that resulted in the death of the patient, three fifths of those were used with the intention of ending the patient's life, and the other two fifths were used as a co-intention to ease pain, but also to end the patient's life. 60% of the physicians thought that neonatal patients should be included in the law.

The results of these two studies underline the acceptance of the practice for the majority of both pediatricians and neonatologists. 17% of pediatricians and neonatologists had already provided PAD or provided medication with the co-intention of easing pain and ending the patient's life. These physicians admitted to already carrying out this practice with the consent of the parents, despite the fact that the law was not yet in place. The majority of surveyed physicians also thought that maintaining the present health trajectory was not always in the best interest of the patient, and therefore, something else was required to end suffering for their patients. There has been no study published after the change in the law to explore how this change has been received within this population or of the health providers that facilitate access.

Although physicians administer the lethal medication, nurses are greatly involved in the process of EOL decision making for patients. In a 2003 survey, 57 % of nurses in

Belgium reported that they had been asked about PAD (van car Heide et al., 2003). Bilsen and colleagues (2003) surveyed 1,925 physicians about the role nurses play in PAD. The age breakdown did not specify if any of these patients were minors. Nurses were reported to be administering the medication in the institutions and at patient's homes (Bilsen, Vander Stichele, Mortier, & Deliens, 2004). Clearly nurses are involved in the process, but to what extent nurses feel they are involved was not investigated in this study, nor have any other studies captured this specific information. If these physician perceptions are accurate, then it seems a very concerning trend. This survey occurred prior to the introduction of the law and no follow-up study has taken place, so the administration of a lethal medication was illegal in all cases (Bilsen, Vander Stichele, Mortier, & Deliens, 2004). If nurses are administering lethal medications they are liable for the death of the patient, and could be prosecuted. Physicians also reported having discussed the PAD option for the patient with a nurse at least half of the time (Bilsen, Vander Stichele, Mortier, & Deliens, 2004). Where PAD is legal, registered nurses and licensed practical nurses are only able to provide information about the process and do not have the ability to administer the medication. This study highlights the importance of looking to other countries and exploring their experience to inform our actions in Canada as MAiD practice is shaped.

The perception and involvement of Belgian nurses and physicians are still unclear. The limited data suggests that the inclusion of minors to the PAD legislation would only legalize a practice that is already taking place as physicians have anonymously admitted to providing PAD for pediatric patients. Physicians have identified that nurses are also administering the lethal medication, a practice that has

hopefully been investigated and curtailed. There have been no published investigations into the public perception of PAD for minors. The annual reports from Belgium show a steady increase in the number of deaths due to PAD. This highlights the importance of an in-depth understanding of this practice for the Canadian health providers and public. Given the recent inclusion of minors into the bill in Belgium, the data that could be obtained from statistics of the Belgian health professionals and minors could be beneficial in informing global practice.

Environmental Scan Summary

The legislations in all states and countries considered here have similarities and differences. All laws insist on some type of suffering that is considered irremediable by the patient. All countries that have changed their criminal code to include PAD or MAiD permit the practice of euthanasia and assisted death, but the US states only permit physician-assisted death. The practices of advance directives, a mental illness as a source of suffering, and the inclusion of minors vary among jurisdictions. Current research into the perceptions of health professionals has shown that some are open to providing access to PPAD; however, opinions regarding the issue remain divided. It is important for federal and provincial institutions to take heed of the experiences of the global community when developing and implementing MAiD practices, and in considering their potential implications for nursing practice

Despite nurses being one of the key education sources for patients (Shields et al., 2012), their experiences and perceptions surrounding PAD have rarely been studied. What research is available has uncovered that most nurses accept the practice, and in some cases have administered the lethal medications themselves. Education for nurses in

areas where PAD has been most requested -- acute care, hospice and community care -- will be paramount to ensure that nurses understand their scope of practice in MAiD. More research surrounding nurses' perceptions, experience and barriers would assist future practice. This lack of data surrounding a major portion of those assisting the practice of MAiD parallels the small number of studies examining MAiD with the pediatric population and their interest in this care option. We are in an era in which there is much to be gained through strategic and thoughtful research.

Only two countries, the Netherlands and Belgium, have legalized the inclusion of minors as eligible to receive PAD. In both countries, roughly 60% of the physicians studied were accepting of the idea of PPAD. The majority of physicians thought that consent from parents was required, while a small minority felt that was not necessary if the child consented to PPAD. For both countries, as the age of the patient increased, the necessity for parental consent decreased. However, although this practice exists in both Belgium and the Netherlands, there has been no substantial data collected that describes the demographics of the children that have died with the assistance of PPAD. Further, for countries where children are not permitted to apply, there has been very little investigation into the perceptions of physicians, patients and parents about the need for and potential acceptance related to this practice.

Policy Analysis and Stakeholder Consolation

Background

MAiD is a new care option for patients throughout Canada. The eligibility criteria for MAiD are stipulated in the Criminal Code of Canada, but the enactment of MAiD was left to the provincial ministries of health, regulatory bodies and health authorities to

determine. This was done partly because Canadian health care is administered at a provincial level, but also it would be difficult to take this federal change and implement something that would work well for every province and territory. Presently there are numerous barriers patients might experience while trying to access MAiD. The process of MAiD is also different for every patient, which is why it is important that analyses like these take place to identify barriers created by regulatory bodies, policies and health care agreements.

My current position as Regional Manager of the Assisted Dying Program in Vancouver Coastal Health allows me unique insight into the way policies are being created, enacted and amended, as well as putting me in regular contact with the patients, assessors, providers and conscientious objectors for MAiD. I am responsible for creating processes within Vancouver Coastal Health to decrease the number of barriers to MAiD for assessors, providers, supporting HCPs and patients. I also usher patients, assessors, providers, HCPs, and units through the MAiD practice. The obstacles all of these groups experience has been multifaceted, ranging in origin from institutional to personal, but often stemming from ambiguous terminology within the legislation, regulatory bodies and consequent health authority policies. In efforts to streamline and solidify the process for all involved, it is important to examine the policies that are presently in place and break down why issues are occurring. In this analysis, I will reflect on those policies and regulatory documents. I will also coalesce the conversations I have had with key stakeholders and create a summary of a few of their concerns and learnings. While the current concerns may not speak directly to pediatric MAiD, issues identified within this

analysis may serve as a list of potential hazards to anticipate and avoid if children are permitted access to MAiD in the future.

Policy analysis

For the purpose of this paper I scanned the available documents to gain an understanding of the policies in place regarding MAiD from Fraser Health, Interior Health, Island Health, and Vancouver Coastal Health. At the time of the investigation I was inquiring as a member of the public for access to these documents, and Northern Health and Provincial Health Services Authority did not provide access to their policies to the public. I also looked at guidance documents from many Colleges: College of Registered Nurses of British Columbia (CRNBC), College of Licensed Registered Nurses of British Columbia (CLRNBC), College of Registered Psychiatric Nurses of British Columbia (CRPNBC), and the College of Physicians and Surgeons of British Columbia (CPSBC). While the regulatory bodies determine scope of practice for each profession, the practice documents that determine how a HCP functions within their place of work are determined by their health authority policy. The following analysis will summarize the major differences between the policies and guidelines in regard to the enactment of MAiD and highlight how these policies have impacted HCP practice as well as patient experience.

Health Authority Policies

The policies within the health authorities differ in a variety of ways. Fraser Health has indicated that all community MAiD deaths will take place in one location. Vancouver Coastal Health (VCH) and Interior Health have identified that there will be no disruption for the patient due to making a MAiD request, and thus, patients can have a

MAiD death in any location, except in the instance of faith-based organizations (Fraser Health Authority, 2016; Interior Health, 2016; Vancouver Coastal Health, 2016). The localizing of services for Fraser Health patients could have both negative and positive outcomes. While having a dedicated place where MAiD is frequently carried out, it will allow the HCPs in that institution to become expert in the process, potentially increasing the quality of the patient's experience. However, this mandate to move patients to one location for MAiD within Fraser Health could also be very disruptive for the patients (Fraser Health Authority, 2016). It is conceivable that patients would like some power over the location of their death, and not be forced to pass away in an unfamiliar location. Within VCH and Interior Health, there is no set destination for patients, which means that the patient has more control over their experience (Interior Health, 2016; Vancouver Coastal Health, 2016). Therefore, for VCH and Interior institutions, is it imperative to have widespread education for all staff, due to a request potentially happening at any site. But while it may take a lot of resources to provide education across the whole health authority, the prospect of moving patients to "death closets," as they are being called by a Fraser Health physician, might increase the stigma of MAiD, creating further barriers for patients.

Another barrier for patients is the Denominational Health Care Agreement, which was passed into law in British Columbia in 1996 (College of Physicians and Surgeons of British Columbia, 2016) and which is followed by all health authorities in BC. It stipulates that the British Columbia Ministry of Health will not force a faith-based organization to provide care that is morally objectionable to that institution. The practice of MAiD has been denounced by the Roman Catholic Cardinal of BC (College of

Physicians and Surgeons of British Columbia, 2016) and, therefore, patients receiving care in faith-based organizations might not be able to receive assessments or provision of MAiD. Presently, patients seeking assessments and provision for MAiD must leave the faith-based site in order to gain access. This puts patients who are already in a fragile state in the position where they must put time and effort into relocation as well as their health providers arranging appointments and transportation. One reason Fraser Health decided to have all MAiD cases from community and residential care go to one site was to ensure there is a place for patients to receive MAiD. VCH has waived the policy surrounding no transfers in the case of a MAiD request; however, patients are being forced to leave their institution of care that rejects MAiD based on religious grounds, where they might have a bond with their HCPs. VCH has committed to taking these patients who are displaced and finding a similar care setting where their request can be assessed. This can also be difficult on the care staff, who are still adjusting to their new roles surrounding MAiD, since MAiD has only existed as an option for nine months.

Guidance from Regulatory Colleges

RNs and LPNs have a major role to play for caring for patients requesting MAiD. RPNs, however, have been instructed by their college not to provide any education or patient request record to support a patient's request for MAiD. RPNs are reminded of their duty to transfer care, by ensuring the patient's request is documented and that the RPN makes an effective connection with the most responsible provider (College of Registered Psychiatric Nurses of British Columbia, 2016). RNs and LPNs are permitted to be more actively involved with MAiD; they are able to insert and administer the IV for the provision of MAiD, but only if they have completed an education package. There are

other areas that are normally within RN and LPN scope of practice that are excluded in the provision of MAiD; nurses are not to draw up and document medication, flush IV lines, or pronounce death. While this is a change of practice for most nurses, the impact to the patient is minimal as those roles are fulfilled by the MAiD provider, which is either a NP or physician (College of Licenced Practical Nurses of British Columbia, 2016; College of Registered Nurses of British Columbia, 2016a). During my clinical teaching sessions, nurses report struggling to discuss with a patient their wish to die. This is not a new concept for staff, but has become a more regular occurrence since the change to the Canadian Criminal Code. This change has underscored the need for further education for all HCPs surrounding death and dying.

The change to the criminal code protects nurses aiding in the provision of MAiD (Ministry of Justice, 2016). The CRNBC considers “aiding” as the insertion of the IV where the sole purpose is to facilitate the provision of MAiD. RN’s and LPN’s are also not committing a criminal offence if they provide MAiD education and resources to requesting patient (College of Registered Nurses of British Columbia, 2016a). However, these acts are not what is most upsetting for nurses; it is the frank discussions now occurring related to death and dying that are most troubling. Since a MAiD request can be made anywhere within a VCH institution, nurses on surgical units and day stay outpatient facilities are discussing death -- a practice that previously wasn’t within their scope. Now that MAiD is a care option for patients, VCH is asking all RNs and LPNs to explore the patient’s wish to die if prompted by the patient. This conversation is not intended to dissuade them from or encourage them to request MAiD, but to ensure the patient has a full understanding of all their care options, including MAiD. This practice

is not encouraged in Fraser Health, and the patient instead is to contact the MAiD Care Coordination Service. The hope within VCH is that death and dying become part of the normal discussion nurses can have with their patients, as opposed to a conversation only intended for specialists. As outlined in the literature review, pediatric patients already have issues with access to palliative care. This new care option highlights the need for death and dying education and comprehension, for not just pediatric nurses, but all nurses.

Physicians and NPs are also finding the transition to MAiD difficult, and the distinct views of their regulatory Colleges are adding to that challenge. CPSBC and CRNBC have stipulated different approaches to education and reporting for their assessors and providers. The CPSBC states that there is no additional training required for physicians to be assessors for MAiD (College of Physicians and Surgeons of British Columbia, 2016), but should discuss every MAiD assessment with the legal services at CPSBC. CRNBC requests that NPs require a preceptorship to become both an assessor and provider for MAiD, but no reports to CRNBC are necessary (College of Registered Nurses of British Columbia, 2016b). This variation between guidelines creates different levels of skill and oversight as well as approaches to MAiD. If every patient a physician sees is also seen through the legal department in CPSBC, then the physician is not making an independent decision, but rather, the CPSBC is advising on who should and should not receive the service. In practice, however, this consultation does not usually occur. Within my practice, I have met with physicians who did not understand the MAiD eligibility criteria. Often these physicians will request more assistance with the assessments, or find the patient ineligible for a reason not related to the criteria. While

there is an element of interpretation required to determine if a patient is eligible, which will be discussed later on, presently patients are not having the same experience or access to services. If the CPSBC wanted to retain some influence over those gaining access to MAiD, rather than having each case discussed with the college, they could provide education for all assessors and providers.

CRNBC has taken a different stance to both oversight and education for NPs. They are required to have a preceptorship to both assess and provide MAiD. Vancouver Coastal Health has determined that an NP must observe two assessments and one provision to be eligible to assess, and observe two assessments and two subsequent provisions to provide MAiD. The other health authorities are similar in requiring two assessments and provisions. The health authorities are permitted to create their own orientation plan for NPs because their college stipulated that a preceptorship was necessary for both assessment and provision. This time and exposure to patient issues allows NPs to gather experiences and work through the eligibility criteria with active cases, rather than expecting them to make decision about death without some previous consideration. This practice will create a network of peers on whom the NPs can rely when needing to discuss the interpretation of the eligibility criteria for different patients. In future, I hope that CPSBC creates guidelines for physicians similar to those specified by the CRNBC for NPs.

Policy Analysis Summary

Health authorities and regulatory bodies create the climate within which British Columbians navigate and gain access to MAiD. The present difference between health authority policies and the Denominational Health Care agreement creates varied

experiences for patients. Patients might also experience different MAiD access challenges based on their HCPs' responses, which could variously be related to their ability to discuss death and dying, or their interpretation of the eligibility criteria. Some HCPs have experience with difficult conversations; however, the majority does not, leading to distress for HCPs who might not understand their scope of practice regarding this new health care option or be comfortable discussing death and dying. Presently, the onus is on the health authorities to educate their health care staff, and to decrease the varied experience for patients. Deciding who needs education and at what level will be different for each health authority, but the implications of not doing so will have a real impact on the patients throughout British Columbia.

The health authority policies are not the only reason that patients might experience different care when requesting MAiD. As mentioned, there are disparate views on the necessary education for assessors and providers between CPSBC and CRNBC. Cohesive college guidance regarding the education requirements for assessors and providers might lead to patients having a more comparable experience, but it does not seem like the CPSBC is eager to make that change. Health authorities could implement an education requirement for their assessors and providers, but that could diminish the pool of those willing to participate in MAiD; a pool of providers that is already small might further diminish.

Stakeholder Consolutions

My position as Regional Manager of the Assisted Dying Program puts me in regular contact with many professional practice leaders within VCH as well as assessors and providers of MAiD who have been providing the service since the change in the

criminal code last June. After many discussions about practice gaps as well as working through patient issues, a number of themes have emerged surrounding the strengths and gaps in the criminal code, VCH policy, and resulting process for MAiD. These issues will be examined and then the insights arising from these themes will be applied to the pediatric population.

Professional practice leaders and MAiD assessors and providers have all experienced frustration with the lack of definition surrounding the eligibility criteria for MAiD; more specifically that death has to be “reasonably foreseeable”, and the patient must have a “grievous and irremediable disease or disability” in an “advanced state of decline” (Ministry of Justice, 2016). These terms have not been clarified in any regulatory documents or the criminal code, leaving limited guidance. As discussed above, the lack of education for physicians surrounding the process, coupled with the lack of definition of these terms, has resulted in patients not receiving comparable assessments for MAiD. The Canadian Association for MAiD Assessors and Providers was created to establish a dialogue within the community about implementation and interpretation issues. This association enables a space for physicians and NPs to discuss the minutia of the eligibility set out by the criminal code in the hope of establishing norms within the community. Every provider I spoke to found this community dialogue helpful, but they also hope for further clarification from the government in future iterations of the criminal code.

The lack of definition surrounding the eligibility criteria, which can create a difference of opinion among assessors, has created a practice of patients “assessor shopping” until they find two assessors that agree that the patient is eligible. There is no

limit to the number of assessors a patient may request, which frightens many of the key stakeholders. While the providers understand that a difference of opinion can exist between assessors, they also believe there should be some limits associated with a patient's request. When patients have an enduring wish to die, but they are not eligible for MAiD, the worry is that patients may cause personal harm to be considered eligible. Frequently general practitioners act as assessors, but for patients whose general practitioner does not want to assess, we reach out to other health providers who have identified themselves as willing to assess but not administer the medication, of which there are only five currently in VCH. Presently, there are only nine practitioners within VCH that are administering the medication, and only nine willing to assess and administer MAiD for any patient, not just their own; also known as assessor/prescribers or assessor/providers. This limits the number of practitioners the patient may seek, but also creates access issues for patients with an eligible wish for MAiD. Our hope is that the number of assessors will grow; however, this will also increase the number of practitioners a patient could see before exhausting their options.

Another issue identified by most stakeholders as well as HCPs is concern with the variations between provincial MAiD programs, resulting in Canadians in different provinces having different experiences. Also, there is no universal plan for oversight, funding, or examining the MAiD processes. A few key stakeholders were hoping the federal government would attach minimum reporting data requests that would provide insight into the common diagnoses, reasons for initiating requesting, and average waiting period, as well as some understanding of the reasons patients are not granted access to MAiD. Many assessors are hoping the health authorities will create a cohesive oversight

and monitoring committee for MAiD. Interior and Island Health have review committees, but Fraser Health Authority and VCH do not. Northern and PHSA have so few patients that their teams have decided not to create a formal process, but rather assess each case after its completion. At present, the BC Coroner is the only central location that gathers information about all the MAiD related deaths (British Columbia Ministry of Health, 2017), but there is no agreement between the health authorities about minimal reporting data for those MAiD requests that do not follow through to completion. This lack of oversight does not permit investigations into the effect MAiD has on the vulnerable groups identified by the criminal code (Ministry of Justice, 2016). Were MAiD to be an option for one of those vulnerable populations, children for example, more robust oversight would be required, particularly for PHSA. Given the experience of the adult caregiving stakeholders, it would be prudent to set up some oversight from the initiation of services in pediatrics as well as have provincial Ministries of Health all determine minimal reporting data requirements for the future.

Stakeholder Consultation Summary

Stakeholders from both Professional Practice and those actively involved in the assessment and provision of MAiD are of the opinion that there are many areas that require work before HCPs can provide a barrier-free service. Both groups would like clarification regarding the eligibility criteria from either the regulatory bodies or the government. Another option the stakeholders identified was to select representatives and meet to determine definitions for the criteria. That, however, requires organization and resources that are currently out of most stakeholders' reach.

A concern for stakeholders, should a national group form, is to ensure there is representation from all provinces. That way a better understanding of the differences in the provision of health care in the provinces and territories could take place, as well as combined decision making surrounding what oversight and reporting is needed. The Canadian Association of MAiD Assessors and Providers (CAMAP) is holding a conference in June of this year to explore these issues. While this conference will be a good starting off point, representation from all provinces and territories is not compulsory, nor are any deliverables expected. It is an arena, however, that will provide these stakeholders a chance to freely exchange experiences, ideas and information. I hope that the gaps and common issues encountered by those involved in delivering MAiD will be explored as the first step to enabling Health Authorities to become better aligned in their approaches across the nation.

Policy Analysis and Stakeholder Consultation Summary

The main gaps in the MAiD's current implementation identified through conversations with members of stakeholder groups and through analysis of existing policies were related to a lack of definition and clarity regarding an aspect of MAiD, and variation in education requirements for assessors, all of which could put vulnerable people at risk or create disparity in access to MAiD for Canadians. Policy variations are affecting nurses across BC, leading to some nurses in some health authorities having more frank talks surrounding death when initiated by patients, while other nurses are not comfortable engaging in these conversations. Although a patient expressing their wish to die is not new, what is new to nurses is the process and words to explain MAiD. The present lack of reporting mechanisms in place to identify these issues make most

stakeholders uneasy, because they would like a greater understanding of the population across Canada that is requesting this care option. The key stakeholders have identified additional issues and they intend to raise these matters with their regulatory body, as well as contribute to a national discussion regarding these matters. After speaking with other HCP from other Canadian provinces, it is evident to the stakeholders that there is a national desire for clarification regarding the fundamental elements of the change to the Criminal Code. If guidance does not occur at the government level, it will be up to this new community of assessors, providers and health authority programs to mobilize and take action.

Given the present apprehensiveness of physicians and NPs to assess adult patients, if children are permitted to request MAiD in the future, there will mostly likely be few practitioners willing to be assessors or providers. Given that the interpretation of the eligibility criteria is so varied, minors may have a limited number of assessors to approach. However, some restriction on the number of assessments permitted might be of benefit for the adult community, but create barriers for pediatric patients.

The age of majority in Canada is 18 years, but in BC is 19 years. In the future, I anticipate there will be an 18-year old who requests MAiD. We are then duty bound to permit access for that patient. At present, none of the policies or guidance documents discuss the care needed for a pediatric patient. It would behoove the health authorities and regulatory bodies to consider this possibility in advance of it becoming an actuality. Not only will this create the kind of discussion that is necessary to examine implications for younger patients in the future, but this will also be a useful opportunity to identify

existing gaps for health authorities and regulatory bodies before a legislative change takes place.

Discussion

The BC Ministry of Health published their strategic and operational priorities in September of 2014 identifying patient-centred care as their primary concern (British Columbia Ministry of Health, 2014). This guiding document is indicating a fundamental shift away from HCP-centred care, towards patient's having more power over their health care choices. This change to the Criminal Code of Canada continues that trajectory, however, that does not mean that the HCPs and systems have also made the shift. It is imperative that consistent examination of new patient choice initiatives, like MAiD, are monitored during their implementation to ensure the health authorities are staying true to the new guiding elements, as well as to review and continue to evaluate the other factors affecting patient health care experience. This iteration of the criminal code permitting MAiD is a significant advancement towards provision of patient autonomy, and as stipulated in the Criminal Code, additional eligibility criteria are being investigated; HCPs and patients should anticipate changes in the future.

The intent of this SPAR project was to consider the current state of health care services and care issues for children at their end-of-life in Canada and gather information about the experiences of other countries as well as the adult community within Canada. This discussion will outline the major learnings from the previous analysis and propose ways to ensure that pediatric patients are permitted equitable access when authorized to apply for MAiD. Apart from the barriers to accessing pediatric palliative care, issues surrounding consent and autonomy for minors, there are also institutional and conceptual

barriers, some of which have already been identified here. This process is in the evolutionary stages, and therefore demands examination of the obstacles evident within the adult population to inform pediatric integration into the Criminal Code in the future.

If children were permitted MAiD within the present climate, there would be many barriers and gaps impeding an eligible and capable minor to receive MAiD. The most significant barrier within the current eligibility criteria would be the issue of capacity to provide consent. The aforementioned lack of definition and individual interpretation by each HCP to determine capability will need to be considered. A more robust examination of pediatric consent and assent could remove ambiguity within an already contentious subject. Additionally, considerable thought will need to be put into determining what it means for a pediatric patient to be capable to consent, as well as additional guidance within the amendment to the Criminal Code or guidance from regulatory bodies to provide a more standardized definition. The adult population has experienced a wide range of interpretations, which will only be compounded for a pediatric patient. Another conceivable way of alleviating the barrier related to a minor's capacity to consent is to provide more aggressive and consistent education for assessors and providers of pediatric MAiD. Without clarity, assessors are nervous that parents or advocacy groups are likely to be litigious. Perhaps regulatory bodies will need to adjust their requirements for assessors of pediatric patients, leading to a more robust education process.

Guidance and standardized education for assessors and providers of MAiD will be needed to shift the culture of pediatrics to accept the concept of pediatric death. Additionally, informing and educating throughout all health authorities, and the Canadian public at large, will be necessary to ensure pediatric MAiD has fewer barriers than are

presently experienced in the adult population. The nurses have identified discomfort discussing death with their patients, especially pediatric nurses (Haut, Michael, & Moloney-Harmon, 2012). Patients and parents heavily rely on the education and support provided by their nurses. If parents of a minor, or the minor themselves are considering or choose MAiD, it is imperative that the nursing staff be able to discuss the topic and provide care leading up to the provision with confidence. This can start by educating nurses about the death and dying process, not just in the pediatric realm, but for all patients. Only by discussing death and dying, do we normalize the process, and decrease the stigma (Bhatnagar & Joshi, 2012). Educational institutions and employers can help by initiating this discussion early and often to help nurses become used to the concept of death and dying.

Pediatric MAiD may well serve as a catalyst for this discussion. The pediatric palliative care community has long been advocating for more discussion around death and dying, but does not see MAiD as one of the care options they ought to be providing. The International Palliative Care Network was a signatory of the Mumbai Declaration of 2014, which states that “euthanasia is not palliative care and is not an alternative to palliative care” (International Children's Palliative Care Network, 2014). In speaking with colleagues from my previous pediatric background, pediatric clinicians will adhere to their international association’s statement. The pediatric palliative care community would like to end suffering through the use of their palliative care options, and are concerned about the conflation of concepts between pediatric palliative care and pediatric MAiD.

These sentiments are echoed by the International Children's Palliative Care Network adult counterpart association and the palliative care communities. Across Canada, the palliative care community has opted to not participate in the assessment or provision of MAiD. This stance creates a major barrier for patients because palliative care physicians and nurses are working with the patients that would most often be eligible for MAiD. This united reaction to the new care option follows a statement released by the International Association for Hospice and Palliative Care in January 2017 (De Lima et al., 2017) that palliative care units and hospices should not be responsible for overseeing or administering euthanasia and physician-assisted suicide. The position statement explains that IAHP “does not think that countries should have physician-assisted suicide or euthanasia until there is universal access to palliative care services, including opioids for pain and symptom relief” (De Lima et al., 2017). IAHP also states that it does not see MAiD within the realm of palliative or end-of-life care because MAiD does not improve the patient’s quality of life. This stance is supported by the WHO definition of palliative care, which states there is no intention to hasten or postpone death (World Health Organization, 2017). Instead of MAiD, IAHP suggests that HCPs offer palliative sedation to patients. In this position statement, IAHP noted that a patient's choice to not have palliative sedation should be respected, but offered no alternative option if palliative sedation is not indeed the patient’s preferred care option. In my clinical experience, MAiD patients rarely want an improved quality of life; rather, they just do not wish to live anymore. That is a distinct difference that does not seem to be addressed within the IAHP position statement or the WHO definition.

These arguments raised by the IAHPCC underscore the importance of comprehensive data gathering about the specific concerns and needs of patients that request MAiD, in order to ensure that MAiD is never the default option due to lack of access to appropriate palliative services. As the Regional Manager of the Assisted Dying Program, I see all patients that seek MAiD within VCH. The vast majorities of these patients are already receiving palliative care, and despite being offered palliative care options, are choosing MAiD to end their life. Thus, from my own clinical perspective, it seems that positioning MAiD and palliative care as mutually exclusive seems to be an additional barrier for patients in this already vulnerable situation. Until we can resolve misconceptions about who is accessing MAiD, and open up a more full and frank discussion with palliative HCPs to clarify the nature of the attitudinal barriers, we can envision increasing challenges with respect to patients receiving the kind of guidance that will support fully informed decisions.

Research is clearly needed to better understand the context and conditions under which MAiD decisions are being made across Canada. Minimal data sets are now being collected by all provinces and territories, which should assist us to better understand population patterns in this regard. Research examining the experiences and reasons for patients seeking MAiD will expose the motives underlying why patients might prefer MAiD to end their life, rather than opting for palliative care options. Until this tension between care communities that do and do not support MAiD is resolved, the comfort level that each HCP has with MAiD will have to be considered on a case by case basis. Over time, as an increasing number of HCPs gain experience with patients asking about, selecting, or receiving MAiD, I believe most will come to appreciate that it

represents a dignified and peaceful way to die – something that many patients will value as a fundamental component of their quality of life. Now that it has been entrenched in the legal code of Canada, Canadian HCPs are duty-bound to do their utmost to provide access for all of their patients to all end-of-life care options, despite the guidance from this international association.

Children deserve the full scope of services available within the Canadian health care system. In the context of the present introduction of MAiD, the adult community is experiencing some barriers to care that require thoughtful examination, additional research to produce a body of evidence around implementation, and more specific guidance on some of the complex challenges to be disseminated by either the regulatory bodies, professional associations or government. If legislation ultimately permits children access to MAiD in Canada, they may experience more equitable access because of the shifts to practice that are born out of the present learnings. However, simply adapting knowledge from the adult experience will not be sufficient. Minors will encounter important additional obstacles not experienced by adults. Thus, in preparation for the time when it may be legislatively possible for minors in Canada to access MAiD, a body of literature will be needed to examine distinctive barriers for pediatric patients surrounding issues around consent. Further we will need expanded mechanisms to support the practice and educational shifts that will be needed for parental understanding of pediatric palliative care to take place. As we move from a culture of physician-dictated care, towards being governed more by a philosophy of patient choice, it is imperative that educational institutions, health care facilities and HCPs develop a culture that is guided by a patient-centred care approach. Equitable access to care can be

improved by cultivating systems to thoroughly analyze and ultimately remove barriers for children to this emerging and increasingly relevant end-of-life care option.

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