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Considering Medical Assistance in Dying for Minors: The Complexities of

Children's Voices

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Abstract

Medical assistance in dying (MAID) legislation in Canada followed much deliberation after the Supreme Court of Canada's ruling in *Carter* v. *Canada*. Included in this deliberation was the Special Joint Committee on Physician Assisted Dying's recommendation to extend MAID legislation beyond the inclusion of adults to mature minors. Children's agency is a construct advanced within childhood studies literature which entails eliciting children's voices in order to recognize children as active participants in constructing their own childhoods. Using this framework, we consider the possible extension of MAID legislation to most minors. We highlight important questions regarding how insights from children's voices could be mobilized in the life or death context of MAID. We conclude that children's voices have the potential to help determine their eligibility for MAID; however, incorporating children's voices in the context of MAID requires careful consideration due to the complexity of voice.

Introduction

In February 2015, the Supreme Court of Canada made its final ruling in the *Carter* v. *Canada*¹ legal case, indicating that the prohibition of medical assistance in dying (MAID) in Canada, as per sections 14 and 241b of the Criminal Code of Canada, was against the Canadian Charter of Rights and Freedoms². The Supreme Court ruled that the prohibition of MAID was a violation of section one of the Charter, as well as section seven, the right to life, liberty, and security². The Supreme Court gave the federal government twelve months to respond to their ruling with legislation, later extending this period by four months².

In considering this ruling, the Canadian government formed a number of working groups to determine how best to create MAID legislation in line with the Canadian Charter of Rights and Freedoms². These working groups included the Expert Panel on Options for a Legislative Response to *Carter*, the Provincial-Territorial Expert Advisory Group on Physician Assisted Dying, and the Special Joint Committee on Physician Assisted Dying².

The Special Joint Committee on Physician Assisted Dying (hereafter referred to as 'the Special Joint Committee') included Senators and Members of Parliament who consulted with experts in multiple fields in order to outline a legislative framework for MAID². Their report consisted of twenty-one recommendations for the future legislation³.

The deliberations of the various working groups, including the Special Joint Committee, helped inform MAID legislation (Bill C-14), which was finally passed in 2016². According to the current legislation, in order to be eligible for MAID, patients must be adults (ages eighteen and over), be eligible for provincial health care coverage, be mentally competent (i.e., able to understand and reasonably evaluate information), provide voluntary and informed consent, and have a grievous and irremediable condition². The presence of a grievous and irremediable condition is defined as: the presence of enduring, intolerable physical or psychological suffering; having a serious illness, disease, or disability; being in an advanced state of irreversible decline; and it being the case that one's natural death is reasonably foreseeable².

MAID legislation is currently limited to adults. One recommendation in the Special Joint Committee's report was to extend this legislation to include mature minors (i.e., children assessed as having the capacity to consent to or decline medical interventions⁴) no later than three years after legislation has been enacted³.

The recommendation states,

That the Government of Canada implement a two-stage legislative process, with the first stage applying immediately to competent adult persons 18 years or older, to be followed by a second stage applying to competent mature minors, coming into force at a date no later than three years after the first stage has come into force^{3(pp.21)}.

In December 2016, the Government of Canada commissioned the Council of Canadian Academies to conduct an independent review of evidence that could inform decision making regarding MAID for mature minors in Canada⁵. The Council of Canadian Academies released a report of their assessment in December 2018⁶.

Key concepts: Autonomy, Capacity, Mature Minors

Current eligibility criteria for MAID require that individuals have the capacity to consent to MAID². Conventional understandings of capacity to consent to medical interventions such as MAID mobilize individualistic conceptions of autonomy. Autonomous individuals are adults who are considered to have sufficient capacity to make independent, voluntary and informed decisions regarding their health and medical care⁷. The term 'capacity' refers to an individual's cognitive ability to understand, appreciate and reason with the information they are provided, and to make rational decisions based on that information⁸. In the Canadian context, capacity for consent is assessed by health care providers^{9,10}. In general, children are not considered 'autonomous'; therefore, they do not, by definition, have capacity to consent¹¹.

The mature minor doctrine is a common law doctrine recognized in many Canadian jurisdictions; an exception is Quebec which is governed by a civil code¹². A child is considered a mature minor if they demonstrate mature (i.e., adult-like) understanding of their medical condition, treatment options, related risks and benefits, and are able to appreciate and reason with this information to make their own medical decisions¹³ If a child is recognized as a mature minor, they can make certain medical decisions for themselves¹⁴.

Children's Agency Framework

The concept of children's agency has been promoted largely by the New Sociology of Childhood literature, pioneered in the early 1970's¹⁵. Recognition of children's agency followed a shift in Western thought towards viewing children as persons rather than as the property of their parents or guardians¹⁵. Children's agency moves away from defining children only as "becomings"^{16(pp.303)} – that is, thinking of children as valuable because they are 'becoming' adults – to also considering children as "beings"^{16(pp.303)} – that is, valued as ends in themselves¹⁷.

Conventional autonomy frameworks cast children primarily as future adults¹⁸, rather than acknowledging that children are persons with morally meaningful perspectives on the world¹⁹. By viewing children as incomplete versions of adults, mainstream conceptions of autonomy can lead to morally objectifying children¹⁹. Moral objectification means denying recognition of children as active agents with morally meaningful subjectivities, instead treating them as depersonalized, 'moral objects' whose perspectives do not need to be taken into account²⁰. This moral objectification is ethically problematic because children are personsⁱ, meaning they have moral status²¹. Moral status is a concept that identifies those individuals towards whom other persons have moral obligations²¹ such as respecting their agency and taking their experiences and feelings into account²⁰. Treating children as objects and denying their subjectivity are violations of moral duties required to respect the moral status accorded to all persons.

Our argument thus far is that while children are not legally autonomous subjects, they still have agency^{18,22}. Montreuil and Carnevale's concept analysis on agency defines it as "the capacity to act deliberately, speak for oneself, and reflect on the social worlds that shape their lives and the lives of others"^{23(pp.510)}. To say that a child has agency is not the same as recognizing a child as having autonomy²⁴. Rather, recognizing children as agents means thinking

ⁱ 'Person' is a philosophical term according strong moral status²⁰. There is no consensus in the literature regarding the specific characteristics required to be recognized as a person, which include, but are not limited to, the ability to have conscious experience, actual or potential moral agency, and the capacity for reason and self-awareness²⁰.

of them as having their own meaningful perspectives of the world and what matters to them²⁵. For example, in a study of the moral experiences of children living at home with assisted ventilation, several children described their lives and assisted ventilation technology as good; as assistive, not burdensome, despite societal beliefs to the contrary²⁶. Young children acknowledged that the technologies improved their lives and helped them participate in activities like other non-disabled children²⁶. These children were able to demonstrate reflections on their views on good and bad, and right and wrong, and express morally meaningful preferences on how they should be treated²⁶. To say that children have agency means acknowledging that they can make judgments and engage in reasoning more than adults think they can, even though these judgements and reasoning skills may not conform to adult-centered conceptions of autonomy²². Children's agential capacities are not less worthy of being recognized than adults' autonomous capacities²⁷.

The Construct of Voice

Valuing children's perspectives entails eliciting, listening and paying attention to these perspectives¹⁵. Voice is a construct that operationalizes access to a person's perspective. In practice, children's voices are communications in any form (i.e., verbal, written, illustrations, actions, using an assistive communication device, and/or silence). Silence is also a part of voice. Silence can be mistaken as a non-response; however, when considered within the context in which it occurs, silence can also convey meaning^{28,29}. Children's voices include the communications of children who communicate differently, such as those who may rely on assistive communicative devices³⁰. Ill children may have a limited ability to communicate verbally, either as a result of their illness, or due to a medical procedure (i.e., tracheostomy, mechanical ventilator). The childhood studies literature is mixed in its use of the phrases

'children's voices' and 'child's voice'. We specifically use the phrase 'children's voices' to acknowledge that all children do not have a single, unified voice. Rather, each child is unique and has their own voice³¹.

Reasons for using a Children's Agency Framework

What are the reasons for using a children's agency framework to think about MAID for minors? Individualistic autonomy discourses, currently conventional in healthcare, exclude children by virtue of children being non-adults (i.e., non-autonomous decision-makers). In so doing, they morally objectify children by discounting the value of their voices, disregarding their perspectives, and reducing the expressions of children to demonstrations of immaturity¹⁹. This failure to treat children as persons thereby risks moral objectification¹⁹. An example comes from research conducted by Carter who provides the following excerpt from the diary of a child with chronic abdominal pain:

I've had pain in my stomach for nearly two years...one doctor told me that what she was seeing on examination and what she was being told were two different things. I was 11 and knew that I was being accused of lying. This made me really angry, because it didn't help the pain (it actually got worse) and it really hurt me to be called a liar when the pain was very real^{32(pp.34)}.

Children's agency frameworks can help prevent moral objectification by recognizing children as active agents¹⁸ – as moral subjects – and emphasizing the importance of promoting children's participation in discussions and decisions pertaining to matters that affect them¹⁵.

Another consideration in support of the children's agency framework is the special privilege that is accorded to first-person accounts of mental states. Generally, unless you know someone very well and have reason to believe that they are lying, you accept what they say about themselves as true³³. This is because people have a special (not absolute) kind of authority with respect to what they say about their own mental states, called first-person authority³⁴. First-

person accounts are treated with a presumption of truthfulness or reliability whereas third-person accounts are not³⁴. This concept need not be applicable only to adults. Young children (beginning as young as 5-6 years-old) demonstrate an ability to recognize themselves as the authority on self-knowledge, especially for knowledge that has not been disclosed to others in order for them to know about it^{35,36}. As the authority on self-knowledge, children's first-person avowals about their mental states have an "intrinsic credibility"^{37(pp.70)} that third-person accounts of the same do not³⁷. Further, adults (clinicians and parents/guardians) often dominate conversation in clinical encounters about children's health, especially when younger children are involved³⁸. Parents or guardians of terminally ill children who are at the end of life may have acute insight into their child's feelings, thoughts, and desires; however, they may rely on indirect measures to, and have difficulty with, gaining insight into their child's perspective³⁹. Parents' accounts of their child's pain and suffering can also reflect their own conceptions of suffering and hopelessness⁴⁰. The combination of these considerations and the concept of first person authority, suggest that more focus on children's own accounts - their first person avowals - of, for example, their feelings, thoughts and suffering in illness, is necessary to understand their experiences and perspective. Input from parents/guardians and healthcare providers can supplement these first-person avowals. .

Medical Assistance in Dying (MAID) for Minors

This manuscript builds upon the Master's work of the first author⁴¹, considering an extension of MAID legislation to minors in Canada. Using children's agency as a framework, we build our argument in two steps. First, we discuss expanding the scope of the proposed MAID legislation extension beyond mature minors to consider most children. Second, we explore the

necessity and complexity of eliciting a child's own perspective in MAID deliberations, with particular concern for the eligibility criterion of intolerable suffering.

Applying a Children's Agency Framework to MAID

The recommendation by the Special Joint Committee to extend MAID legislation to minors refers specifically to mature minors³, which is a designation given to some children in accordance with the previously described mature minor doctrine. Even though mature minor designation is open to all children regardless of age¹⁴, adolescents are more likely to be recognized as mature minors than younger children. The favouring of adolescents in the mature minor doctrine is signaled in the Canadian Pediatric Society's definition of mature minors: "Mature minors are adolescents who have demonstrated decision-making abilities..."^{11(pp.139)}. Thus, the recommendation of the Special Joint Committee to extend MAID legislation to mature minors may foreclose on the inclusion of children younger than adolescence. Failure to meaningfully acknowledge the perspectives of younger children by excluding them from MAID is to risk morally objectifying them¹⁹. Applying a children's agency framework, we suggest moving beyond the mature minor limit on the Special Joint Committee's recommendation to consider a possible extension of MAID legislation to young people more broadly. The rest of this paper focuses on this broader consideration of extending MAID legislation to most minors in Canada.

We recognize that there is potential for debate on the ability to elicit and pay attention to the perspectives of some younger children, such as infants. The literature contains some examples of agency being demonstrated by infants^{42,43,44}. Agency frameworks do not place any age or functional capacity limits on agency; however, there is uncertainty about how to understand agency in younger children due to a lack of sufficient knowledge or research on this

topic^{44,45}. Further, the inclusion of individuals with mental health and/or intellectual or developmental disorders is subject to ongoing discussions in Canada, and these discussions are focused primarily on adults at this time⁴⁶. The agential perspectives of children who communicate differently and/or with difficulty would need to be sought through alternative forms of communication and by working with parents as interpretive interlocutors; however, we recognize that there may be limitations to this in some cases, such as children with severe autism.

Children's Voices in the Context of MAID.

In regards to the previous discussion of first person authority, children's voices may play an important role in the context of MAID for minors by providing insight into the degree and extent of the suffering experience of the child. This insight can help determine whether the child is suffering intolerably, thus meeting a key eligibility criterion for MAID.

Intolerable suffering carries significant moral weight in justifying MAID⁴⁷, as evidenced in the Supreme Court of Canada's ruling in *Carter* and the Special Joint Committee report³. The moral argument behind allowing MAID for mature minors is based on the cruelty of forcing any person, regardless of age, to continue to suffer intolerably until their natural death occurs⁴⁸.

The experience of suffering and its intolerability entails subjectivity⁴¹. Intuitively, the best person to describe an experience that is subjective is the person themselves. As such, a child would have first-person authority with respect to accounts of their own suffering. If this special privilege is attributed to a child's own account of their suffering, then it is necessary to elicit children's voices to understand their suffering experiences and determine their eligibility for MAID.

Complexity of 'Voice'

We have identified two different reasons for recognizing children's voices within the context of MAID. However, one must be careful when recognizing voice in this context because voice is not an independent, authentic entity that can be narrowly attributed to a single person^{30,49,50,51}. Further, whereas children's voices will provide valuable and meaningful insight regarding the degree and extent of their suffering, that insight may not be straightforward to acquire⁵² and cannot be the complete picture. This lack of a straightforward and complete understanding exists because voice - a child's or an adult's – is always mediated^{51,52} and multi-layered⁵⁰.

Following Russian philosopher and literary theorist, Bakhtin, voice is co-constructed and situated within the context of dialogue³⁰. Imagine, for example, that you are engaging in dialogue with a close friend. The meaning of what you express to your friend in this dialogue is subject to interpretation by your friend. Similarly, you interpret what your friend means based on the words and gestures they use. Your friend responds to you based on their interpretation of the meaning behind your words and gestures. If you feel that your friend has misinterpreted what you were trying to convey, you can attempt to correct their understanding, perhaps by restating or providing an example. In this way, you and your friend engage in a back-and-forth dialogue, working together to co-construct the meanings behind what each of you has expressed. This co-constructed meaning is a Bakhtinian understanding of 'voice'³⁰. Voice is embedded within this back-and-forth process of interpretation²⁹; therefore, it is always mediated⁵¹.

Children (like many adults) are deeply embedded in social contexts (e.g., family, friends, school)⁵³. Children are reliant on the networks within these social contexts to meet their daily needs in order to survive¹⁷, and to navigate contexts such as the health care system. This social embeddedness is important to acknowledge for adequately recognizing both the contextual and

relational nature of their voices. This context-dependent nature of children's voices is explained by Spyrou in his comments on his research on Greek-Cypriot children's constructions of national identities⁵⁰. Children's expressions of their national identities varied with respect to context⁵⁰. For example, when the children were constructing their identities in their neighbourhood, they drew on the local culture to do so, which could be seen, for example, in the themes of their games and their choice of language⁵⁰. When the children were constructing their identities within the school context, they expressed their identities in a more politically correct and nationalistic voice⁵⁰.

Much like relational conceptions of autonomy^{54,55}, children's perspectives are influenced by the experiences and perspectives of others in their social contexts⁵³. For example, the family is a social context in which there can be significant interrelation between the beliefs and values of parents and their children, and family members influence each other's outlook, while also allowing for each individual member to have their own beliefs, values, and ways of thinking⁵⁶. Although children are agents, they are relationally embedded, adding an additional layer of complexity to understanding children's voices⁵⁶.

Voice can be ambiguous and is multi-layered⁵⁰. Spyrou's research demonstrates this multi-layered nature of voice, and how the deeper layers of meaning in children's voices can be uncovered⁵⁰. In an initial interview with Greek-Cypriot children, Spyrou asked the children about their views on Turks and the situation in Cyprus⁵⁰. Most Greek-Cypriot children participating in the interview(s) described the Turks as evil and invaders⁵⁰. Follow up interviews by Spyrou with the Greek-Cypriot children revealed that they were not referring to all Turks, but only to specific groups of Turks, such as those in government⁵⁰. These follow up interviews are not an indication that the children were lying in the initial interview, or that their responses had been inauthentic⁵⁰.

Rather, a deeper layer of meaning behind the children's voices, and consequently a deeper understanding of their perspectives on the Turks, was revealed in the follow up interviews⁵⁰. Spyrou's work demonstrates that voice can be ambiguous and difficult to unravel, and this possible ambiguity is a challenge that must be worked through⁵⁰.

Reflections on Extending MAID to Minors

Due to the complexity of the construct of voice, policy-makers should proceed with caution when considering an extension of MAID legislation to minors, by taking time to carefully deliberate questions about when and how to give weight to children's perspectives within the context of MAID. Health care professionals are already being approached about MAID by the parents or guardians of children, many of whom would not meet the adult-centered requirements of capacity to be considered mature minors⁵⁷. Just as the prohibition of assisted dying under the Criminal Code of Canada was challenged on the basis of Charter rights in *Carter*, parents or guardians may challenge the ineligibility of their children for MAID on the grounds of section seven of the Charter, the right to life, liberty, and security⁵⁷. In the context of MAID, section seven of the Charter pertains to the protected right of each Canadian to waive their right to life, and the right to freedom from the threat of physical and psychological suffering – as a result of not having access to MAID^{1,58(s 7(2)(iii))}.

Insight into a child's illness and suffering experience, as acquired by paying attention to children's voices, could be a strong consideration in decision making about MAID for a minor, given how central the concept of intolerable suffering has been in justifying MAID legislation in Canada. We believe that children's voices should compel conversations pertaining to MAID for a minor among children, parents/guardians, and health care providers. For example, if a child expresses the extent of their suffering to a parent or guardian, this could motivate a dialogue

about MAID among the child, the parents/guardians, and healthcare providers. Alternatively, the parent or guardian may be the first to think about MAID for the minor and should work with healthcare providers to elicit children's voices in a dialogue about MAID. By providing information about the presence of intolerable suffering (or lack thereof) in a child, the insight provided by children's voices can help determine whether the child is eligible for MAID.

The complexity of voice has significant implications for eliciting children's voices in the context of MAID for minors. Voice is embedded within a process of multilayer avowal and interpretation^{30,50}. Therefore, eliciting children's voices may not result in a clear understanding of a child's suffering experience. Nonetheless, eliciting children's voices still holds the potential for providing invaluable insight into a child's experiences and their perspective on those experiences. In the case of MAID for minors, it is important to consider whether an uncertain picture of a child's suffering and illness experience, as acquired by paying attention to children's voices, would be sufficient to determine whether a minor is eligible for MAID.

By questioning the sufficiency of the knowledge that may be acquired from eliciting children's voices in the context of MAID, we are not suggesting that children's voices should not be elicited, nor that they must prove worthy of consideration. To abandon the elicitation and acknowledgement of children's voices would be a moral harm because it would entail failing to recognize children as persons with their own perspectives that are inherently worthy of consideration¹⁹. By asking whether the understanding of a child's suffering experience derived from their voice would be enough, we are questioning the specific epistemological role that children's voices play within the context of MAID. Whereas children's voices can provide meaningful insight into a child's perspective and experience that could not likewise be acquired

from third-person accounts, it is uncertain whether this meaningful insight would be ethically and legally sufficient when making a life or death decision such as MAID for a minor.

Would it ever be ethically acceptable to rely on the uncertainty that can exist from information derived through children's voices in such a high stakes decision? The presence of uncertainty means that some degree of risk of false determinations regarding the presence of intolerable suffering continues to exist. The presence of this risk is ethically significant because a failure to adequately assess the eligibility of a child for MAID may result in unjustified use or denial of MAID. The unjustified denial of MAID would entail a failure to fairly provide a medical intervention (i.e., MAID) to a child who experiences morally significant intolerable suffering like others who do receive this intervention. Alternatively, the unjustified use of MAID could entail the unjustified ending of a child's life through providing MAID due to an incorrect assessment of eligibility. Everyone is potentially vulnerable in the context of MAID, including adults³; however, children are in a position of compounded vulnerability in this context due to their existing childhood-related vulnerabilities (e.g., being embedded in adult-privileging power dynamics, inability to defend oneself from risk of harm⁵⁹). Given this compounded vulnerability and the irreversibility of death, it is essential to ensure that MAID is truly justified in each case of a minor. Therefore, uncertainty about a child's degree of suffering is especially concerning. Safeguards

The risk of false determinations of eligibility for MAID is legally significant because the objective of the law is to protect persons from risks (e.g., risk of abuse and error)¹. Acts like MAID for minors may be permitted despite the presence of these risks when appropriate safeguards are put in place to minimize the risks¹. Given the risk of error associated with

working through the complexity of children's voices in the context of MAID, it is important to consider possible legal safeguards.

A requirement by provincial and territorial governments to consider multiple factors in decision making pertaining to MAID for a minor, such as the child's medical situation, family dynamics, the emotional and physical impact of further medical interventions on the child, and availability and potential efficacy of further palliative care measures is one possible safeguard⁶.

Other potential safeguards entail using the very mediated nature of voice that contributes to its complexity as part of the solution. One possibility is a requirement for the involvement of a psychologist or psychiatrist in MAID discussions (as is the case in Belgium and the Netherlands)⁶, not as a means of evaluating the child's voice for validity, authenticity, or worthiness of consideration, but as a means of helping work through some of the complexity of voice through dialogue with children. The involvement of a psychologist is in line with the existing inter-professional approach to pediatric healthcare⁶. When already integrated into the inter-professional healthcare team, psychologists and psychiatrists already have an intimate knowledge of the child's medical, psychosocial, and personal history⁶ which could help address some of the complexity of voice. Parental involvement can also be a similarly important safeguard when parents/guardians serve as interpretive interlocutors, using iterative dialogue with the child to facilitate a clearer understanding of the perspective a child is trying to express.

Substitute decision makers(often parents/guardians) for minors are obligated to make healthcare decisions in minors' best interests¹¹. A decision is in the best interest of a child if it maximizes benefits and minimizes burdens for the child, and meets a standard of care that any ordinary, reasonable person would expect¹¹. We believe that eliciting children's voices is a key component of this assessment, informing an understanding of benefits, burdens, and

consequently, what is in an individual child's best interests. Given the importance of the best interests standard in decision-making in pediatric healthcare, it is not difficult to imagine that incorporation of the best interests standard is one way in which MAID for (non-mature) minors would differ from MAID for adults. Can MAID ever be linked to a child's best interests? It is unclear what a decision in the best interests of a child would look like in the context of MAID for (non-mature) minors. Possible use of the best interests standard as a supplemental protective safeguard ought to be considered, since it is required for all other healthcare decisions affecting non-mature minors.

Conclusion

Children's voices can provide meaningful insight into their illness and end-of-life experiences, such as the degree and extent of their suffering, thereby holding the potential to help determine their eligibility for MAID. If policy makers and legislators are to extend MAID legislation to minors in Canada, they need to carefully consider when and how to incorporate this information from children's voices. Policy makers and legislators need to engage in this careful consideration because the information from children's voices may not always be clear or certain enough to make it morally acceptable for use towards making decisions pertaining to MAID for a minor. Further, policy makers would have to deliberate about legal safeguards that could be put in place to mitigate the possible negative repercussions of operating under some level of uncertainty.

If legislators are to consider extending MAID legislation to most minors in Canada, they will need to exercise caution in determining if and how to implement the legislation. Exercising caution would entail carefully deliberating, perhaps through enlisting further independent reviews and communication with experts, about whether there may be too much uncertainty in

individual instances of using the insights derived from children's voices to make decisions pertaining to MAID. If insights derived from children's voices are not considered to entail too much uncertainty to serve this specific epistemological purpose, there would be a need to consult with the appropriate experts to consider what degree of uncertainty is morally acceptable and how any legal risks of operating under some uncertainty could be mitigated.

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