Medical Assistance in Dying (MAID) for Minors in Canada:

Considering Children's Voices

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Preface

This thesis is entirely the work of the student, Harprit K. Singh.

Abstract[♦]

The Special Joint Committee on Physician Assisted Dying has recommended the extension of current medical assistance in dying (MAID) legislation in Canada (Bill C-14) to include mature minors. A mature minor is anyone under the age of 18 demonstrating sufficient capacity to understand their medical condition, and the risks and benefits of available treatments. Although mature minors are the only minors being considered under the current recommendations regarding future legislation, Canadian health care professionals are already being approached with inquiries about MAID for minors who do not meet mature minor criteria.

Current eligibility criteria for MAID include a requirement of informed consent, and that of intolerable suffering. Most minors are presumed, by the law and in health care practice, not to have the capacity to consent. Parents/guardians would therefore have to act as surrogate decision makers. Reliance on parents/guardians as surrogate decision makers increases the risk of inaccurately assessing the more subjective eligibility criteria for MAID, particularly suffering intolerably, by excluding the subjective perspective of the minor regarding her own intolerable suffering. Health care professionals' accounts of a minor's intolerable suffering also increase this risk. When factored into determinations of a minor's eligibility for MAID, inaccurate assessments of intolerable suffering raise concern about justice in the context of MAID for minors.

This research began with a hypothesis that the subjectivity of suffering makes it important to incorporate the sufferers' own voice in an accurate assessment of intolerable suffering. This thesis explores how the child's voice, as representative of the child's experience,

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[♦] A large portion of this abstract has been submitted to the 29th Annual Canadian Bioethics Society Conference.

can be useful in adequately assessing that a minor is suffering intolerably, and thus factor into determinations of that child's eligibility for MAID.

The conceptual framework of children's agency from the New Sociology of Childhood literature provides a theoretical foundation for elicitation of the child's voice, and hence a plausible means of assessing the intolerable suffering of a minor. The 'child's voice' refers to communication from the child using words, illustration, actions, assistive devices, or silence, that serves as a metaphor for children's perspectives, and may provide epistemological access to a child's experience.

This thesis demonstrates that children's voices can provide valuable information for decision-making pertaining to MAID for a minor; however, it is not clear whether the insight that children's voices can provide in assessing intolerable suffering is sufficient for the context of MAID for minors. This thesis identifies this matter as something that would have to be considered in greater detail if considering an extension of MAID legislation to all minors in the future.

Résumé[◆]

Le Comité mixte spécial sur l'aide médicale à mourir a recommandé d'inclure les mineurs matures dans la loi sur l'aide médicale à mourir au Canada (projet de loi C-14). Un mineur mature est une personne de moins de 18 ans qui démontre une capacité suffisante à comprendre son état de santé ainsi que les risques et les avantages des traitements disponibles. Bien que les mineurs matures soient les seuls mineurs désignés dans les recommandations concernant la législation future, les professionnels de la santé au Canada sont déjà sollicités pour obtenir des renseignements sur l'aide médicale à mourir pour des mineurs qui ne correspondent pas aux critères de mineurs matures.

Les critères d'admissibilité actuels pour l'aide médicale à mourir comprennent l'exigence du consentement éclairé et la présence d'une souffrance insupportable. Toutefois, la Loi et la pratique médicale ne reconnaissent pas la capacité, chez la plupart de ces mineurs, de prendre les décisions liées à ces critères. Par conséquent, les parents/tuteurs doivent agir en tant que mandataires/décideurs de substitution. Compter sur les parents/tuteurs en tant que mandataires spéciaux augmente le risque d'évaluer de manière inexacte les critères d'éligibilité subjectifs de l'aide médicale à mourir, notamment celui lié à la souffrance intolérable. En effet, les modalités légales actuelles pose le risque d'exclure de la prise de décision le vécu subjectif du mineur quant à sa souffrance. L'estimation par des professionels de la santé de la souffrance ressentie par un mineur augmente également ce risque. Ce risque soulèvent des enjeux de justice d'admissibilité et d'accès à l'aide médicale à mourir, pour les mineurs.

[◆] Une grande partie de cette résumé a été soumis à la 29ème Conférence annuelle de la Société Canadienne de Bioéthique.

Cette recherche a commencé avec l'hypothèse selon laquelle la subjectivité de la souffrance fait en sorte qu'il est important d'incorporer la voix du patient dans une évaluation précise du degré de souffrance ressentie. Cette thèse examine comment les voix des enfant (comme une représentation de ses expériences) peut être utile pour évaluer adéquatement si sa souffrance est intolérable et le rend admissible à l'aide médicale à mourir.

Les constructions théoriques d'agentivité des enfants et la voix de l'enfant exprimé dans la littérature dite la "Nouvelle sociologie de l'enfance" contribuent à établir une fondation théorique pour mettre en évidence l'importance de la voix de l'enfant, et par conséquent un moyen potentiel d'évaluer le degré de tolérance de sa souffrance. La voix de l'enfant fait référence à la communication de ce dernier à l'aide de mots, d'illustrations, d'actions, de dispositifs d'aide ou de silence; le concept de voix représente une métaphore désignant l'opinion des enfants, et permettant d’accéder à une compréhension de son expérience.

Cette thèse démontre que les voix des enfants peuvent fournir des informations de valeur pour la prise de décision relative à l'aide médicale à mourir pour un mineur. Cependant, il n'est pas clair si l'information que les voix des enfants peut fournir dans l'évaluation des souffrances intolérables est suffisante dans le contexte d l'aide médicale à mourir pour les mineurs. Cette thèse conclut que cette question devrait être considéré plus on détail si l'on envisage d'étendre la législation sur l'aide médicale à mourir aux mineurs de tout âge à l'avenir.

Introduction

Legislative Background

The Government of Canada's passing of Bill C-14 in June 2016 (Bill C-14, 2016) amended the Criminal Code of Canada by de-criminalizing medical assistance in dying (MAID) (Nicol & Tiedemann, 2016). This Bill served as a legislative response to a ruling by the Supreme Court of Canada in the *Carter* v. *Canada* (2015) case, declaring that the prohibition on assistance in dying in sections 14 and 241(b) of the Criminal Code of Canada violates sections 1 and 7 of the Canadian Charter of Rights and Freedoms (Government of Canada, 2017b).

Following the Supreme Court of Canada's decision in *Carter*, the Canadian Ministers of Justice and Health established the External Panel on Options for a Legislative Response to *Carter* (Expert Panel, 2015). This panel was mandated with the task of holding discussions to determine how to synthesize legislation in response to the *Carter* ruling (Expert Panel, 2015). This panel consulted with twenty-six organizations who had intervened (i.e., weighed in on the litigation) in *Carter,* medical authorities, such as the Canadian Medical Association, and experts in Canada and abroad (Expert Panel, 2015). They published a report summarizing the results of their discussions and consultations in December 2015 (Expert Panel, 2015).

A Provincial-Territorial Expert Advisory Group on Physician Assisted Dying was also established, and worked simultaneously to the Expert Panel (Nicol & Tiedemann, 2016). This advisory group released a report in December 2015 as well, outlining 43 recommendations pertaining to those aspects of synthesizing MAID legislation relevant to the provincial level of government (Nicol & Tiedemann, 2016).

Following the report by the Expert Panel, a committee of Senators and Members of Parliament, known as the Special Joint Committee on Physician Assisted Dying was appointed to review the Expert Panel's report (Parliament of Canada, 2016). They were mandated by the Senate and the House of Commons of the Canadian Parliament to make recommendations regarding how the federal government should respond to the *Carter* ruling in a way that respects the Canadian Charter of Rights and Freedoms (Parliament of Canada, 2016). The Special Joint Committee heard from sixty-one witnesses and received one hundred submissions from stakeholder organizations (cf. Government of Canada [2016a] for full list) regarding MAID in Canada (Parliament of Canada, 2016). They invited experts to present testimony during meetings, which was used to help formulate the recommendations in the Special Joint Committee's final report (Parliament of Canada, 2016). The Committee's report, published in February of 2016, is significant because it outlines a legislative framework for MAID in Canada (Government of Canada, 2016a).

The legislative response to *Carter*, Bill C-14, received royal assent in June 2016 (Bill C-14 ,2016); approximately four months after the publication of the Special Joint Committee's report. The Committee's report consisted of twenty-one recommendations (Government of Canada, 2016a). Not all of these recommendations were acted upon in formulating Bill C-14 because the Supreme Court of Canada had mandated that Parliament formulate a legislative response that adhered to the reasoning in *Carter*, and some of the Committee's recommendations in the report went beyond what was specifically indicated in the *Carter* ruling (Government of Canada, 2016a). One of these excluded recommendations is Recommendation 6 in the report (p.18), which pertains to extension of MAID legislation to competent mature minors (Government of Canada, 2016a). Recommendation 6 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 (Government of Canada, 2016a, p.21).

This recommendation was not acted upon in formulating the current MAID legislation because, according to *Carter* (2015), there is a strong societal consensus that MAID "...would only be ethical with respect to voluntary adults..." (para. 358). Recommendation 6 is the inspiration for the topic of this thesis.

Current eligibility criteria for MAID in Canada include being eligible for provincial health coverage, being mentally competent (i.e., demonstrating the ability to understand and reasonably evaluate information), being eighteen years of age or older, having a grievous or irremediable medical condition, and being able to provide voluntary and informed consent (Nicol & Tiedemann, 2016). In order for a patient to qualify as having a 'grievous or irremediable condition', they must meet all of the following criteria: a) have a serious illness, disease, or disability; b) be in an advanced state of irreversible decline; c) have intolerable suffering; and d) the patient's natural death must be reasonably foreseeable (Nicol & Tiedemann, 2016).

No official definition is provided in these criteria for the term 'intolerable or unbearable suffering'. For the purpose of this thesis, unbearable or intolerable suffering exists when one experiences one's circumstances as overwhelming as a result of perceiving them as exceeding one's coping abilities, as having significantly deteriorated one's ability to enjoy a life of value, and as inescapable. This definition is based on the definitions of 'suffering' provided by Cassell

(2004) and Edwards (2003). Cassell (2004) defined 'suffering' as distress caused by something that is perceived to be a threat to one's integrity as a person. Edwards' (2003) account of 'suffering' preceded Cassell's account, but it demonstrates that the emphasis on maintaining the integrity of the person in Cassell's definition is not easily applicable to certain groups of individuals, such as young children, who do not have a concept of integrity of the person or of their overall "intactness" (Cassell, 2004, p.32). Edwards (2003) provided a different definition of 'suffering' as something that is felt for a significant duration of time, and significantly impacts one's ability to enjoy one's life (Edwards, 2003).The definition of intolerable suffering employed in this thesis draws on the strengths of both definitions: Edwards' (2003) emphasis on impact on quality of life, and Cassell's (2004) indication that suffering is distress resulting from a perceived threat, a danger that cannot be easily overcome (i.e., something that is overwhelming, inescapable).

Rationale and Objective

Most minors are presumed, by the law and in health care practice, to not have the capacity[1] to consent (Harrison, 2016). As a result, parents/guardians would have to act as surrogate decision makers to provide informed consent (Harrison, 2016). Further, as surrogate decision makers, parents/guardians would likely be the primary individuals communicating with health care professionals, and health care professionals are likely to rely on parents/guardians for information about their child (Tates Kiek, 2003). This limiting of the participation of children is ethically problematic because it entails moral objectification of children through a failure to

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[1] 'Capacity' is determined by physicians and/or psychologists. The term 'capacity' refers to an individual's cognitive abilities to understand and reason with the information that they are provided, and to make rational decisions. Someone who lacks capacity is considered *de facto* incompetent (Leo, 1999).

recognize their unique agency and incorporate their perspective (Carnevale, 2012). Further, having parents/guardians speak on behalf of their children (which can be beneficial to children in the case of parental advocacy) might increase the risk of inaccurately assessing the more subjective eligibility criteria for MAID, particularly suffering intolerably (Carnevale, 2009), because these eligibility assessments would not entail the subjective perspective of the minor regarding her own intolerable suffering. Health care professionals' accounts of a minor's intolerable suffering also increase this risk. Inaccurate assessment of intolerable suffering could result in inadequate determination of whether MAID is in a minor's medical best interest[2], which raises concern about justice in an extension of MAID legislation to minors.

I hypothesize that the subjectivity of suffering makes it important to incorporate the sufferers' own voice in an accurate assessment of intolerable suffering. The main objective of this thesis is to explore how eliciting the child's own perspective can be useful in adequately assessing if she is suffering intolerably, and thus factor into determinations of that child's eligibility for MAID, so as to ensure that every instance of providing MAID to a minor is justified in accordance with the ethical principle of justice.

The considerations I address contribute to a broader set of issues that would be applicable to determining how to implement an extension of MAID legislation to minors in Canada. These future considerations may inform legal and clinical policy, resulting in, for example, revisions to policies pertaining to inclusion of children's perspectives, and/or recommendations to health professionals about when and how to have minors participate in the decision to provide them

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[2] Although the definition of best interest is highly contested, use of the best interest standard entails making a decision with the intent of maximizing the child's benefits and minimizing their burdens (Bensimon & Zlotnik Shaul, 2016).

with MAID. Children's agency and voice is brought to the fore in the realm of health care ethics in this thesis through application to a topic that is currently of political significance. Finally, the work in this thesis serves as a novel contribution to the childhood ethics and voice literature because that literature has not discussed children's agency and voice in the context of MAID.

Overview of Chapters

This introductory section has described the legislative history that has paved the path to the topic of this thesis, and has provided the objective of this thesis. The following chapters of the thesis are an exposition of the ways in which the literature challenged my hypothesis that it would be important to incorporate the sufferer's own voice in an accurate assessment of the presence of intolerable suffering.

Chapter One provides a review of relevant literature in bioethics, identifying bioethics principles and frameworks that are applicable to the thesis topic. Further, I identify the specific ethical problem addressed in this thesis, and argue that the topic of this thesis is ethically relevant in two ways: a) as a matter of the moral objectification of children, and b) as a matter of justice pertaining to the potential for an unfairness in providing MAID to minors due to inadequate assessments of their intolerable suffering as an eligibility criterion.

Chapter Two introduces the methodology implicit in the children's agency framework. Most minors are not considered to have the capacity to make medical decisions for themselves (Harrison, 2016) because children do not meet adult-centric notions of autonomy (which I refer to as the 'autonomy model'). As such, traditionally, there has been a tendency to dismiss what children have to say as immature expressions (Carnevale, 2012). The children's agency framework provides an antidote to this approach due to its emphasis on the unique agency and perspectives of children. I first provide a review of the literature pertaining to the constructs of children's agency and voice. The roots of this framework in the 'New Sociology of Childhood' literature will be acknowledged, and issues with the autonomy model (i.e., an emphasis on developmental psychology, and the reasoning abilities typical of adult individuals in determining capacity for consent) will be discussed. I present an account of 'voice' as an embodiment of children's experiences and perspectives that can exist in multiple forms, such as verbal and written communication, illustration, communication through assistive devices (Teachman, McDonough, Macarthur & Gibson, 2017), and silence (Lewis, 2010; Spyrou, 2016). The chapter concludes by outlining both moral and epistemic reasons for preferring the children's agency framework over the dominant autonomy-based discourse in health care and law.

Chapter Three begins with an exploration of how incorporating children's voices might be useful, given a conception of intolerable suffering as a subjective phenomenon. The exploration unfolds in an exposition of the challenges in taking a presumed authenticity of children's voices as the foundation for incorporating them. Responses to this concern from the literature are presented, which provide an understanding of children's voices as situated within the context of dialogue, rather than as independent and belonging to a single individual, and as necessarily mediated, messy, and multi-layered.

Chapter Four discusses the implications of this novel understanding of 'voice' (i.e., mediated and multi-layered) for determining whether a child is suffering intolerably; thus, factoring into their eligibility for MAID. I tie the discussion from Chapter Three to the problem of justice in the provision of MAID, and present specific reasons to proceed with caution if considering an extension of MAID legislation to include all minors in the future.

Chapter 1: A Problem of Justice in the Context of MAID for Minors

Introduction

This first chapter will, in the context of a bioethics literature review, demonstrate the ethical significance of the topic of this thesis. It will demonstrate that if MAID legislation were to be extended to include all minors, the principle of justice would be the best prima facie ethical justification for such an extension. In doing so, this chapter will justify identification of the problem of justice as a key ethical problem addressed in this thesis.

Biomedical Ethics

Since MAID is a medical intervention that raises various ethical questions, application of moral reasoning from the field of biomedical ethics to this practice is important to ensure that MAID is practiced ethically. This application of moral reasoning is important in order to ensure that individual's moral rights, and the inherent worth that individuals have as persons, is not violated in providing, or excluding them from, MAID.

Biomedical ethics is an interdisciplinary field that began between the 1960s and 1970s, (Pabst Battin, 2013) and pertains to ethical issues emerging from health care practices. It is an academic field that brings together three core domains: philosophy, medicine, and law (Pabst Battin, 2013). Several other academic areas supplement biomedical ethics, including anthropology, sociology, economics, humanities, theology, and political science (Pabst Battin, 2013). Biomedical ethics consists of philosophical inquiry and theoretical reflection, clinical consultation in health care settings medical domain; and policy development in the legal domain (Pabst Battin, 2013).

Biomedical ethics began with real life ethical dilemmas that were faced by clinicians within the limited context of the physician-patient interaction (Pabst Battin, 2013). Ethical reasoning was applied to these real cases to allow for practical solutions to these ethical dilemmas (Pabst Battin, 2013). Over time, these dilemmas became generalized into larger theoretical issues, such as the distinction between killing a person and letting a person die, criteria for personhood, truth-telling, and informed consent (Pabst Battin, 2013). The field has evolved, and issues that were once limited to the bed-side have now expanded their scope to the societal level (Pabst Battin, 2013), such as concerns regarding distributive justice and resource allocation across entire health care systems.

Initially, the types of moral reasoning employed in bioethics were primarily utilitarianism (i.e., measuring the morality of an action based on its ability to maximize the good consequences for the greater number, deontology (i.e., measuring the morality of an action based on alignment with rules and/or duties), as well as some virtue ethics (Pabst Battin, 2013). Beauchamp and Childress introduced principlism to the field of bioethics, which has made a significant contribution to the growing recognition and utility of the field (Pabst Battin, 2013). Principlism is a framework that consists of four main principles: respect for autonomy, beneficence, non-maleficence, and justice (Beauchamp, 2010). These principles are defined in more detail below. Principlism is the most commonly employed bioethics framework (Pabst Battin, 2013) due to its ease of applicability by health care professionals to address the dilemmas seen in daily medical practice. As opposed to having to think of various theoretical concepts and trying to apply them to a real life situation in a limited amount of time, principlism provides health care professionals with a few clear principles to consider when confronted with an ethical dilemma in the health care context. Principlism has been subject to criticism and challenge over the years (Pabst Battin, 2013), creating space for other frameworks, such as feminist ethics, ethics of care, narrative ethics, and casuistry. Feminist ethics is concerned with drawing attention to the moral significance of those groups who have traditionally been ignored, or of those who are systemically disadvantaged (e.g., women, children) (Clement, 2013). Care ethics emerged from research in feminist ethics (Friedman, 2013). Care ethics emphasizes caring in interpersonal relations (Friedman, 2013). Narrative ethics emphasizes the importance of eliciting the story behind how the patient, their family, health care workers, and other parties involved have come to face the ethical dilemma, revealing information about their personal moral worlds (i.e., moral agency, values), and reflecting on this information and the narrative to determine how to resolve the ethical dilemma (Montello, 2014). Casuistry focuses on finding analogous paradigm cases to the current ethical dilemma and using them to find an ethical solution (Cudney, 2014). It is important to note that both principlism and casuistry acknowledge the importance of appealing to principles and reflecting on paradigm cases, but the former takes application of principles as a primary approach, and the latter focuses on drawing analogies with like cases rather than starting with the specification of principles (Cudney, 2014).

Ethical Relevance of the Thesis Topic

The ethical problem addressed in this thesis

This thesis is based on the assumption that the requirement for informed consent and the presence of intolerable suffering for MAID eligibility would not change if Bill C-14 were to be extended to include all minors. I make this assumption because removing the requirement for informed consent would lead to ethical concerns regarding involuntary euthanasia (Brouwer, Kaczor, Battin, et al., 2018); further alleviating intolerable suffering is, as evidenced in *Carter* (2015), one of the prominent justifications for allowing MAID in Canada. In order to provide voluntary and informed consent, an individual must have the capacity to understand information about the proposed medical treatments and alternatives, and to be able to appreciate the consequences of refusing treatment (Evans, 2016). Most minors are not regarded as having this capacity under the law and in health care contexts (Harrison, 2016); thus, most minors could not provide independent, informed consent for MAID.[3] In pediatric health care, parents typically act as surrogate decision makers for their children using the best interest standard (Harrison, 2016). Bill C-14 does not currently allow surrogate decision making for MAID (Nicol & Tiedemann, 2016). However, I am working with the assumption that if it were extended to include minors, MAID legislation would be revised to allow parents to act as surrogate decision makers in order to meet the requirement for informed consent because this would align with the standard of practice in pediatric health care.

In acting as surrogate decision makers, parents have historically played, and continue to play a key role in the clinician-patient interaction (Tates Kiek, 2003). This key role of parents is contributed to by parents' eagerness to be involved in health care decisions pertaining to their child and to voice their own concerns (often at the expense of limiting their child's participation), and by a tendency by clinicians to rely on parents as sources of health information about their child (Tates Kiek, 2003). As a result, it is not difficult to imagine that clinicians would approach,

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[3] One exception to this is mature minors, which is the group of minors to whom the Special Joint Committee on Physician Assisted Dying (2016b) limit the extension of MAID legislation. Reasons for abstracting from a limited emphasis on mature minors in this thesis are discussed below.

and largely rely on, parents to determine MAID eligibility criteria, such as the presence of intolerable suffering. This is especially the case because parents of children at the end of life are thought to have acute insight into their child's feelings, thoughts, and desires (Kars, Grypdonck, de Bock & van Delden, 2015).

In this thesis, I question whether parent's or clinicians' claims regarding a child's suffering would be truly reflective of the child's experience. Since suffering is often described as a subjective phenomenon (Cassell, 2004), there is a risk that parents might inaccurately assess whether or not their child is suffering intolerably (Carnevale, 2009), resulting in an inaccurate assessment of whether MAID is in the best interest of the minor.

In writing on assisted dying for minors in the Netherlands, where euthanasia is allowed for minors above the age of twelve, Bolt and colleagues (2016) point to the difficulty of assessing suffering in an incompetent patient (i.e., minors), suggesting the need to consider the views of various parties (i.e., parents, nurses, and physicians) on the suffering of the patient. On the other hand, Carter (2016) is concerned that parents' accounts of their child's pain and suffering may entail an imposition of their own notions of suffering and hopelessness on the child. This problem is ethically relevant in two ways: a) as a problem of moral objectification, which will be discussed in Chapter Two, and b) as a problem of justice, which is described further in the current chapter. The problem of moral objectification consists of the moral objectification of children through a failure to recognize their unique agency, and incorporate their perspectives (Carnevale, 2012). The problem of justice pertains to unfairly not providing MAID to a minor despite her experiencing intolerable suffering (assuming that palliative care interventions have not been successful[4]), which is morally significant, whereas someone else (perhaps an adult), who also has morally significant intolerable suffering, is able to receive MAID. Similarly, if a parent or clinician is deciding that the minor is suffering intolerably, whereas it is unknown or unclear whether the minor finds their condition intolerable and wants MAID, there is potential for injustice in the form of a wrongful death or an unjustified violation of the minor's right to life. I hypothesize that it is important to incorporate the sufferer's (i.e., child's) own voice in an accurate assessment of the presence of intolerable suffering in order to avoid such violations of the principle of justice.

Why an emphasis on justice?

The ethical problem of justice is inspired by statements in the report authored by the Special Joint Committee on Physician Assisted Dying indicating that, "...minors can suffer as much as any adult" (p.20-21), and thus they claim, "...it is difficult to justify an outright ban on access to MAID for minors" (p.21) (Government of Canada, 2016a). These statements suggest that it would be wrong to let minors continue to suffer due to ineligibility for MAID. Three ethical principles and one framework[5] might underlie these statements, namely the principle of beneficence, the principle of non-maleficence, the ethics of care framework, and the principle of justice. As will be demonstrated below, all provide a plausible rationale for the emphasis on

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[4] High quality palliative care is an integral component of providing care to minors facing death (Davies, 2017). In some cases, even when excellent palliative care is provided, it may not be sufficient to alleviate the suffering of the minor patient, prompting patients and their families to consider MAID. Nonetheless, palliative care ought to stay available for patients regardless of whether or not they are considering MAID (Davies, 2017).

[5] The term 'framework' refers to a way of thinking about or approaching ethical issues. 'Principles' are specific rules of ethics that comprise the principlism framework in bioethics.

alleviating the equivalent suffering of minors (to that of adults) expressed in the Special Joint Committee's report[6]. I also consider the principle of autonomy because the supplementary opinion provided by the New Democrat Party of Canada, included in the appendices of the Special Joint Committee's report, refers to the use of this principle by the Committee (Government of Canada, 2016a).

In this section, I demonstrate that the principle of justice is the strongest underlying principle for the aforementioned statements from the Special Joint Committee's report, pertaining to Recommendation 6. Further, this section lends support to my identifying of the problem of justice as a key ethical problem in this thesis. I first discuss the principle of respect for autonomy in relation to Recommendation 6 from the Special Joint Committee, demonstrating the issues and limitations with using this ethical principle to justify an extension of MAID legislation to minors. In doing so, I begin to justify my choice to focus on children's agency, rather than respect for autonomy, in this thesis; a discussion that carries forward into Chapter Two. I proceed with descriptions of the principles of beneficence and non-maleficence, and the ethics of care framework. Finally, I argue that the principles of beneficence and non-maleficence, and the ethics of care framework do not provide the best justification for Recommendation 6. I demonstrate how the principle of justice provides the best justification for the Special Joint Committee's Recommendation 6, which lends support to my identification of the problem of justice as a key ethical concern in this thesis.

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[6] Although consideration of these principles was inspired by the Special Joint Committee's meeting discussions and report, I acknowledge that their rationale need not be the most, or only, appropriate rationale. I used the Special Joint Committee's statements as an initial source of guidance in determining the ethical problem my thesis aims to tackle.

The principle of respect for autonomy, and minors

The term autonomy refers to the presence of capacities required to understand and reason with information, and act voluntarily and intentionally (Beauchamp, 2010), such as making independent medical decisions, and providing informed consent, which is required by the current eligibility criteria for MAID in Canada (Nicol & Tiedemann, 2016). Although most minors are not presumed to be autonomous in the eyes of the law or in health care practice (Harrison, 2016), some minors are recognized as having the requisite capacity to provide informed consent due to the mature minor doctrine (*A.C.* v. *Manitoba*, 2009). The mature minor doctrine is a common law doctrine (and thus not recognized in Quebec) which allows children, who are assessed by clinicians to be sufficiently mature in understanding their condition and the risks and benefits of various treatment options, to make their own treatment decisions (Government of Canada, 2017a). The doctrine is applied by courts to designate a minor as a mature minor in contested cases (Driggs, 2001). However, the existence of this doctrine has also enabled changes in clinical practice to allow clinicians to recognize, without reasonable doubt, some young patients (i.e., below the age of majority) as capable of making independent medical decisions, and to allow these young patients to independently consent to medical treatment.

The Special Joint Committee limits Recommendation 6 to mature minors (Government of Canada, 2016a). The restricted scope of this recommendation is due in part to the Supreme Court's use of the term ' adult ' in the *Carter* ruling (Government of Canada, 2016b). The use of this term is interpreted by experts, such as Dr. Jennifer Gibson[7], who contributed to the Committee's deliberations, as purposefully limiting the practice of MAID to those who are recognized as having the capacity to consent independently (Government of Canada, 2016b). As

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[7] Director of the University of Toronto Joint Centre for Bioethics, and Sun Life Financial Chair in Bioethics

a result, the Committee has recommended an extension to minors, but only to that group of minors that are recognized as having this capacity. Further, since mature minors are recognized as having the capacity to refuse treatment, it has been argued that it is inconsistent not to include them as an eligible group in MAID legislation (MacIntosh, 2016).

Limiting MAID to mature minors appears to be an attempt by the Special Joint Committee to balance the principle of justice and the principle of autonomy by extending MAID legislation to allow equal access for groups that are currently excluded from the legislation, while balancing this with the requirement for informed consent. However, the success of this attempt at balancing is questionable. In theory, any minor, regardless of age, can be assessed and deemed by a clinician to be a mature minor (Harrison, 2016). However, in my review of the literature, I have found that adolescents are more likely to be deemed mature minors, by clinicians, than younger children due to the notion, as identified by Fortin (2009a), that some cognitive skills are simply not available to young children because of their early position in the cognitive developmental trajectory. This tendency to think of the construct 'mature minor' as primarily applicable to adolescents is evidenced in the literature through the terms 'youth' and/or 'adolescent' frequently being used interchangeably with 'mature minor' (cf. Guichon, Mohamed, Clarke & Mitchell, 2017; Driggs, 2001; Hendrick, 2010; Fortin, 2009a, 2009b). As such, limiting MAID to mature minors would, in practice, result in a tendency to exclude younger children. This potential exclusion of younger children, by limiting MAID to mature minors, does not fit with the principle of justice because younger children would be likely to continue to experience morally significant intolerable suffering like those that are deemed mature minors, without being eligible to receive MAID. As such, the way in which health care professionals typically conceive of and apply the mature minor doctrine does not adequately fulfill the principle of justice; thus, tipping the metaphorical scale in the Special Joint Committee's balancing act in favour of respect for autonomy.

An issue with emphasizing the principle of respect for autonomy is that doing so entails a failure to recognize children's unique agency (Carnevale, 2012). To say that children have a unique form of agency is to acknowledge that children can make judgments to a greater extent than adults typically think they can, and that they have skills pertaining to decision making (i.e. rationality, impartiality), even though these skills are not the same as those possessed by adults (Graf, 2015). In fact, as argued by Carnevale (2012), it is inappropriate to judge the skills that children have by comparing them to adults. These concepts are discussed in greater detail in Chapter Two.

In light of the issues identified above with limiting eligibility for MAID to mature minors, my investigation is not limited to mature minors; rather as previously indicated, I consider the extension of Bill C-14 to all minors. One reason why there is a need to engage in a broader exploration of this kind is because Canadian health care professionals are already increasingly being approached by parents for MAID for children that do not meet mature minor criteria (Davies, 2017).

When the principle of respect for autonomy is employed, there is an emphasis on the ability to provide informed consent, which can be regarded as contributing to the Special Joint Committee's limiting of Recommendation 6 to mature minors. However, the principle of justice also underlies this recommendation, and when this recommendation is limited to mature minors, the balance between these two principles is tipped in favour of the principle of autonomy. This tipping effect means that sufficient weight is not given to considerations of justice, such as the unfairness of considering one group eligible for MAID, while not giving the same consideration to another group despite an equal presence of morally significant intolerable suffering amongst members of both groups. Further, as will be discussed in Chapter Two, this emphasis on autonomy entails an overlooking of children's unique form of agency.

The limits of beneficence, non-maleficence, and ethics of care

The principle of beneficence

Beneficence refers to striving to "...create a positive balance of goods over inflicted harms" for another (Beauchamp, 2010, p.39), such as through the removal or minimization of existing harms. In the context of MAID, acting beneficently would entail health care professionals alleviating the intolerable suffering (i.e., the harm) of their patients; thus, tipping the balance in favour of goods or benefits. The Supreme Court of Canada implicitly invoked the principle of beneficence by indicating that it would be cruel to leave any patient to endure intolerable suffering (*Carter* v. *Canada*, 2015). The *Carter* (2015) ruling indicates,

> ...people who are grievously and irremediably ill cannot seek a physician's assistance in dying and may be condemned to a life of severe and intolerable suffering. A person facing this prospect has two options: she can take her own life prematurely, often by violent or dangerous means, or she can suffer until she dies from natural causes. This choice is cruel. (para. 1).

Guichon and colleagues (2017) also suggest the principle of beneficence as a possible ethical justification for the Special Joint Committee's Recommendation 6. The principle of beneficence is relevant the recommendation because this principle creates a moral obligation to relieve the harm of suffering (James, 1982) of the minor. Palliative care interventions could help achieve this outcome, while also keeping the patient alive; we do not intuitively think of death as being beneficial for persons in most circumstances. As such, palliative care interventions would fulfill the principle of beneficence. However, if palliative care interventions prove insufficient to alleviate the suffering of a particular minor, then death may be conceivable as being beneficial for that patient through alleviating their intolerable suffering.

The principle of non-maleficence

The principle of non-maleficence mandates that health care professionals avoid causing unnecessary harm (Beauchamp, 2010) (i.e., harm or risk above what is reasonably expected for a medical intervention). This principle is different from beneficence because acting beneficently often entails removing or minimizing harms that are already being experienced by a person, so as to maximize the person's well-being, whereas non-maleficence requires that one "avoid *causing* a harm" (Beauchamp, 2010, p. 38[8]). Although the principle of non-maleficence can be used to argue against an extension of MAID legislation to minors, if death through unnatural means is regarded as harm, it could also support the Special Joint Committee's recommendation if the future (continued) intolerable suffering of the minor is viewed as a failure to avoid unnecessary harm. In this sense, this principle is closely linked to the principle of beneficence in calling for a balancing of goods over harms (Beauchamp, 2010). By allowing minors to continue to experience intolerable suffering, health care professionals enable a current and future unnecessary harm to their patient(s).

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[8] emphasis added

Ethics of care framework

The ethics of care framework captures the Special Joint Committee's emphasis on alleviating suffering in their recommendation, as evidenced by statements such as, "...suffering is suffering, regardless of age" (Government of Canada, 2016a, p. 19), and "...a competent mature minor...should not be forced to endure intolerable suffering" (Government of Canada, 2016a, p. 21). Acting to eliminate pain and suffering by providing MAID meets the definition of caring outlined by the ethics of care framework, namely through Manning's (1998) concepts of "sympathetic understanding" (p. 98) and "response" (p. 99). Providing MAID to minors would require sympathetic acknowledgment by health care providers that the minor is experiencing intolerable suffering that is not adequately controlled by any available palliative techniques. Furthermore, it would require acknowledgement by health care providers that the minor has an interest in alleviating their intolerable suffering. This acknowledgement is what Manning (1998) would refer to as sympathetic understanding: appreciating the needs of the patient, as well as their interest(s). However, understanding that the minor is suffering is not enough; rather, it is important to respond to these needs and interests (Manning, 1998). Enabling provision of MAID to minors may be the appropriate response. It is in this manner that Manning's (1998) ethics of care components of sympathetic understanding and response may be applicable to the Special Joint Committee's recommendation.

Ethics of care differs from the principles of beneficence and non-maleficence because it is a relational form of ethics; it emphasizes the moral aspects of relations of caring (e.g., physician-patient relationship) (Held, 2006). An ethics of care entails a recognition by the clinician that the patient is in a role relationship with them (i.e., care provider and care recipient), but also as a fellow fragile human in need of assistance that he/she is able to provide

(Manning, 1998). This role relationship creates a moral obligation to engage in sympathetic understanding to identify what the patient wants and needs, and to act on this understanding (Manning, 1998).

The vulnerability counter-argument

The ethics of care framework and the principles of beneficence and non-maleficence can successfully be used to argue that MAID ought to be permissible in general. However, these principles and framework would not prevent the implementation of certain limits on its practice, such as restricting it to adults on the basis that most children lack capacity to make independent medical decisions, because they are not absolute. In order to rebut the implementation of such an autonomy-based limit on the practice of MAID, one could argue that children have a unique agency (James & Prout, 2015; Carnevale, 2012), such that applying the adult-centric concept of autonomy to them is inappropriate (Carnevale, 2012). However, it has been argued that recognizing children as unique agents does not eliminate their vulnerability (Van Praagh, 2005), and this may be the distinguishing factor between adults and minors that supports continued restriction of the availability of MAID to adults, even though it would be beneficent, non-maleficent, and caring towards minors as well.

The principle of justice

The principle of justice is not susceptible to the vulnerability counter-argument in the manner that the principles of beneficence and non-maleficence, and the ethics of care framework are. Deliberations of the Special Joint Committee leading up to the synthesis of their report (cf. Government of Canada, 2016b) suggest a justice argument as an additional justification for extending MAID legislation to minors, namely that even though children are vulnerable, they are morally equivalent to adults because they too can suffer intolerably, making it unfair not to extend eligibility for MAID to them. This additional justification invokes the principle of justice by proposing an argument of the form, *if X is available to Y, and Y=Z in some morally relevant way,*[9] *then X ought to be available to Z.* As indicated by Benoit Pelletier[10] in a meeting of the Special Joint Committee, "being vulnerable does not disqualify a person that is suffering intolerably from seeking an assisted death" (Government of Canada, 2016b, §1740). As stated in *Carter* (2015), the risk of abuse is "...part and parcel of our medical system" (para. 115). Being vulnerable need not entail disqualification because safeguards can be implemented to protect those that are vulnerable from these risks (*Carter* v. *Canada*, 2015). This statement by Pelletier demonstrates how the justice requirement of fair and equal provision of MAID, on the basis of intolerable suffering as a morally relevant factor of equivalency between adults and minors, is not outweighed by children's vulnerability.

Guichon et al. (2017) apply the principle of justice to the case of MAID for mature minors by making a comparison between two different groups of mature minors, as opposed to comparing minors and adults. They compare those mature minors who are suffering intolerably and can consent to withdrawal of life sustaining medical treatment, and mature minors who are not receiving this type of treatment, but are also experiencing intolerable suffering (Guichon et al., 2017). In doing so, they argue that it is unjust for the former group to be able to access a means of alleviating their intolerable suffering, whereas the latter cannot (Guichon et al., 2017). I question the limited scope of this argument because, if the morally significant suffering of the

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[9] This morally relevant equivalence may exist in the form of shared human dignity, to which suffering is an equal threat for all humans (Pullman, 2002), a shared ability to experience morally significant suffering, and/or sharing an interest in alleviating one's intolerable suffering.

[10] A lawyer in Quebec, professor in the Faculty of Law at the University of Ottawa, and member of the External Panel on Options for a Legislative Response to *Carter* v. *Canada* (Government of Canada, 2016b)

two different groups of mature minors is the important factor, then it is not clear why the argument has not been extended beyond these two groups, since suffering threatens all humans, be they adults or children. Moreover, as I argue in Chapter Two, thinking of most children's inability to meet the adult-centric concept of autonomy as a factor that prevents extension of the argument beyond two groups of mature minors to a comparison of adults and minors is incorrect. As previously mentioned, it entails a failure to acknowledge the unique agency of children; thus, inappropriately requiring that they meet adult-based standards of autonomy in order for their needs and interests to be taken seriously (Carnevale, 2012).

I conclude that the principle of justice provides the best ethical justification for the Special Joint Committee's concerns pertaining to the morally significant intolerable suffering of the minor, which are at the core of the Special Joint Committee's sixth recommendation; thus, justifying my identification of a key ethical problem addressed by this thesis as a matter of justice. The principle of respect for autonomy focuses on an adult-centric understanding of decision-making capacity which, as will be demonstrated in Chapter Two, is not best applied to children. Furthermore, whereas the principles of beneficence and non-maleficence, and the ethics of care can be used to argue for the permissibility of MAID, such arguments are subject to objection on the grounds that unlike adults, children are vulnerable, such that even if de-criminalizing MAID is supported by these principles and frameworks, the vulnerability of children can serve as grounds to limit the practice of MAID to adults. However, the principle of justice would call for equal eligibility for MAID for minors on the grounds that both adults and minors can suffer intolerably, and as discussed above, the vulnerability of minors does not outweigh this morally relevant factor.

Even if MAID legislation is extended to minors on the grounds of the principle of justice, there is potential for this ethical reasoning to be undermined in the practice of providing MAID to minors in two ways: a) false negative assessments of intolerable suffering, and b) false positive assessments of intolerable suffering. In the false negative scenario, parents/guardians' and/or health care professionals' accounts of the degree of a child's suffering are not accurate, and a child unfairly fails to receive MAID, even though both she, and those who do receive MAID, experience intolerable suffering which is morally significant. In the false positive scenario, parents/guardians and/or health care professionals inaccurately deem the child to be suffering intolerably; thus, resulting in an unjustified violation of the child's right to life through MAID. Inaccurate assessment of intolerable suffering could result in inadequate determination of whether MAID is in the minor's medical best interest, which raises concern about justice in the context of MAID for minors, and this is the main ethical problem addressed in this thesis.

Chapter 2: Children's Agency & Children's Voices

Introduction

The theoretical construct of children's agency is used methodologically in this thesis to provide a conceptual framework to understand the significance of children's experiences and perspectives, and to rebut the requirement that eligibility for MAID be based on a minor's capacity for autonomy. Agency is represented through children's voices in the literal sense, and with 'voice' serving as a metaphor for children's perspectives (James, 2007). This chapter describes the children's agency framework, and demonstrates that there are moral and epistemic reasons to prefer it over the dominant discourse in pediatric health care derived from the autonomy principle. The chapter begins with an exposition of the conventional way of thinking about children in health care and in law that uses the principle of autonomy, followed by an exposition of the children's agency framework as operationalized through the construct of voice. The chapter ends with an argument in favour of the latter framework over the conventional way of thinking.

The 'Autonomy Model'

The dominant account in law and health care regarding the ability to participate in medical decision making is what I refer to in this thesis as the 'autonomy model'. It is important to note that this is not an actual 'model', but rather a conventional way of thinking in law and health care. Autonomy (in the context of health care) refers to an individual's capacity to make independent, voluntary, informed decisions for oneself (Beauchamp, 2010). It presupposes that one comprehends the nature of one's condition, and the risks and benefits of available treatment options (Beauchamp, 2010). Adults are presumed to be autonomous and meet the required threshold of capacity for consent (Kleinig, 2013). Most children are not regarded as meeting the threshold of capacity to consent to medical treatment (Harrison, 2016) because, as is argued using evidence from developmental psychology, some cognitive skills or traits are considered to be absent in children as a result of their position in the early stages of the cognitive developmental trajectory (Fortin, 2009a).

The Children's Agency Framework

Background

The 'children's agency' framework comes from the New Sociology of Childhood literature dating back to the early 1970s (Prout, 2003). This thinking follows a shift towards individualization in Western society, which resulted in children being viewed as individual persons, rather than the property of adults (Prout, 2003). Taking childhood to be a social construct, rather than being bound to biological immaturity, this framework views children as actively contributing to the construction of their own social lives (James & Prout, 2015). As a result, it argues that children should be regarded as agents (James & Prout, 2015). Thinking of children as agents means regarding and treating them as social (Graf, 2015) and moral subjects, rather than as passive objects (Carnevale, 2012).

The children's agency framework refrains from an emphasis on defining children as "becomings" (Uprichard, 2008, p. 303), which entails viewing them as 'not quite' adults, as progressing towards the stage of adulthood wherein they will be considered independent rational beings (Graf, 2015). The children's agency framework draws attention to defining children as "beings" (p. 303), namely recognizing the child, here and now, as an agent who is active in contributing to constructing her childhood (Uprichard, 2008), or in Kantian terms, as ends in themselves (Arneil, 2002). The former conceptualization of children is future oriented, and does not place value on children qua children (Uprichard, 2008). When they are defined primarily as 'becomings', children's worth is based on their future adult selves[11] (Uprichard, 2008). Furthermore, by treating capacity as a hallmark of adulthood, this definition treats children as not having any competence in the health care and legal contexts; thus, this approach fails to give recognition to children's agency (Uprichard, 2008).

Having agency is not the same as having autonomy. To say that children are agents is to acknowledge that children can make judgments to a greater extent than law and those in health care typically think they can, and that they have skills pertaining to decision-making competency[12] (i.e. rationality, impartiality), even though these skills may not meet the required adult threshold to make independent decisions (Graf, 2015). In recognizing children as agents, it is important to make room (alongside parents/guardians) for children to participate in discussions pertaining to matters affecting them (Prout, 2003). Even though children may not have the same cognitive capacities and ways of reasoning as adults (i.e., those that would enable those in health care and law to consider them autonomous), they can be seen to have social (Graf, 2015) and moral agency (Carnevale, 2012). Having social and moral agency means being an active

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[11] It is important to note that the children's agency framework does not ignore the fact that children are in a process of growing into adults, and that this process is an important characteristic of childhood (Uprichard, 2008).

[12] 'Competency' is a legal term referring to the presence of relevant characteristics (required under the law) within an individual to engage in a certain activity (Leo, 1999).

contributor to the construction of one's social world, having and fulfilling socially-ascribed responsibilities within the social contexts in which one is embedded, being able to defend one's own point of view and express wishes, and according to Frankel's (2012) definition of moral agency (as cited in Graf, 2015), being able to understand and negotiate complex moral issues in one's own life and in interactions with others (Graf, 2015). In the health care context, this agency exists in the form of children being able to speak for themselves, and engage with health knowledge and skills as part of medical decision making (Montreuil & Carnevale, 2016), even though they may not have the capacity to independently make an informed, voluntary medical decision. Children have agential capacities that are different from adults' autonomous capacities, but this does not mean that they are necessarily of low quality or unworthy of being recognized (Terry & Campbell, 2001). As such, use of the children's agency framework in this thesis justifies the departure that I have made from Recommendation 6 of the Special Joint Committee by focusing on a possible extension of MAID to all minors, as opposed to only mature minors.

As agents, children have their own points of view on the world; they are not just silent witnesses (James, 2007). Children's perspectives consist of how they each experience the world, what matters to them (James, 2007), and judgments that they make using the agential capacity they have. These perspectives are meaningful because they are unique (Carnevale, 2012), providing another lens through which to view and grasp the complexity of a situation, allowing for recognition of problems that may have otherwise been missed, and influencing responses to a situation (Sherwin, 1999). Studies have been conducted by social scientists presenting children's voices, revealing what is important to children on topics such as bullying, racism, social relationships, accounts of their daily experiences at home and at school, and even their thoughts on mental health issues (James, 2007). As such, the idea that children have distinct perspectives is supported by empirical evidence.

Children's perspectives ought not be judged based on how much they resemble adults' perspectives (i.e., adults in a similar situation, or parents trying to put themselves in the child's shoes) (Carnevale, 2012). The feminist philosopher, Carol Gilligan (1982), argued that it is important to take women's differing responses to ethical scenarios to be thoughtful and sophisticated in their own right, rather than judging them based on male-centric views of human morality. Gilligan (1982) disagreed with Kohlberg's conclusion that women lack the ability for adequate moral reasoning simply because their responses to moral scenarios in his experiment differed from those of men. Parallels can be drawn to the case of children in terms of recognizing their distinct views, rather than dismissing them as expressions of immaturity from under developed versions of adults (Carnevale, 2012).

For example, siblings between the ages of five and nineteen have been observed to express outrage over the attention their parents/guardians give to their seriously ill or deceased sibling(s) (Carnevale, 2012). Although parents/guardians may not agree with this expression of outrage, this outrage expresses the child's own concepts of right and wrong, and according to the children's agency framework, should not be judged based on comparison to adults' conceptions of right and wrong (Carnevale, 2012).

Another example of the unique perspectives of children has been provided by Johansson (2011) who presents a story from a Swedish children's picture book, *Var ar min Syster?* (*Where is my sister?*). In the picture book, an animal child is telling an adult animal about things his sister told him (Johansson, 2011). The sister's argument about flying amongst the clouds in the story does not follow adult logic; however, it demonstrates a way of reasoning that is unique to the child (Johansson, 2011). To evaluate what children communicate based on how closely it resembles what a rational adult would say is to ignore this uniqueness.

Children's voices

The concept of 'children's voices' is a metaphorical representation of children's unique perspectives. It is through listening for such 'voices' that we can understand what these perspectives are (Prout, 2003). A literal definition of 'voice' is communication from the child, through words, illustrations, actions, assistive devices and/or silence. As a metaphor, 'voice' is a representation of a child's experience and perspective; thus, it provides those who receive the communication —through listening, watching, being present— with some understanding of the child's experience.

In this thesis, I use the term 'voice' in both the literal and metaphorical senses. To distinguish, I will use 'literal voice' and voice. In most cases, the metaphoric representation subsumes the literal; thus, distinctions will not be made in those cases. It is important to note that children are not a homogenous group; thus, there is no singular voice that can be attributed to all children (Smart, 2002). Rather, there are multiple unique voices across individual children (Smart, 2002). Whereas the singular phrases 'the child's voice' or 'the voice of the child' are used most commonly in the literature, some writers use the term or phrase 'children's voices' to acknowledge this multiplicity, as is the case in this thesis. The account of children's voices employed in this thesis is relational, recognizing the embeddedness of children within social contexts[13] (Meloni, Vanthuyne & Rousseau, 2015), such as the family unit. As such, whenever the construct of children's voices is used in this thesis, it is acknowledging the experiences and perspectives of children as being involved in and constructed from a co-influencing with the experiences and perspectives of others within these social contexts (Meloni, Vanthuyne & Rousseau, 2015).

Silence in the context of voice

Listening to children's voices includes thinking of silence, not as non-response, but as a form of communication in itself, and being attentive to when and how children make use of silence (Lewis, 2010; Spyrou, 2016). Silence may be interpreted as non-response; however, both adults and children can manipulate silence or pauses within a dialogue for their own purposes (Lewis, 2010). For example, adults can use silence to put pressure on children, or children may use silence to take time to think of the speaker's intentions, or think about their own views (Lewis, 2010). When analyzed in the context of a particular dialogue or interaction, a child's silence can provide useful information, such as elucidating the impact of power dynamics within the interaction, or conveying emotions such as discomfort or embarrassment (Lewis, 2010).

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[13] Although adults are also embedded within social contexts, children are especially regarded by society as socially embedded. Children are regarded in this way because agency is not the same as autonomy (Carnevale, Campbell, Collin-Vézina & Macdonald, 2015), which means that they cannot be considered completely self-sufficient. Children are more reliant on the networks within the social contexts in which they are embedded to meet their daily needs and to navigate social contexts, such as the health care system. This strong social embeddedness of children is important to acknowledge so as to adequately recognize the relational nature of children's voices.

Voice and non-verbal communication

The construct of children's voices may appear exclusionary towards those who make use of non-verbal forms of communication, such as children with disabilities, by alluding to a privileging of verbalization (Komulainen, 2007; Tisdall, 2012) when considered in its literal sense. In the context of MAID, it is important to consider that children with grievous and irremediable medical conditions might have limited ability to communicate verbally as a result of an illness or medical procedure (e.g., tracheotomy, mechanical ventilation) that impacts the ability of the child to produce oral speech. Irreversible decline might reduce a child's energy, and/or the child might have a cognitive or language impairment that makes it difficult for them to communicate verbally. Also, young children (i.e., neonates and infants)[14] who have not yet developed speech and language skills cannot provide a verbal account of anything (Freitag, 2015). In recognition of this possibility, the literal definition of children's voices employed in this thesis is not limited to verbal communication. Thus, eliciting children's 'literal voices' involves being attentive to all of a child's modes of communication, whether in the form of writing or illustration, body language, communication through assistive devices, silence, and other non-verbal methods of communication.

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[14] This group is important to consider in the context of MAID because the Canadian Pediatric Society's survey of requests for MAID for minors revealed a significant amount of explicit requests for MAID for neonates and infants under one year of age (Davies, 2017).

Making a Case for the Children's Agency Framework

Issues with the 'autonomy model'

Under the 'autonomy model', in order for children's views and decisions to be considered worthy of recognition in law and the health care context, they must meet an adult-centric threshold of capacity (Driggs, 2001; Lemmens, 2009). Only those determined to have capacity comparable to adults are considered capable of making treatment decisions, such as refusing life-saving treatment (Lemmens, 2009). Thus, the requisite criterion for involvement in decision making is, to put it simply, similarity to adults.

The 'autonomy model' would require that children demonstrate an understanding of death and dying that is similar to that of adults in order to be involved in decision making pertaining to MAID. There is empirical evidence suggesting that children's capacity can be similar to that of adults in some cases. Sourkes' (1995) work indicates that young children's (age ten and younger) expressions of anticipatory grief demonstrate an understanding of death. Children with personal experiences of life-threatening illness or direct experience of the death of a loved one have a better understanding of death (including their own susceptibility to it) than age-matched peers without such experiences (Kanyon, 2001). According to Bates & Kearney (2015), partial understanding of death can be seen in children between the ages of five and seven, with more adult-like understanding emerging around age's ten to twelve. This evidence shows that some children could be considered capable of engaging in the medical decision-making process under the autonomy model. In Canada (except Quebec), this recognition of competency would be achieved through deeming the child a mature minor.

In theory, mature minor designation is open to children of all ages (under the age of eighteen) as long as they demonstrate sufficient maturity, and have sufficient understanding of their condition(s) and available treatment options to make a well-informed, voluntary medical decision (Driggs, 2001). What is 'sufficient'? Based on my review of the literature, I believe that the term 'sufficient' implicitly refers to a level of possession of the relevant trait(s) akin to those typically seen in adults. One reason I have this belief is the interchangeable use of the terms 'mature minor' and 'adolescents' or 'youth' in the literature (cf. Hendrick, 2010; Fortin, 2009b; Guichon et al., 2017). Further, since the concept of autonomy is adult-centric, such that children are being compared to adults, older children who are biologically (i.e., cognitive development) closer to adulthood are more likely to meet the expectations of this model and the concept of a mature minor, as exemplified by Bates and Kearney's (2015) work, and Fortin's (2009a) exposition of research evidence on the developmental trajectory of cognitive skills for decision-making. Thus, the autonomy model is problematic in regards to unfairly favouring adolescents as mature minors.

The autonomy model also fails to acknowledge that cognitive capacities do not completely map on to competence. Full development of one's cognitive capacities in later stages of childhood (i.e., adolescence) does not ensure mature judgment (Fortin, 2009a). For example, adolescence is a period of life known for experimentation and rebellious and risk-taking behaviour, such as trying illegal substances. Mature judgment is influenced by context (i.e., family environment), and it requires emotional and social stability (Fortin, 2009a). Lack of sufficient emotional and social stability in the adolescent years due to social and emotional change and transition can result in the absence of mature judgment in adolescence, even though the adolescent has achieved a neuropsychological and cognitive level of development similar to adults (Fortin, 2009a).

Reasons for adopting the children's agency framework

There are both moral and epistemic reasons for adopting the children's agency framework over the autonomy model. The moral reason is that children's perspectives are important because children are moral subjects, and to ignore their accounts of their experiences and perspectives is to risk their moral objectification (Carnevale, 2012). Those using the autonomy model take the experiences of individual children and reduce them to expressions of immaturity (Carnevale, 2012). This reduction of the children's expressions is demonstrated in medical encounters between health care professionals and children with chronic pain. Carter (2002) provides an excerpt from the diary of a child with chronic abdominal pain who was enrolled in her study:

> "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" (p. 34).

To ignore children's own accounts of their suffering experience, such as by not taking seriously a child's claims that her suffering is intolerable when the child believes it is truly needed, would be a moral harm. Similarly, to not give due weight to a child's claims that her suffering is not intolerable to her, rather attributing greater credibility to of parental/guardian accounts of the child's suffering, fails to respect the child as a person. The children's agency framework does a better job than the autonomy model of giving recognition to the process of socialization that childhood entails, rather than focusing too narrowly on the outcome (i.e., becoming an adult) (James & Prout, 2015). In drawing attention to the process, the framework allows for an acknowledgment of children as agents (James & Prout, 2015) or beings so as to avoid objectifying them.

The epistemic reason for adopting the children's agency framework is that sometimes clinicians' own observations and assessments are not enough to understand a child's condition; clinician's may need the child's insight (Dedding, Reis, Wolf & Hardon, 2015). The same can be said for parent/guardians' observations and assessments. Children's perspectives must be elicited especially because sometimes adults can make the wrong assumptions about what a child is experiencing (Carnevale et al., 2015). In the context of MAID for minors, it may similarly be important to access a child's account of their own unique experience to understand whether she is suffering intolerably. Wrong assumptions about whether a child is suffering intolerably can, in combination with other considerations, create the risk of wrongfully refusing MAID to a minor, while others who, like the minor, are also in a morally significant state of suffering are able to receive it. Alternatively, incorrect assessment of intolerable suffering can result in wrongfully providing MAID, resulting in an unjustified death.

This chapter has outlined the moral and epistemic reasons to prefer the children's agency framework, as operationalized through children's voices, over the autonomy model. The implications of accepting the children's agency framework in the context of MAID would be to enable considerations of extending MAID legislation beyond mature minors, and making room for children to participate in discussions pertaining to MAID. The latter would entail eliciting, being attentive to, and giving due weight to, a child's account of her suffering experience to determine if she is suffering intolerably, factoring into her eligibility for MAID. Having rebutted the autonomy model in the current chapter, I apply the children's agency framework in Chapter Three to engage in a discussion of how incorporating children's voices maybe useful for assessing intolerable suffering to fulfill the principle of justice in the context of MAID for minors.

Chapter 3: Children's Voices in Assessing Intolerable Suffering

Introduction

This chapter applies the children's agency framework in the context of MAID for minors by exploring how incorporating children's voices may be useful for assessing intolerable suffering, so as to avoid injustice due to inaccurate determinations of eligibility for MAID. I begin with the claim that there is a subjective component to intolerable suffering that makes it important to consider incorporating children's voices. The notion that incorporating children's voices might be important to assess the presence of intolerable suffering in a minor derives from the philosophical concept of first-person authority, which attributes authenticity to first person accounts of experience (Davidson, 1984; Falvey, 2000; Bagnoli, 2007). If the value of eliciting children's voices is presumed to be that they provide an authentic account of children's experiences, then some argue that this authenticity can be diminished through adult interpretations of children's voices (Terry & Campbell, 2001; James, 2007; Komulainen, 2007). Responses to this concern from the literature are presented, providing an understanding of children's voices as situated within the context of dialogue, rather than belonging to a single individual, and as necessarily messy, and multi-layered.

Is Intolerable Suffering Subjective?

What is subjectivity?

Use of the term 'subjectivity' in this chapter refers to an "experienced interiority" (de Quincey, 2000, p. 137). Experienced interiority refers to the internal perspective that one has of one's experience, namely what it feels like from within (de Quincey, 2000). Given this definition, a subjective experience is that wherein there is something that it is like for the person that is having the experience to have it (de Quincey, 2000). This internal perspective is different from another's understanding of that experience (de Quincey, 2000) which indicates that it cannot be fully grasped by others. This definition does not treat subjective experiences as *wholly* private or isolated. Further, this definition does not suggest that no other individual can ever know or understand *any* aspect of the relevant experience. I have chosen this definition because, as will become clearer below, it is able to withstand arguments that the experience of suffering can be shared between persons (i.e., intersubjectivity), and perceived by a third-person.

The subjective and intersubjective nature of suffering

The subjectivity of suffering

According to Cassell (2004), human suffering pertains to suffering of persons, and in accordance with mind-body dualism, is situated in the mind. Therefore, suffering is a mental phenomenon. Cassell (2004) argues that since mental phenomena cannot be objectively measured or assessed, suffering cannot be measured objectively. Whereas suffering might be observable through facial, vocal, and physiological cues given by the sufferer, these cues do not allow for an accurate assessment of the intensity or intolerability of a person's suffering, or how it matters to them (Carnevale, 2009). Suffering is related to the values of the sufferer through having an impact on the things that matter to that person (Carnevale, 2009). A person's condition impedes them from acting in line with their values (i.e., by doing things that they value), and this inability to do the things that one values is what causes suffering (Carnevale, 2009). For example, person α has a disease that causes reduced mobility, which means that person α can no longer be completely independent, which is something they really valued. As a result, person α is suffering. How one's suffering bears on the things that matter to one will vary from person to person, such that how one's suffering matters to oneself, and what it is like for the person experiencing it, is the experienced interiority that can only be fully grasped by that person (Carnevale, 2009); thus, demonstrating the subjectivity of suffering.

Suffering is not synonymous with pain (Cassell, 2004). Physical pain can be a major cause of suffering in humans (Cassell, 2004); however, pain and suffering should not be conflated because pain can exist without suffering, and there are forms of suffering (e.g., existential suffering) that do not involve physical pain. Cassell (2004) uses the example of childbirth to differentiate between pain and suffering. Childbirth entails a significant amount of pain, and can be significantly distressing to the woman giving birth; however, the experience of childbirth is not commonly considered suffering (Cassell, 2004). Pain can also be considered subjective like suffering; however, it manifests in ways that are more amenable to objective measurement, whereas suffering is less accessible. As a result, it is difficult to know that suffering exists, and the degree of the suffering, without acquiring a personal, subjective account of it.

The intersubjectivity of suffering

Suffering need not be only subjective; some authors also describe suffering as intersubjective. Two accounts of this intersubjectivity are particularly compelling. De Quincey (2000) provides both a "weak-experiential" (p.138) and "strong-experiential" (p.138) definition of intersubjectivity. Kimsma (2012) provides an account of the intersubjectivity of suffering as a function of a reciprocal relationship between clinician and patient.

In de Quincey's weak-experiential definition, subjectivity is viewed as ontologically prior to intersubjectivity, in that the 'inter' prefix refers to a reciprocal relation among two individual subjective experiences (de Quincey, 2000). The strong-experiential definition of intersubjectivity refers to a "mutual co-arising" (p. 138) of subjects and their experiences from a network of relations from which individual subjects come into being (de Quincey, 2000). Thus, the strong-experiential meaning describes intersubjectivity as ontologically prior to individual subjectivity (de Quincey, 2000). De Quincey's (2000) strong-experiential definition of intersubjectivity presents a dramatic shift from conventional Western philosophical and scientific thinking. It is a dramatic shift because we tend to think that in order for a relation to exist, there must already be two independent entities to relate with one another (de Quincey, 2000), which aligns with the weak-experiential definition. Regardless of which of these definitions is employed, subjectivity (i.e., experienced interiority) is recognized by and/or implicit in both (de Quincey, 2000), such that saying that suffering is intersubjective does not eliminate the possibility of viewing it as subjective as well.

Kimsma's (2012) intersubjective account of suffering defines suffering as an experience that human beings share, such that a patient's suffering experience is not isolated from others, but rather other persons (e.g., clinicians) are able to engage in the patient's suffering as well (Kimsma, 2012). For example, clinicians can engage in a "deep reciprocal [clinician]-patient relationship" (p. 333), wherein the suffering of the patient is a function of that reciprocal relationship (Kimsma, 2012). Since suffering is shared by clinician and patient within the context of this relationship, clinicians can access and understand the suffering of their patient(s), enabling them to co-establish with the patient that suffering exists, as well as the extent of that suffering (Kimsma, 2012).

In describing suffering as intersubjective, Kimsma does not suggest that suffering is not subjective in the sense that I have defined this term at the beginning of this chapter. First, Kimsma conceptualizes the term 'subjective' more strongly than I have defined it. He thinks of the term 'subjective' as wholly private, meaning that the relevant experience is isolated and unshared (Kimsma, 2012). Thus, the conflict that Kimsma (2012) presents between thinking of suffering as subjective and treating suffering as intersubjective does not exist when the term 'subjective' is defined in the way that I have defined it. Second, Kimsma's account does not deny that there is an experienced interiority to suffering, allowing that there is some level of subjectivity (as I have defined it) to suffering. This granting of some level of subjectivity in suffering is evidenced in Kimsma's (2012) description of intersubjective assessment of suffering as including the patient's own account of their suffering experience, which the patient presents in a dialogue with her clinician. Kimsma (2012) acknowledges that the first-person, qualitative description of the suffering experience will differ across individuals, and that this makes it important to incorporate when drawing an intersubjective conclusion regarding the suffering of the patient. Thus, much like de Quincey's (2000) definitions of intersubjectivity, Kimsma's account leaves room for experiences such as suffering to be regarded as both intersubjective and subjective.

This discussion on suffering as an intersubjective experience suggests that whereas it is important to acknowledge that a person's suffering experience can be shared and mediated by other people or factors within a given social context, this does not eliminate the subjective aspect of suffering. Even though others can know how I feel, there is a way in which I know my own feelings (i.e., a first-personal, experiential understanding) that is unique to me (Wijsbek, 2012). For example, children are embedded within the context of a family environment, and members of the child's family (such as the parents/guardians) can, to some extent, be aware of the child's suffering. This awareness can in turn cause suffering or distress in the parents/guardians, which can create a feedback loop that increases the child's own distress. Thus, the child's suffering is not isolated from those within her social context. Yet there is something that it is like for the child to be experiencing her suffering, and its meaning, of which only she can provide an account. This example suggests that, in the context of MAID for minors, it would be important to communicate with children to more fully grasp their suffering experience, so as to accurately determine whether they meet the requirement of suffering intolerably to be eligible for MAID.

The subjectivity of intolerability

Although much of the discussion thus far has dealt with the concept of suffering, it is important to note that what matters in the context of MAID is not so much the presence of enduring suffering, but the *intolerability* of said suffering (Wijsbek, 2012). Intolerability is important because it is the factor that sanctions action, namely MAID, which would otherwise be forbidden (Wijsbek, 2012). As a result, it is important to understand whether intolerability is subjective (as opposed to being objective, or a matter of social norms, for example) in order to know how best to determine whether a child's suffering is truly intolerable, and whether the child could, in principle, be eligible for MAID.

According to Wijsbek (2012), a Dutch scholar, whereas suffering may be subjective, the intolerability of suffering is normative, with the term 'normative' serving as an adjective meaning 'a matter of social norms'. What it means for the intolerability of suffering to be normative is that instead of 'intolerable' meaning, "I can't bear this any longer" (p.329), it is socially determined in particular contexts. For Wijsbek (2012), this translated as, "We, the Dutch political community, don't require you to bear this any longer" (p.329). Thus, Wijsbek (2012) argues, the provision of MAID is supported in cases in which a patient is in a state that is agreed upon by society to meet the standard. I do not wish to deny that intolerability could be a matter of social norms, but I want to argue that even if society determines the standard of intolerability, this standard or threshold would be informed by subjective accounts of the intolerability of suffering. In other words, the *subjectivity of intolerability* serves as a necessary foundation for society's norms of intolerability.

Consider the examples of cancer and ALS provided by Wijsbek:

> ...there is no real work to do for the criterion in standard cases where the patient is suffering from ALS or incurable cancer accompanied by intractable pains and extreme fatigue...90% of the Dutch population is of the opinion that euthanasia is justifiable in such cases (Wijsbek, 2012, p.330).

Even if a society has determined that the suffering of a patient with these conditions and accompanying symptoms is of the intolerable kind, there would need to be some sort of a basis for making this determination, without which the norm would not be justified. I argue that this basis is the sufferer's own subjective determination of intolerability. I further argue that the identification of a pattern of these subjective assessments across individuals is what allows society to acknowledge that suffering in these cases can be intolerable, and hence to adopt a social norm. Note that I am using the words 'can be' in recognition that not all cases of a condition are exactly the same, and because there are many other (non-physiological) factors that can contribute to a patient's suffering experience.

Consider the following thought experiment in support of my argument. Imagine that there is a patient who is in condition *x,* a disease that has never been heard of before. How would we, as members of Canadian society, know whether condition *x* is associated with intolerable suffering? Some may suggest that observers can be attuned to the patient's suffering, but as I have argued earlier, the accounts of others cannot fully account for an individual's subjective experience of suffering. Some might suggest that it is possible to tell that condition *x* entails intolerable suffering based on the severity of particular symptoms and/or losses of function (if any) caused by the novel disease; however, this line of reasoning is vulnerable to counter argument on the basis of the disability paradox[15]. Also, intolerable suffering need not be caused by the disease itself, but by a constellation of factors associated with having the disease (i.e., inability to engage in meaningful activities, loss of identity, and negative impact on loved ones). Ultimately, unless the patient says that they are suffering intolerably, we would not know that to

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[15] The term 'disability paradox' refers to the discrepancy in how external observers rate the quality of life of those with disability, and how those with disability rate their own quality of life (Albrecht & Devlieger, 1999). Whereas the former group tends to hold a negative bias towards disabled persons, causing them to rate the quality of life of the latter group as low, disabled persons frequently report their own quality of life as good or excellent (Albrecht & Devlieger, 1999).

be the case. Thus, society initially requires a subjective assessment of intolerable suffering by the patient with condition *x*.

Now, imagine that multiple verified cases of the novel disease emerge across the country within a short period of time following the initial case mentioned above. Since it is possible that the first patient's suffering experience may be the result of circumstances specific to them, and no two instances of the same disease are the same, it should not be assumed that all of these other patients are suffering intolerably as well. A trend of subjective assessments of intolerable suffering by each new patient with condition *x* would allow us, as members of society, to establish that the suffering associated with being in condition *x*, as a result of the novel disease, can be generalized as being of the intolerable kind.

When subjective assessments of suffering present a pattern of intolerability, it is possible to establish the norm that suffering associated with condition *x* can be of the intolerable kind. The vague term 'condition *x*' could be replaced by any real condition (such as cancer or ALS with intractable pains and extreme fatigue (Wijsbek, 2012)) in the thought experiment to draw the same conclusion, while allowing that not all individuals in this condition will suffer intolerably. As a result, the thought experiment demonstrates that even if the intolerability of suffering can be a matter of social norms, it is subjective assessments of intolerable suffering that ground and justifies the social norm(s). This suggests that any test of intolerability is first and foremost subjective.

Understanding Subjective Phenomena through Children's Voices

Having argued that there is subjectivity to both dimensions of intolerable suffering (intolerability and suffering), I now provide an exposition of the link between this subjective phenomenon and employing the children's voice framework to assess intolerable suffering in the context of MAID for minors. The key underlying factor required to explain this link is the concept of first-person authority, which takes first-person avowals, such as children's own accounts of their suffering experience, to be the most authentic.

Subjective experience and first person authority

Generally, unless we know a person really well and know that they are lying, when someone expresses something about their beliefs, values, desires, or experiences, we as listeners tend to take it to be the truth (George, 1970). Listeners accept what the speaker says about herself because they attribute first-person authority to the speaker (Falvey, 2000). An utterance from someone with first-person authority does not require proof or evidence; rather it is accepted on the basis of the attribution of this authority (Christman, 2005).

First-person authority can be considered a form of epistemic authority, which consists of recognizing the individual as knowing them best, and being able to provide the most accurate account of their experiences (Christman, 2005). This epistemic authority is often attributed to privileged epistemic access, namely being aware of our own selves and mental states in a special way (Falvey, 2000). However, this notion of privileged epistemic access is highly contested because people can be mistaken about themselves and their mental states (Falvey, 2000). Another explanation for first-person authority as a form of epistemic authority is that knowing oneself, or more specifically, one's own mental states, best is the result of one's being the creator of those mental states (Bagnoli, 2007). To say that I have a special awareness of my own mental states is to say that I am merely a spectator of my mental states (Bagnoli, 2007). A spectator can only provide possible empirical, impersonal reasons for something, but when I have a particular mental state, I am able to provide personal justifying reason for my having the mental state; something which a mere spectator would not be able to do (Bagnoli, 2007). The reason why I am able to provide a justifying reason for my having the mental state is not that I have a special awareness of my mental states, but rather that I am the creator of my own mental states (Bagnoli, 2007). Thus, being the creator of one's own mental states is presented as a stronger reason for thinking that the first person knows their own mental states best (Bagnoli, 2007). A first-person avowal is authoritative because it is considered as close to the truth as it is possible to get (Falvey, 2000), or the best evidence of the truth, assuming that the person is sincere. Note that first-person authority is not absolute because, as previously mentioned, people can be wrong about themselves (Falvey, 2000). There are forms of self-deception to which we are sometimes subject, such as thinking that we can complete more tasks than there is time to complete.

Alternative explanations of the basis of first-person authority appeal to other characteristics such as the directness of first-person claims (Davidson, 1984). Seeing as one's knowledge of oneself can be mistaken, privileged access to knowledge about one's own experiences, perspective, and beliefs may not be sufficient for first person authority (Davidson, 1984). According to Davidson (1984), the directness of a first person claim is due to information about one's own experiences and perspective not requiring interpretation by oneself. Others would have to interpret a person's beliefs, desires, and/or perspective from their actions, words, and other cues before being able to ascribe them to the person (Davidson, 1984). Further, there is no guarantee that the others would interpret the person's experiences, perspective, or beliefs accurately (Davidson, 1984). For example, when I make the statement, "*I had a great day yesterday"*, I know exactly what I mean by this statement. However, in reading this statement, you are forced to interpret what I mean, such as what constitutes my conception of a 'great day'. Perhaps your understanding of this statement is that I had many exciting things happen to me yesterday; however, I know that what I mean by a 'great day' is a relatively uneventful and relaxing day. I do not need to think about or question what I mean by the statement, "*I had a great day yesterday"*. Since first-person avowals are not subject to interpretation by oneself before they are made, they are attributed special authority (Davidson, 1984).

When it comes to subjective phenomena, it is thought that the first person avowal will provide the most authentic[16] account of the experience, because the person experiencing the phenomenon is regarded as knowing best, for example, what it feels like to them, or how that experience matters to them (Falvey, 2000; Christman, 2005). Furthermore, first person avowals are thought to provide the most authentic account of a person's experience and/or perspective because of their directness, as described by Davidson (1984). As such, the epistemological rationale behind incorporating the child's own voice, which in its literal form, consists of first-person avowals, in considerations of a child's eligibility for MAID, appears to be getting the most 'authentic' account of the child's suffering experience in the two senses described above.

The Problem of Interpretation

In the pediatric health care setting, what children communicate is often subject to adult interpretation (James, 2007). Children's communications are subject to interpretation because

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[16] The term 'authentic' is being used to describe something as epistemically reliable, genuine, or closest to the truth.

parents/guardians often play an intermediary role between the young patient and their health care professional (Tates Kiek, 2003; Taylor, 2006), and/or due to health care professionals' attempts to understand what a child has communicated to them directly. Adults' interpretations of what children communicate raise concerns about the feasibility of acquiring a truly authentic account of the child's suffering experience (James, 2007; Komulainen, 2007).

Parents and/or guardians play a key role in clinical encounters between children and health care professionals. Often, parent/guardians' desire to be involved in treatment decisions regarding their child leads them to dominate conversations with health care professionals (Tates Kiek, 2003). Also, parents often serve as advocates for their children, providing an important mechanism through which children's voices can reach health care professionals (Taylor, 2006). Consider Taylor's (2006) example of her four-year-old daughter, Martha, who was diagnosed with leukemia. Martha expressed a desire to have her central venous catheter removed; it was being used for a monthly injection of a chemotherapy agent, and for regular blood tests (Taylor, 2006). She wanted to have the drug administered, and the blood tests done, in the manner that they were done prior to insertion of the catheter (Taylor, 2006). Martha expressed her desire and rationale to her mother, who communicated this information to the nurses responsible for Martha's care (Taylor, 2006). It was through the mother's advocacy, namely in making a case for her daughter's reasoning and approaching the appropriate health care staff, that removal of the catheter was accomplished (Taylor, 2006).

Whereas parents/guardians play an important role as advocates to help children's voices reach health care professionals (Taylor, 2006), this intermediary role means that what children communicate is subject to interpretation in a way that makes sense to adults (James, 2007). Interpretation is also present when children communicate with health care professionals directly.

This issue of interpretation is not about an intentional skewing of the meaning of a child's communication; rather it is about the influence of one's existing beliefs and biases on how the child's communication is understood. Interpretation potentially undermines the notion that children's voices, as constituted by first-person avowals, provide an authentic account of children's own experiences (James, 2007) because what adults claim to understand through children's voices may not exactly reflect what the child meant to convey. The potential for adult interpretation to weaken the seemingly direct relation between children's voices and their experiences suggests that it is not possible to be certain that an accurate understanding of a child's suffering experience has been acquired. Without an accurate understanding of whether the child is suffering intolerably, it would be difficult to determine whether provision of MAID is truly justified.

A more pronounced challenge exists with respect to children who primarily communicate through non-verbal methods. As discussed in the previous chapter, there is a high likelihood, given the conditions used to define a grievous and irremediable condition in MAID eligibility criteria, that many minors who would qualify for MAID would be in a state that prevents or makes it difficult for them to communicate verbally. Also, a recent survey conducted by the Canadian Pediatric Society on requests for MAID for minors revealed that over fifty percent of requests for MAID by parents on behalf of ninety-one children were for neonates and infants (Davies, 2017). Newborns and young infants cannot express their suffering through speech; however, they can do so through other means such as crying, movement, and reactions to feeding (Verhagen & Sauer, 2005).

In an observational study of interactions between staff and children, many of whom were disabled, researchers found that staff interpretations of children's non-verbal communications were ambiguous (Komulainen, 2007). For example, staff could never be sure, based on a child's communications, whether a child wanted the food items they provided until the child ate them (Komulainen, 2007). In fact, this ambiguity was seen as existing in all adult-child interactions, not just those that occurred with disabled children (Komulainen, 2007). Teachman and colleagues (2017) presented the case of children whose communication is mediated by assistive devices and support persons. Boggis (2011) presented concerns about the authenticity of accounts derived from children using a speech generating device because these devices are usually programmed by someone (usually adult) other than the user themselves. Boggis (2011) questioned whether the voice being elicited in interviews with a child using such a device is truly that of the child because what the child can communicate is limited by the language that adults have programmed into the device. Further, there is dispute in the literature pertaining to the ability of parents and/or health care professionals to interpret the degree of a newborn's suffering; some authors say that it is possible (i.e., Verhagen & Sauer, 2005), while others disagree (i.e., Kodish, 2008; Kon, 2009). Therefore, when children's voices are elicited, the possibility of ambiguous interpretation raises concerns that the understanding acquired of the child's suffering experience may not accurately reflect the child's actual experience.

The myth of an 'authentic voice'

The previous section seems to presuppose a conceptualization of 'voice' as existing as a pure, independent entity that belongs to a single person. However, this emphasis on an authentic form of voice has been contested (Mazzei, 2009; Spyrou, 2011; Teachman et al., 2017; Wyness, 2013). It may be misguided to think of children's voice as pure entities that are tarnished by the mediation of adults or technology because children's voices are never completely unmediated, just as there is no such thing as completely unmediated adult voices (Wyness, 2013). As such, asking that children's voices be able to provide a complete picture of a child's experiences is asking too much. It is impossible to grasp the essence of voice through people's verbal and non-verbal communications (Spyrou, 2011).

Children's voices are not unmediated because they are not isolated from the social contexts in which they are embedded, such as in their family stories, their social environments, and their relationships of trust (Meloni, Vanthuyne, Rousseau, 2015). Consider, for example, the case of Maria, a fourteen-year-old participant in research conducted by Meloni and colleagues (2015). In speaking to the interviewer, Maria's mother describes Maria as adapting well to moving to Canada (Meloni et al., 2015). Maria remained silent and shifted uncomfortably in her chair in response to her mom's statements, and avoided the interviewer's question when asked if she disagreed with her mother's description of her migration experience (Meloni et al., 2015). Maria's silence is meaningful in the context of her mother's presence (not outside of it), demonstrating how her life is closely dependent on the decisions made by the adults in her life, such as the decision to migrate to Canada in the first place (Meloni et al., 2015). Children's voices are shaped and constrained by the pre-existing knowledge, biases, and assumptions of listeners, and the contexts in which these voices are elicited (Komulainen, 2007).

Further, children's voices are never completely unmediated because, as per Russian philosopher and literary theorist, Bakhtin, voice is constructed and is situated within the context of a dialogue (Teachman et al., 2017). In this dialogue, the meaning of what is said is subject to interpretation by both parties, consisting of a co-construction of meaning (Teachman et al., 2017). For example, when you speak to your friend about how you feel, your friend interprets what you mean to say based on your words. If your friend misunderstands what you have tried to convey, then you can correct her understanding by presenting an example. Through this back and forth dialogue, both you and your friend work together to establish the meaning behind what you have said regarding how you feel. Seen with a dialogical lens, it is this co-constructed meaning that is 'voice' (Teachman et al., 2017). These co-constructed meanings are always dynamic, relational, and ambiguous (Murris, 2013), so a complete, authentic understanding of a child's suffering experience may not be feasible.

Not only is voice never completely unmediated, it is messy (i.e., not straightforward to make sense of), ambiguous, and multi-layered (Spyrou, 2011). Spyrou (2011) uses his interview with Greek-Cypriot children to demonstrate this messy, multi-layered nature of voice, and how the deeper layers of meaning in children's voices can be uncovered. In the interview, when Greek-Cypriot children were asked for their views on Turks and the situation in Cyprus, most Greek-Cypriot children described the Turks as evil and invaders (Spyrou, 2011). Whereas these initial opinions of the children were not necessarily less authentic or truthful, through spending more time speaking to the children, Spyrou (2011) was able to acquire a more detailed understanding of the children's views, namely that they were referring primarily to specific groups of Turks, such as those in government. To point to ambiguity in interpreting what children mean from what they communicate as a significant problem simply reveals a failure to recognize that voice does not exist in some pure, authentic form from which an understanding of children's experiences can be straightforwardly acquired (Komulainen, 2007). Rather, voice is ambiguous and difficult to unravel by nature, and this ambiguity is a limitation of voice that must be accepted (Spyrou, 2011).

Thinking of voice as necessarily mediated, messy, and multi-layered has significant implications for the usefulness of eliciting children's voices in order to assess whether intolerable suffering is present as part of determining the eligibility of a minor for MAID. The concept of first-person authority took the value of children's voices to be that they provide the most truthful and reliable understanding of a child's suffering experience; thus, enabling objections to the ability of children's voices to provide an authentic account of children's individual suffering experiences due to the problem of interpretation. This current chapter has demonstrated that these objections do not apply because the presumption that they rest on, namely that of an 'authentic voice' of the child (or adult), is false. Rather, voice is relational, complex by nature, and subject to interpretation even in adults. It may not be feasible to acquire a complete and authentic understanding of a child's suffering experience through her voice, but eliciting her voice still provides invaluable insight into the child's experiences and her individual perspective on those experiences. The question that remains to be answered is whether the understanding of children's suffering experiences that children's voices are able to provide to health care professionals is sufficient for the context of MAID for minors, which is the focus of the next chapter. Further, in the next chapter I address whether the issues associated with voice outlined in the current chapter are specific to the pediatric context.

Chapter 4: The Complexity of Children's Voices and Implications for the Context of MAID for Minors

Introduction

What the previous chapter has revealed is that the construct of voice is messy, multi-layered, and ambiguous by nature. As a result, it is not possible to get a complete picture of a child's perspective and experiences from what they communicate to others (Spyrou, 2011). However, this does not mean that children's voices are not important or meaningful. As demonstrated by Spyrou (2011) in his interviews with Greek-Cypriot children, it is possible to acquire some understanding of children's perspectives by eliciting their voices, as was the case for Spyrou in determining the children's views on the Turks. This information is not necessarily inauthentic, or false; it is a basic understanding of the layers of complexity that children's voices entail (Spyrou, 2011). Furthermore, it may not be possible to completely unravel the complexity of children's voices (Spyrou, 2011) in order to be able to say that the degree and extent of a child's suffering has been understood exactly (Carnevale, 2009). In the case of MAID for minors, the consequences of determining that a minor is eligible for MAID are significant. As a result, it is important to consider whether the limited understanding of a child's suffering experience that can be acquired through engaging in dialogue with them is enough when the stakes are so high.

Ethical and Policy Implications for Incorporating Children's Voices in MAID

The elicitation of children's own accounts of their suffering should not be abandoned for moral reasons. To abandon the elicitation of children's voices would be a moral harm because it would consist of failing to recognize children as ends in themselves, individuals with their own perspectives that are worthy of consideration (Carnevale, 2012). Also, even though it is not possible to acquire an authentic understanding of children's suffering experiences through their voices, voice is able to provide us with *some* valuable insight into those experiences. Striving for a pure, authentic voice would result in overlooking what children's voices do offer, which is the potential to increase understandings of the degree and extent of the child's suffering through their perspective (Mazzei, 2009), such as what it is like for them, and how it matters to or impacts them (Carnevale, 2009).

Whereas I agree that the ambiguity and complexity of voice makes it the case that chasing after an authentic version of voice is misguided, I differentiate between the notion of an authentic or true voice of the child and the truth of a child's experience. According to Alcoff (2009), there is no truth of a situation outside of that which is co-constructed in dialogue. I disagree with Alcoff's claim because I believe that there is a truth about the child's suffering experience, even though there is no one pure and authentic account of it, such that the meaning that is co-constructed in dialogue with a child can either be closely reflective of that truth or less so. The question that remains is whether the meaningful, yet humble understanding of this experience that can be acquired by eliciting children's voices is ethically sufficient for determining eligibility for MAID given that the stakes are so high. Note that by asking this question, I am not suggesting that children's voices need to prove that they are worthy of consideration; rather I am questioning the specific epistemological role that I hypothesized these voices as playing in the context of MAID for minors. This question remains to be answered.

Even with the ability to acquire some understanding of children's suffering through their voices, the presence of some degree of uncertainty means the risk of false determinations regarding the presence of intolerable suffering remains. This risk continues to exist due to challenges associated with working through the messiness and complexity of children's voices. Recall that in Chapter One, I argued that the principle of justice provides the best ethical justification for the Special Joint Committee's recommendation to extend MAID legislation. Then, in describing the ethical problem addressed in this thesis, I hypothesized that failure to incorporate children's voices in assessing intolerable suffering could lead to children not acquiring MAID due to an incorrect eligibility assessment, even though both they and others who are deemed eligible for MAID experience morally significant intolerable suffering. This individual case would violate the principle of justice; thus, undermining the motivating ethical reason for extending MAID legislation to minors. Now, it is not clear whether the understanding of a child's suffering experience that could be acquired through a child's voice would be sufficient to avoid an incorrect assessment of intolerable suffering, and thus, a violation of the principle of justice. As a result, it is essential to think carefully about whether the meaningful, yet humble and potentially ambivalent understanding of a child's suffering that could be acquired through eliciting children's voices is enough in the life and death scenario of MAID.

Although the aforementioned ethical concern exists, it does not automatically translate into a policy conclusion because, although the moral and legal realms often intertwine, they are distinct. Even when presented with the ethical concern of a slippery slope resulting from the de-criminalization of MAID, the judgment in *Carter* (2015) focused on safeguards as determinant of the legal permissibility of MAID in Canada, and allowed the decriminalization. In doing so, the *Carter* ruling demonstrated how an ethical conclusion can factor into, but need not be the final arbiter in, the making of policy or law. Without the possibility of implementing safeguards against inaccurate assessments of intolerable suffering, caused by ambiguity or uncertainty in the understanding of a child's suffering experience through their voice, it is not clear that this understanding would be sufficient from a legal or policy perspective. It is important to consider whether the ambiguity and uncertainty that is part of eliciting children's voices can be mitigated through the use of safeguards; I discuss two possibilities below.

One practical response or safeguard may be that health care professionals ought not to put too much weight on the intolerable suffering criterion when determining the eligibility of a minor for MAID. Perhaps health care professionals should focus more on the other eligibility criteria pertaining to a grievous and irremediable medical condition, such as an incurable illness, disease, or disability; an advanced state of irreversible decline; and a reasonably foreseeable natural death. A foreseeable problem with this suggestion is that the presence of intolerable suffering carries significant moral weight in justifying MAID (Wijsbek, 2012). As already discussed in Chapter One, this significant moral weight is evident in the Supreme Court of Canada's ruling in *Carter*, as well as, in the reasons provided by the Special Joint Committee for Physician Assisted Dying (2016a) in their report. Even if other eligibility criteria are given greater consideration, the significance of the intolerable suffering criterion cannot be ignored.

Another possible safeguard in response to the uncertainty is having health care professionals practice reflexivity in eliciting children's voices (Komulainen, 2007; Spyrou, 2011). Reflexivity would entail accepting the complexity of voice, and trying to work with it by being critically aware of the social and cultural ideologies that might be influencing the way that children's voices are both presented and understood (Spyrou, 2011). Spyrou (2011) calls for an awareness of the discourses that inform children's voices in trying to understand their perspectives, as well as an awareness of the discourses one brings to the table in engaging with children and analyzing or interpreting their communications. Reflexivity involves reflecting on what one hears, what one expects to hear, and how the latter might be influencing the former (Komulainen, 2007). What might reflexivity look like in the context of eliciting children's voices in a clinical setting? At the very least it would involve a questioning of one's own personal values and biases when engaging in dialogue with children (Timmins, 2006). The types of questions that health care professionals may want to ask themselves in practicing reflexivity may include questioning how they have come to know what they think they know about the patient and the situation, and/or whether or not there is an alternative way of understanding what has been communicated to them by the child (D'Cruz, Gillingham & Mendelez, 2007). Further, an awareness of some of the literature on children's agency and the mediated, multi-layered nature of voice (e.g., Prout, 2003; Komulainen, 2007; and Spyrou, 2011) would help health care professionals in this endeavor. Even though a reflexive approach could help with the issue of uncertainty in understanding children's voices, completely eliminating any uncertainty is impossible; thus, it would still not be feasible to claim that an authentic and exact understanding of the child's suffering experience has been acquired.

The uncertainty entailed in the information that can be derived through voice is applicable to any utterance or dialogue (Teachman et al., 2017), not just with children. Even if a clinician were to engage in dialogue with an adult patient pertaining to his/her suffering experience and eligibility for MAID, there would be some degree of uncertainty in the meaning that is co-constructed. Yet, we tend not to be overly concerned about this uncertainty when dealing with adult patients, so why the concern over uncertainty or ambiguity when eliciting children's voices? It is important to note that the issue is not so much about accepting that uncertainty exists, but rather whether it would be ethically appropriate to rely on this uncertainty in such a high stakes decision (i.e., MAID for minors). Everyone is potentially vulnerable in the context of MAID, including adults (Government of Canada, 2016a). Since children are considered vulnerable outside of this context as well (Prout, 2003), they are in a position of compounded vulnerability in it. The irreversibility of death makes it essential to ensure that the provision of MAID is truly justified in each case; thus, making uncertainty about whether or not a child is suffering intolerably especially concerning.

Considerations pertaining to extending MAID legislation to all minors are not an abstract possibility. The Canadian Paediatric Society reports that health care professionals are already being increasingly approached about MAID by parents/guardians of children who do not meet mature minor criteria (Davies, 2017). Further, parents/guardians may challenge the ineligibility of their children for MAID on the grounds of the right to life, liberty, and security (Davies, 2017), just as the criminalization of assisted dying under the Criminal Code of Canada was challenged on the basis of this Charter right in *Carter*.

There is no in principle ethical reason against considering extending MAID legislation to all minors given the presence of intolerable suffering, which is morally significant, in combination with arguments against the autonomy based limitations to eligibility presented in previous chapters of this thesis. Further, children's voices can provide some meaningful insight into their suffering experience, to assess MAID eligibility; thus, contributing to justice in providing MAID to minors. However, a question remains as to whether or not this valuable, yet potentially incomplete and uncertain insight about the extent and degree of children's suffering experiences, acquired through children's voices, would be enough for the context of MAID for minors, wherein the consequences of making an error would be of life or death? The response to this question is something that must be considered in greater depth and at greater length.

If MAID legislation were to be extended to all minors based (even partially) on an argument of justice, there would still be potential for injustice in the context of MAID for minors. This potential would remain due to the continued possibility of inaccurate assessments of intolerable suffering, even when children's voices are elicited, due to the challenges associated with working through the messiness of children's voices described in this chapter. Thus, the motivating goal of justice in extending MAID legislation to minors at the policy level could be undermined at the bedside. Further, it is unclear what legal safeguards (if any) could be put in place to mitigate this ethical concern; thus, the potential for implementing legal safeguards is something that requires careful deliberation. As a result, the policy conclusion that I draw is that if considering an extension of MAID legislation to all minors, it is essential to proceed with caution.

Exercising this caution would include taking time to carefully deliberate whether there is too much uncertainty inherent in understanding the degree and extent of a child's suffering for use in determining a minor's eligibility for MAID. If not, what degree of uncertainty is morally acceptable? It would be necessary to engage in thoughtful discussion on how the effects of operating under some uncertainty, namely the possibility for even one false negative or false positive, in determining the eligibility of a minor for MAID, could be mitigated. It would be imperative for policy makers to determine what, if any, legal safeguards could be implemented to prevent an unjust lack of provision of MAID or unjust termination of life amongst minors in an extension of MAID legislation to all minors.

Conclusion

Recall that the objective of this thesis was to see how children's own accounts of their experiences may be useful in assessing intolerable suffering in the context of MAID for minors. It was hypothesized that it would be important to incorporate the sufferer's own voice in order to get an accurate understanding of her suffering experience. The specific ethical problem is a possible violation of the principle of justice caused by unjust provision of MAID. There was concern that relying on parent/guardian's accounts, or the accounts of health care professionals, to understand whether or not a child has intolerable suffering could result in false negatives or false positives. In the case of a false negative, a child that is experiencing intolerable suffering fails to receive MAID. My argument was that failure to receive MAID would be unjust because, although the child is suffering intolerably, as do others who are able to receive MAID, the child unfairly fails to receive MAID. In the case of a false positive, there is the risk of a wrongful death due to a minor receiving MAID in a situation where she herself may not have evaluated her suffering as intolerable. This would entail an unjustified violation of the minor's right to life.

My thesis has now established that the child's own account of her suffering is messy and multi-layered, and the understanding of the child's suffering experience that can be acquired from these accounts is never going to be as complete and authentic as health care professionals would ideally want it to be (Spyrou, 2011). Thus, although there is value in eliciting children's voices, the epistemological merit attributed to a sufferer's own account of their suffering experience in my initial hypothesis has not been fully supported. What this result means in terms of how the child's perspective can be useful in assessing that the child is suffering intolerably is that voice can provide us with some valuable insight into a child's suffering experience, but health care professionals would not be able to claim that they have an authentic and exact (and perhaps adequate) understanding of the degree and extent of this experience for the purpose of determining a child's eligibility for MAID. It is not clear whether the insight that could be acquired is sufficient to determine a child's eligibility for MAID. As a result, the potential for a violation of the principle of justice through an insufficient understanding and assessment of a child's suffering experience remains. Further, it is not clear what (if any) legal safeguards could be implemented to protect against the aforementioned ethical concern. Therefore, it is essential to exercise caution by engaging in more thoughtful deliberation on these knowledge gaps, if considering an extension of MAID legislation in Canada to all minors in the future.

References

A.C. v. Manitoba (Director of Child and Family Services), 2009 SCC 30, [2009] 2 S.C.R. 181

Albrecht, G.L. & Devlieger, P.J. (1999). The disability paradox: High quality of life against all odds. *Social Science & Medicine, 48*(8), 977-988.

Alcoff, L.M. (2009). The problem of speaking for others. In Alecia Y. Jackson & Lisa A. Mazzei (eds.), *Voice in qualitative inquiry: Challenging conventional, interpretive, and critical conceptions in qualitative research* (pp.117-136). New York: Routledge.

Arneil, B. (2002). Becoming versus being: A critical analysis of the child in liberal theory. In David Archard & Colin M. Macleod (eds.), *The moral and political status of children* (pp.70-96). New York: Oxford University Press.

Bagnoli, C. (2007). The authority of reflection. *THEORIA: an International Journal for Theory, History and Foundations of Science, 22*(58), 43-52.

Bates, A. T., & Kearney, J. A. (2015). Understanding death with limited experience in life: Dying children's and adolescents' understanding of their own terminal illness and death. *Current Opinion in Supportive and Palliative Care, 9*(1), 40-45.

Beauchamp, T.L. (2010). The four principles approach to health care ethics. In Tom L. Beauchamp (ed.), *Standing on principles: Collected essays* (pp. 35-49). New York: Oxford University Press.

Bensimon, C. M., & Zlotnik Shaul, R. (2016). Pediatrics. In H. ten Have (Ed.), *Encyclopedia of global bioethics* (pp. 2172-2182). Cham: Springer International Publishing.

Bill C-14: An Act to amend the Criminal Code and to make related amendments to other Acts (medical assistance in dying). [2016]. Royal Assent Jun. 17, 2016, 42nd Parliament, 1st session. Retrieved from the Parliament of Canada website: http://www.parl.ca/DocumentViewer/en/42-1/bill/C-14/royal-assent

Boggis, A. (2011). Deafening silences: Researching with inarticulate children. *Disability Studies Quarterly, 31*(4), doi: http://dx.doi.org/10.18061/dsq.v31i4.1710

Bolt, E. E., Flens, E. Q., Pasman, H., Willems, D., & Onwuteaka-Philipsen, B. D. (2016). Physician-assisted dying for children is conceivable for most Dutch pediatricians, irrespective of the patient's age or competence to decide. *Acta Paediatrica*, *106*(4), 668-675.

Brouwer, M., Kaczor, C., Battin, M.P., et al. (2018). Should pediatric euthanasia be legalized? *Pediatrics, 141*(2), e20171343.

Carnevale, F. A. (2009). A conceptual and moral analysis of suffering. *Nursing Ethics, 16*(2), 173-183.

Carnevale, F.A. (2012). Listening authentically to youthful voices: A conception of the moral agency of children. In J.L. Storch, P. Rodney, & S. Starzomski (eds.), *Toward a moral horizon: Nursing ethics for leadership and practice (2nd ed)* (p.315-332). Toronto: Pearson Education Canada.

Carnevale, F.A., Campbell, A., Collin-Vézina, D. & Macdonald, M.E. (2015). Interdisciplinary studies of childhood ethics: Developing a new field of inquiry. *Children & Society, 29*(6), 511-523.

Carter, B. (2002). Chronic pain in childhood and the medical encounter: Professional ventriloquism and hidden voices. *Qualitative Health Research, 12*(1), 28-41.

Carter v. Canada (Attorney General), 2015 SCC 5, [2015] 1 S.C.R. 331

Cassell, E. J. (2004). The nature of suffering. In *The nature of suffering and the goals of medicine* (p.29-53). New York: Oxford University Press.

Christman, J. (2005). Autonomy, self-knowledge, and liberal legitimacy. In John Christman & Joel Anderson (eds.), *Autonomy and the challenges to liberalism: New essays* (pp.330-357). New York: Cambridge University Press.

Clement, G. (2013). Feminist ethics. In H. LaFollette, J. Deigh, S. Stroud & E. LaFollete (eds.), *International encyclopedia of ethics.* Retrieved from http://onlinelibrary.wiley.com.proxy3.library.mcgill.ca/doi/10.1002/9781444367072.wbiee108/full

Cudney, P. (2014). What really separates casuistry from principlism in biomedical ethics. *Theoretical Medicine and Bioethics, 35*(3), 205-229.

Davidson, D. (1984). First person authority. *Dialectica, 38*(2-3), 101-111.

Davies, D.; Canadian Paediatric Society, Bioethics Committee. (2017). *Position statement. Medical assistance in dying*: *A paediatric perspective*. Retrieved from https://www.cps.ca/en/documents/position/medical-assistance-in-dying

D'Cruz, H., Gillingham, P. & Mendelez, S. (2007). Reflexivity: A concept and its meaning for practitioners working with children and families. *Critical Social Work, 8*(1), 1-18.

Dedding, C., Reis, R., Wolf, B., & Hardon, A. (2015). Revealing the hidden agency of children in a clinical setting. *Health Expectations, 18*(6), 2121-2128.

de Quincey, C. (2000). Intersubjectivity: Exploring consciousness from the second person perspective. *The Journal of Transpersonal Psychology, 32*(2), 135-155.

Driggs, A.E. (2001). The mature minor doctrine: Do adolescents have the right to die? *Health Matrix: Journal of Law-Medicine, 11*(2), 687-717.

Edwards, S. D. (2003). Three concepts of suffering. *Medicine, Health Care and Philosophy, 6*(1), 59-66.

Evans, K.G.; Canadian Medical Protective Association. (2016). Consent: A guide for Canadian physicians (fourth edition). Retrieved from https://www.cmpa-acpm.ca/en/advice-publications/handbooks/consent-a-guide-for-canadian-physicians

Expert Panel on Options for a Legislative Response to Carter v. Canada. (2015, December 15). *Consultations on physician-assisted dying: Summary of results and key findings.* (Final report). Retrieved from http://www.justice.gc.ca/eng/rp-pr/other-autre/pad-amm/pad.pdf

Falvey, K. (2000). The basis of first-person authority. *Philosophical Topics, 28*(2), 69-99.

Fortin, J. (2009a). Chapter 3: Adolescent autonomy and parents. In *Law in Context : Children's Rights and the Developing Law (3 ed.)* (pp. 81-105). Cambridge: Cambridge University Press.

Fortin, J. (2009b). Chapter 5: Adolescent decision making and health care. In *Law in Context : Children's Rights and the Developing Law (3 ed.)* (pp. 146-186). Cambridge: Cambridge University Press.

Freitag, L. (2015). Witnesses to mute suffering: Quality of life, intellectual disability, and the harm standard. *Journal of Clinical Ethics, 26*(1), 24-26.

Friedman, M. (2013). Care ethics. In H. LaFollette, J. Deigh, S. Stroud & E. LaFollette (eds.), *International encyclopedia of ethics.* Retrieved from http://onlinelibrary.wiley.com.proxy3.library.mcgill.ca/doi/10.1002/9781444367072.wbiee057/full

George, R. T. D. (1970). The function and limits of epistemic authority. *The Southern Journal of Philosophy, 8*(2-3), 199-204.

Gilligan, C. (1982). *In a different voice*. Massachusetts: Harvard University Press.

Government of Canada. Department of Justice. (2017a, January 19). *Article 12 of the convention on the rights of the child and children's participatory rights in Canada.* Retrieved from Department of Justice website http://www.justice.gc.ca/eng/rp-pr/other-autre/article12/p3a.html

Government of Canada. Department of Justice. (2017b, January 19). *Legislative background: Medical assistance in dying (Bill C-14).* Retrieved from Department of Justice website http://www.justice.gc.ca/eng/rp-pr/other-autre/ad-am/p1.html

Government of Canada. Department of Justice. (2017c, August 4). *Putting children's interests first - federal-provincial-territorial consultations on custody and access and child support.* Retrieved from Department of Justice website http://www.justice.gc.ca/eng/rp-pr/fl-lf/famil/cons/consdoc/cscam-paem.html

Government of Canada. Parliament. House of Commons. Senate. Special Joint Committee on Physician-Assisted Dying. (2016a). *Medical assistance in dying: A patient-centered approach. Report of the special joint committee on physician-assisted dying.* 1st report. 42nd parliament, 1st session. Retrieved from Parliament of Canada website https://www.parl.ca/DocumentViewer/en/42-1/PDAM/report-1

Government of Canada. Parliament. House of Commons. Senate. Special Joint Committee on Physician-Assisted Dying. (2016b, January 26). *Evidence.* 42nd parliament, 1st session, meeting no.5. Retrieved from Parliament of Canada website http://www.parl.ca/DocumentViewer/en/42-1/PDAM/meeting-5/evidence

Graf, G. (2015). Conceptions of childhood, agency, and the well-being of children. In Gunter Graf & Gottfried Schweiger (eds.), *The well-being of children: Philosophical and social scientific approaches 1st ed* (pp.20-33). Berlin: De Gruyter.

Guichon, J., Mohamed, F., Clarke, K., & Mitchell, I. (2017). Autonomy and beneficence in assisted dying in Canada: The eligibility of mature minors. *Alberta Law Review, 54*(3), 775-831.

Harrison, C.; Canadian Paediatric Society, Bioethics Committee. (2016). Treatment decisions regarding infants, children and adolescents. *Paediatrics and Child Health, 9*(2), 99-108.

Held, V. (2006). The ethics of care as moral theory. In *The ethics of care: Personal, political, and global* (pp. 9-28). New York: Oxford University Press.

Hendrick, J. (2010). Autonomy and consent. In *Law and ethics in children's nursing* (pp. 65-85). West Sussex: Wiley-Blackwell.

James, S. (1982). The duty to relieve suffering. *Ethics, 93*(1), 4-21.

James, A. (2007). Giving voice to children's voices: Practices and problems, pitfalls and potentials. *American Anthropologist, 109*(2), 261-272.

James, A. & Prout, A. (2015). A new paradigm for the sociology of childhood?: Provenance, promise, and problems. In *Constructing and reconstructing childhood: Contemporary issues in the sociological study of childhood* (pp. 6-28). Abingdon: Routledge.

Johansson, V. (2011). ‘In charge of the truffula seeds’: On children's literature, rationality and children's voices in philosophy. *Journal of Philosophy of Education, 45*(2), 359-377.

Kanyon, B.L. (2001). Current research in children's conceptions of death: A critical review. *OMEGA*, *43*(1), 63-91.

Kars, M. C., Grypdonck, M. H. F., de Bock, L. C., & van Delden, J. J. M. (2015). The parents' ability to attend to the "voice of their child" with incurable cancer during the palliative phase. *Health Psychology, 34*(4), 446-452.

Kimsma, G.K. (2012). Assessment of unbearable and hopeless suffering in evaluating a request to end life. In G. K. Kimsma & S. J. Youngner (eds.), *Physician-assisted death in perspective: Assessing the Dutch experience* (pp. 333-348). Cambridge: Cambridge University Press.

Kleinig, J. (2013). Consent. In H. LaFollette, J. Deigh, S. Stroud & E. LaFollete (eds.), *International encyclopedia of ethics.* Retrieved from http://onlinelibrary.wiley.com.proxy3.library.mcgill.ca/doi/10.1002/9781444367072.wbiee377/abstract

Kodish, E. (2008). Paediatric ethics: A repudiation of the Groningen protocol. *The Lancet, 371*(9616), 892-893.

Komulainen, S. (2007). The ambiguity of the child's ‘voice’ in social research. *Childhood, 14*(1), 11-28.

Kon, A. A. (2009). Neonatal euthanasia. *Seminars in Perinatology, 33*(6), 377-383.

Lemmens, C. (2009). End- of- life decisions and minors: Do minors have the right to refuse life preserving medical treatment? A comparative study. *Medicine & Law, 28*(3), 479-497.

Leo, R.J. (1999). Competency and the capacity to make treatment decisions: A primer for primary care physicians. *The Primary Care Companion to the Journal of Clinical Psychiatry, 1*(5), 131-141.

Lewis, A. (2010). Silence in the context of ‘child voice’. *Children & Society, 24*(1), 14-23.

MacIntosh, C. (2016). Carter, medical aid in dying, and mature minors. *McGill Journal of Law & Health, 10*(1), S1-S33.

Manning, R. (1998). A care approach. In Helga Kuhse & Peter Singer (eds.), *A companion to bioethics,* (pp.98-105). Oxford: Blackwell Publishing.

Mazzei, L.A. (2009). An impossibly full voice. In Alecia Y. Jackson & Lisa A. Mazzei (eds.), *Voice in qualitative inquiry: Challenging conventional, interpretive, and critical conceptions in qualitative research* (pp. 45-62). New York: Routledge.

Meloni, F., Vanthuyne, K., & Rousseau, C. (2015). Towards a relational ethics: Rethinking ethics, agency and dependency in research with children and youth. *Anthropological Theory, 15*(1), 106-123.

Montello, M. (2014). Narrative ethics. *The Hastings Center Report, 44*(s1), s2-s6.

Montreuil, M. & Carnevale, F.A. (2016). A concept analysis of children's agency within the health literature. *Journal of Child Health Care, 20*(4), 503-511.

Murris, K. (2013). The epistemic challenge of hearing child's voice. *Studies in Philosophy and Education, 32*(3), 245-259.

Nicol, J. & Tiedemann, M. (2016, April 21). *Legislative summary of Bill C-14: An act to amend the Criminal Code and make related amendments to other Acts (medical assistance in dying).* [Publication No.42-1-C14-E]. Retrieved from Library of Parliament, Parliament of Canada website http://www.lop.parl.gc.ca/About/Parliament/LegislativeSummaries/bills_ls.asp?Language=E&ls=C14&Mode=1&Parl=42&Ses=1&source=library_prb

Pabst Battin, M. (2013). Bioethics. In H. LaFollette, J. Deigh, S. Stroud & E. LaFollette (eds.), *International encyclopedia of ethics.* Retrieved from http://onlinelibrary.wiley.com.proxy3.library.mcgill.ca/doi/10.1002/9781444367072.wbiee782/full

Parliament of Canada. (2016, February 25). *Medical assistance in dying: A patient-centered approach report of the Special Joint Committee on Physician Assisted Dying* [Press release]. Retrieved from http://www.parl.ca/DocumentViewer/en/42-1/PDAM/news-release/8123428

Prout, A. (2003). Participation, policy, and the changing conditions of childhood. In Christine Hallett & Alan Prout (eds.), *Hearing the voices of children: Social policy for a new century* (pp. 11-25). New York: Routledge Falmer.

Pullman, D. (2002). Human dignity and the ethics and aesthetics of pain and suffering. *Theoretical Medicine and Bioethics, 23*(1), 75-94.

Sherwin, S. (1999). Foundations, frameworks, lenses: The role of theories in bioethics. *Bioethics, 13*(3/4), 198-205.

Smart, C. (2002). From children's shoes to children's voices. *Family Court Review, 40*(3), 307-319.

Sourkes, B.M. (1995). Anticipatory grief. In *Armfuls of time: The psychological experience of the child with a life-threatening illness* (pp.137-154). Pittsburgh: University of Pittsburgh Press.

Spyrou, S. (2011). The limits of children's voices: From authenticity to critical, reflexive representation. *Childhood, 18*(2), 151-165.

Spyrou, S. (2016). Researching children's silences: Exploring the fullness of voice in childhood research. *Childhood, 23*(1), 7-21.

Tates Kiek, K. (2003). Doctor-parent-child relationships: a 'pas de trois'. *Patient Education and Counseling, 48*(1), 5-14.

Taylor, B. (2006). Giving children and parents a voice - The parents' perspective. *Paediatric Nursing, 18*(9), 20-23.

Teachman, G., McDonough, P., Macarthur, C. & Gibson, B.E. (2017). A critical dialogical methodology for conducting research with disabled youth who use augmentative and alternative communication. *Qualitiative Inquiry, 24*(1), 35-44.

Timmins, F. (2006). Critical practice in nursing care: Analysis, action, and reflexivity. *Nursing Standard, 20*(39), 49-54.

Terry, L., & Campbell, A. (2001). Focus on children's nursing. Are we listening to children's views about their treatment? *British Journal of Nursing, 10*(6), 384-390.

Tisdall, E. K. M. (2012). The challenge and challenging of childhood studies? Learning from disability studies and research with disabled children. *Children & Society, 26*(3), 181-191.

Uprichard, E. (2008). Children as "being and becomings:" Children, childhood and temporality. *Children & Society, 22*(4), 303-313.

Van Praagh, S. (2005). Adolescence, autonomy and Harry Potter: The child as decision-maker. *International Journal of Law in Context, 1*(4), 335-373.

Verhagen, E., & Sauer, P. J. (2005). The Groningen protocol--euthanasia in severely ill newborns. *The New England Journal of Medicine, 352*(10), 959-962.

Wijsbek, H. (2012). The subjectivity of suffering and the normativity of unbearableness. In G. K. Kimsma & S. J. Youngner (Eds.), *Physician-assisted death in perspective: Assessing the Dutch experience* (pp. 319-332). Cambridge: Cambridge University Press.

Wyness, M. (2013). Children's participation and intergenerational dialogue: Bringing adults back into the analysis. *Childhood, 20*(4), 429-442.