Pediatric Dissent:
An Underdeveloped and Challenging Concept

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Abstract:

Introduction. There have been many news articles reporting on court cases where a minor and/or their parent(s) have refused lifesaving treatments. These make for interesting debates, but not all paediatric refusals to care end up before the courts. What should healthcare providers do when a minor refuses to participate in a care plan the adults believe to be in the minor's best interest? The objective of this literature review is to identify the current discussions surrounding paediatric dissent in research and clinical settings as well as the strengths and limitations of the most prominent perspectives on dissent.

Methods. For this qualitative study, the MEDLINE® ALL (1946-March 22, 2022) database was used. One thousand two hundred and twelve articles were found in the initial search, ninety-five of which were retained after screening. Articles were included from research and clinical settings as well as case studies. Only 19 articles discussed dissent in detail. An additional search was done examining the existing legislative and regulatory frameworks across Canada regarding a minor's ability to consent to treatment.

Results. Three main categories – research, clinical, and legislative and regulatory frameworks – were subdivided into three subcategories: Current Views on Dissent; A Minor's Capacity and its Complexity; and Lack of Guidelines and Clarity Regarding a Minor's Capacity to Dissent. First and foremost, this review revealed a significant gap in knowledge surrounding paediatric dissent. In research settings, it is well established that assent should be sought from minors. In these settings, many authors agree that dissent should be respected, but disagreement exists regarding what dissent may look like, or when a child truly is capable of dissenting to something they may not understand. In clinical settings, the debate surrounding dissent is intertwined with the concept of assent. Some authors argue that obtaining assent is synonymous to seeking the minor's preferences. Others argue that if assent is to be sought, then dissent should be respected equally. Most of the literature in this review (92% of manuscripts reviewed) spoke to minors' decision-making capacity regarding treatment. In both the research and clinical settings, the difficulty of assessing a minor's capacity was noted. Authors argue that minors who are capable of assent can also dissent, although others say that minors do not have sufficient life experience or maturity to make life-altering treatment decisions.

Finally, many authors have noted the absence of guidelines and regulations regarding a minor's dissent to treatment or to participate in research. A review of the Canadian legal and regulatory landscape regarding minor's ability to consent to treatment revealed another significant gap in knowledge related to paediatric dissent.
Conclusion. The limitations of grounding dissent on similar principles used in discussions on assent and capacity are presented, and other potential avenues in interdisciplinary studies of childhood ethics are considered in place of pediatric dissent.

Résumé:

Introduction. De nombreux articles de presse font état d'affaires judiciaires dans lesquelles un mineur et/ou ses parents ont refusé des traitements vitaux. Ces cas donnent lieu à des débats intéressants, mais tous les refus de soins pédiatriques n'aboutissent pas devant les tribunaux. Que doivent faire les professionnels de la santé lorsqu'un mineur refuse de participer à un plan de soins que les adultes estiment être dans son meilleur intérêt? L'objectif de cette étude exploratoire est d'identifier les discussions actuelles entourant le dissentiment[1]pédiatrique dans les milieux de la recherche et clinique ainsi les forces et les limites des principaux points de vue sur le dissentiment. Méthode. Pour cette étude qualitative, la base de données MEDLINE® ALL (1946-Mars 22, 2022) a été utilisée. Mille-deux-cent-douze articles ont été trouvés dans la recherche initiale et quatre-vingt-quinze d'entre eux ont été retenus après un examen approfondi. Les articles portaient à la fois sur des recherches, des contextes cliniques et des études de cas. Seuls 19 articles traitaient du dissentiment de manière approfondie. Une autre recherche sur le cadre réglementaire du Canada concernant la capacité des mineurs à consentir à un traitement a été effectuée de manière systématique.
Résultats. Trois catégories principales – milieu de recherche, milieu clinique et cadre juridique et réglementaire – ont été subdivisées en trois sous-catégories : les opinions

[1] Translation for the word dissent in the health and research fields in French. *Traduction du mot* dissent *dans les domaines de la santé et de la recherche scientifique.*

actuelles sur le dissentiment; la capacité du mineur et sa complexité; le manque de lignes directrices et de clarté concernant la capacité d'un mineur à exprimer son dissentiment. Tout d'abord, cette étude a mis en évidence un manque important de connaissances sur le dissentiment pédiatrique. Dans le domaine de la recherche, il est bien établi que l'assentiment doit être recherché auprès des mineurs. De nombreux auteurs s'accordent à dire que le dissentiment doit également être respecté, mais il existe des désaccords sur la nature du dissentiment et sur le fait de savoir si un mineur est réellement capable d'exprimer son dissentiment sur quelque chose qu'il ne comprend peut-être pas. En milieu clinique, le débat sur le dissentiment est lié au concept d'assentiment. Selon certains auteurs, l'assentiment sollicite les préférences du mineur. D'autres soutiennent que si l'assentiment doit être recherché, le dissentiment doit être respecté également. La plupart des publications, soit 92 %, sur lesquelles se sont penchées cette étude traitent de la capacité des mineurs à prendre des décisions en matière de traitement. Tant dans le cadre de la recherche que dans le cadre clinique, la difficulté d'évaluer la capacité d'un mineur a été soulignée. Des auteurs affirment que les mineurs capables de donner leur assentiment peuvent également exprimer leur dissentiment, alors que d'autres soutiennent que les mineurs n'ont pas suffisamment d'expérience de vie ou de maturité pour prendre des décisions de traitement susceptibles de changer leur vie. Enfin, de nombreux auteurs ont noté l'absence de lignes directrices et de réglementations concernant le dissentiment d'un mineur à l'égard d'un traitement ou de la participation à une recherche. C'est le cas dans la législation et les cadres réglementaires canadiens (voir tableau 1). L'examen du paysage juridique canadien concernant la capacité des mineurs à consentir à un traitement a révélé une autre lacune importante dans le système de connaissances sur le dissentiment pédiatrique.

Conclusion. Les limites du fondement du dissentiment sur des principes similaires à ceux de l'assentiment et de la capacité sont présentées et d'autres voies potentielles dans les études interdisciplinaires sur l'éthique de l'enfance sont envisagées à la place du dissentiment pédiatrique.

Acknowledgements:

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I would also like to thank our McGill librarians for advising me in my literature search. Genevieve Gore, our Bioethics librarian, has met with me and guided me through the complexity of the bioethics searches.

Contribution of Authors

Phoebe Friesen – Editing and Revision

Amber Wojtowicz – Editing

List of Abbreviations

AAP – American Association of Pediatrics
CPS – Canadian Paediatric Society
HCP – Health Care Provider
IAF – Informed Assent Form
ICF – Informed Consent Form
N/A – Not Applicable
N/S – Not Specified
NWT – Northwest Territories

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Chapter 1 – Paediatric Dissent: An Underdeveloped and Challenging Concept

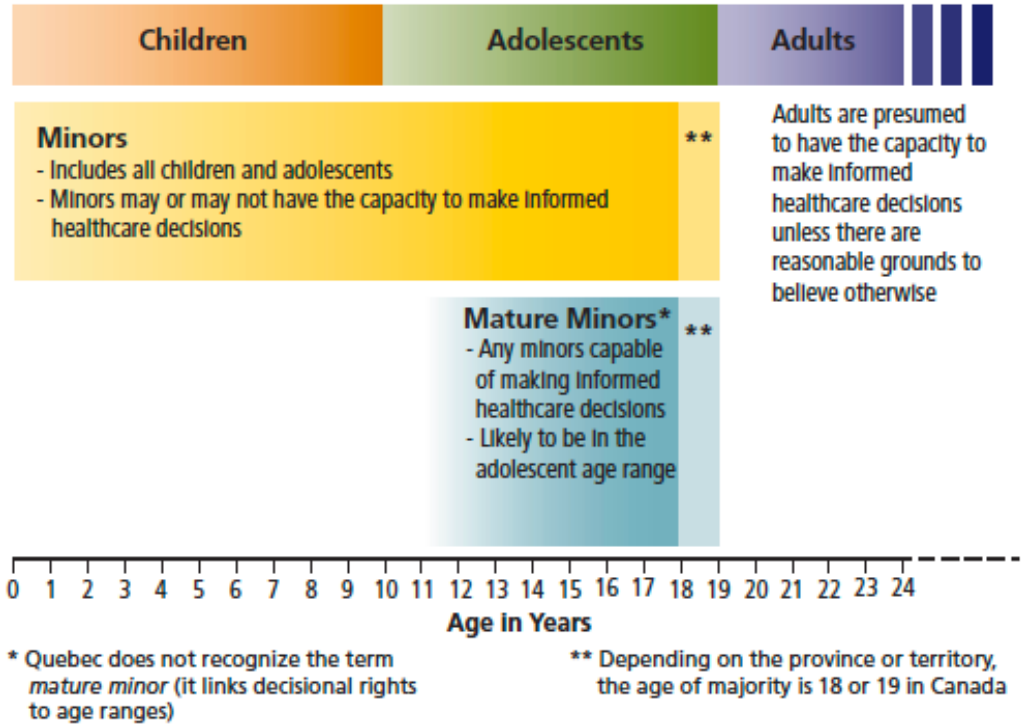
There have been many news articles reporting on court cases where a minor and/or their parent(s) or guardian(s) have refused lifesaving treatments. These make for interesting debates, but not all paediatric refusals to care ends up before the courts. Many healthcare professionals attempt to resolve disagreements surrounding care quickly and set out to find common ground. What then, should a paediatrician do when a minor disagrees to or refuses treatment? What if that minor is seven years old? If the minor is 16, do adults' attitudes and approaches towards the refusal change? Can every minor refuse to participate in all research? These are all questions that need to be explored in greater detail. The aim of this literature review is to examine the different discussions surrounding dissent in paediatric care and research settings, and to map the regulatory and legislative landscape in Canada surrounding treatment decision-making and minors. A critical analysis will determine if the overall approaches currently taken are beneficial for respecting a minor's dissent and the inclusion of dissent policies in clinical and research settings.

Definitions and Orientation

Terms such as *minor*, *youth*, *child*, *children*, *adolescent* and so on can be a little disorienting when discussing the field of paediatrics. For ease of comprehension, the term *minor* will be used to designate any individual below the age of majority. In Canada this age varies between 18 and 19 years old. Figure 1 is a visual representation from the Council of Canadian Academies of the age groups and terminology used for the purposes of this thesis; the term *minor* encompasses both children and adolescents. *Mature minors* are a specific subgroup of minors who are considered to have sufficient capacity to make

decisions regarding their own healthcare. In certain provinces and territories, mature minors are defined by age, while other provinces and territories rely on an individual capacity assessment to define this group (see Table 1).

Figure 1:
Visual Representation of Terminology Used to Differentiate Stages of a Minor's Life (Council of Canadian Academies, 2018)



Three important terms must be introduced: consent, assent, and dissent. The American Academy of Pediatrics (AAP)[2] makes a clear distinction between consent and assent. The AAP maintains that minors lack the more "robust autonomy" (2016, p. e5) that competent[3] adults have to make their own medical decisions, requiring a developmental approach to acquire authorization to medical decision making with minors

[2] Although this review is centered on the Canadian context, the definitions offered by the American Academy of Pediatrics are useful for framing the issue of dissent.
[3] The words *capacity* and *competence* will be used interchangeably in this document as is often done in the bioethics literature.

(American Academy of Pediatrics, 2016). According to the AAP, consent requires three important elements:

1. Disclosure: “Patients and their surrogates should be provided explanations, in understandable, developmentally appropriate language, of the nature of their illness or condition; the nature of the proposed diagnostic steps and/or treatments and the probability of their success; the existence and nature of the risks and anticipated benefits involved; and the existence, potential benefits, and risks of potential alternative treatments, including the option of no treatment” (2016, p. e4).
2. Understanding and Capacity: “The patient’s and/or surrogate’s understanding of the above information should be assessed. Because decisional capacity is a critical requirement in providing consent, the capacity of the patient and/or surrogate to make the necessary decisions should be assessed (often, assessment of the capacity to make decisions and the understanding of the pertinent medical information occurs simultaneously)” (2016, p. e4).
3. Voluntariness: “There should be assurance, insofar as is possible through ongoing dialog, that the consent is voluntary and that the patient and/or surrogate has the freedom to choose among the medical alternatives without undue influence, coercion, or manipulation. This condition recognizes that we are all subject to subtle pressures in decision-making and that medical decision-making cannot occur in isolation from other concerns and relationships.” (2016, p. e4).

Assent follows a similar pattern but is adapted to a pediatric patient's level of understanding. Information should be shared in a developmentally appropriate manner and the minor's level of understanding must be assessed. Although this assessment occurs with adults, the assumption of capacity is different between minors and adults. Minors are assumed to be incompetent and must prove to have a certain level of capacity to make decisions about treatments, whereas adults are presumed competent and healthcare providers (HCPs) must prove otherwise.

In the literature, the concept of assent is developed to a greater extent than is that of dissent. This raises many important questions and leaves dissent woefully misunderstood and undefined. Oftentimes, dissent is presented in contrast to assent, and it takes on many formsincluding refusals, objections, withdrawals, non-assent, silence, and unwillingness. This thesis aims at clarifying some of the discussions on pediatric dissent.

Important Notes on Childhood Ethics and Dissent

Inclusion of Minors in Research Background information is necessary to understand the importance of discussions on dissent and the inclusion of minors in their own care. An official regulatory framework for research on humans was put in place in 1964 with the Declaration of Helsinki (Office for Human Research Protections, 2018). The declaration originally excluded minors from participating in research and this limitation was later recognized in another report entitled *Research Involving Children by the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research in the United States* (Office for Human Research Protections, 2018). This report included the three ethical principles from the *Belmont Report*: Respect for Persons, Beneficence, and Justice. The Belmont Report played a crucial role in the

development of conceptions of assent in research that are discussed widely to this day. Under the principle of respect for persons, assent, and parental permission emerged as means to acquire a form of consent or authorization from a minor and their parents. As will be discussed below, this has had implications for how dissent in research is understood. While the *Belmont Report* and the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research were based in the United States, their influence on ethical research involving humans was global.

Patient's Right to Make Treatment Decisions In many Western societies, autonomy and individual patient rights are guiding principles in health care. Applying them to minors is particularly difficult because to make autonomous decisions, an individual must be able to give informed consent. The process and guidelines to obtain informed consent can vary slightly from jurisdiction to jurisdiction. The general requirements, similar to the ones presented above, are that the individual a) has sufficient capacity to make the decision; b) is given all the necessary information that a reasonable person would require to make an informed decision; and c) the decision is voluntary (Canadian Paediatric Society, 2018).

In the case of pediatrics, the first hurdle is that "[i]n the law, children are not recognised as fully autonomous agents capable of moral reasoning or assuming full responsibility for their choices and conduct. Thus, they are not endowed with the full set of rights and duties extended to competent persons of full age" (Carnevale et al., 2015). Many minors, especially younger minors, are deemed incompetent with limited decision-making capacity and need protection given that they are a vulnerable group (Canadian Paediatric Society, 2018; Hickey, 2007; Unguru, 2011; Unguru et al., 2010). Montreuil

and colleagues, advocates in childhood ethics, corroborate the above, saying: “Children are sometimes described as morally incompetent and unable to participate in decisions affecting them, with adults being in charge of decision-making for children in their best interests, because they are considered vulnerable. Limiting participation from children has important implications for them, as it is unclear how what is considered as in the child’s best interests is decided” (Montreuil, Noronha, et al., 2018). When minors are considered morally incompetent, or incapable of decision-making, they are excluded from treatment decisions affecting them, be it to ask questions about, or authorize, refuse, or modify treatment options. This can cause moral harm. Moral harm can occur when injury or damage has been done to a person’s conscience, beliefs, values, or moral compass, and the person has strong negative response to it (Williamson et al., 2021). Studies have shown that exclusion of minors from their care is detrimental and can cause distress (Bluebond-Langner, 2020; Carnevale et al., 2017; Wangmo et al., 2017). Minors being unable to participate in medical decisions affecting them is now hotly debated in the literature. Article 12 of the UN Convention on the Rights for Children states that minors have a right to be heard and express their views freely in all matters (Carnevale et al., 2017; Convention on the Rights of the Child, 1989).

To help narrow the field of study, this review will focus on minors’ dissent to care and/or participation in research. A particular attention will be given to articles discussing the ethics of enabling minors’ dissent in the context of care and/or research. Including minors in decision-making regarding their care and/or participation in research builds trust between the minor and the HCP, helps reduce anxiety and empowers the minor (Canadian Paediatric Society, 2018; Hickey, 2007; Lindeke et al., 2000). What happens,

then, when the minor is included in the decision-making process and dissents to the proposed treatment or to participate in research? Coercing a minor to get treatment by force or the use of restraints raises many ethical issues and should be a last resort solution for HCPs. How then can HCPs and parents balance the goals of best interests and autonomy, knowing that minors may sometimes refuse? This is precisely the dilemma approached within this review.

Organization of the Thesis

The organization of this document is straightforward. First, the following chapter includes a presentation of the methods used for the bioethics literature search followed by the methods used for the systematic search of the legislative landscape of Canada. In the following chapter, the results related to clinical and research settings are separated into three subcategories: Current Views on Dissent; Minors' Capacity and its Complexities; and Lack of Guidelines and Clarity Regarding a Minors' Capacity and Dissent. The results from the systematic search of the Canadian legislative and regulatory landscape are synthesized in Table 1. The next chapter includes a brief discussion of current dilemmas in terms of pediatric dissent, in particular, how different models of assent and capacity affect understanding of dissent. Finally, the last chapter offers an examination of the interdisciplinary studies on childhood ethics, which suggest that minors are moral agents and that both the best interest standard and vulnerability can coexist within a person. Also discussed are potential avenues for bettering minors' inclusion in care.

Chapter 2 - Methods

Literature Search on Paediatric Dissent

A scoping review was conducted to identify the current discussions and gaps in the literature on pediatric dissent to care or research. This method of review allowed a broad search to be conducted, which fit with the aim of this thesis. The updated methodological guidance for conducting scoping reviews published in JBI Evidence Synthesis was applied throughout (Peters et al., 2020).

Context This review was done within the context of Canada and the United States, focusing on discussions around dissent in clinical and research settings for minors.

Search Strategy To help focus in on the topic of choice and necessary keywords a general Google Scholar search was done to get acquainted with the literature. With the help of the McGill Bioethics librarian, the Ovid MEDLINE® ALL (1946-March 22, 2022) database was chosen, and the literature and research method were developed. Search limits were set prior to running the search in MEDLINE. Languages were set to English and French; Special Ovid Filters for MEDLINE was set to Children – Focus, and the Subject Subset was listed as Bioethics. An initial search using only the word dissent and/or refusal in conjunction with keywords for minor yielded too little results.

A second search used the search string Assent OR Dissent OR shared decision-making AND a predetermined set of keywords (neonat*, infan*, child*, adolescen*, pediatric* or paediatric* and minor*) created by McGill Librarians was used to run the preliminary search. The following Boolean operators were used to combine the search terms:

1. Assent* OR dissent* OR shared decision-making*.mp.
2. (neonat* OR infan* OR child* OR adolescen* OR paediatric* OR paediatric* OR minor*).jw.
3. Limits to 2 (([]children or children – focussed] English and French)
4. 1 AND 3

This search yielded 1212 articles. The literature selected for the review was comprised of peer-reviewed articles and case studies. Since the articles were primarily found through MEDLINE, no exclusion was imposed on the type of literature used. An additional 73 articles were also handpicked from reference lists to help further the search. At the very end of the selection and data collection, a second database search, using MEDLINE once more, was done specifically on dissent to cross-reference the results and the articles found in the first search. This second search yielded 36 articles that had all been found in the original search.

Evidence Screening and Selection Using the program Rayyan to screen the 1212 initial articles from the database search, the exclusion criteria brought the final number of articles down to 99 after primary screening was done. During the preliminary screening, articles that did not refer to assent and/or dissent were excluded, as were articles that discussed a very specific subtopic such as sexual health, HIV, vaccination and so on, as they were too specific to speak on the general discussions of dissent in research or clinical care. Upon review, the topic of shared decision-making was also excluded as it did not speak to the topic at hand. A more thorough screening was done

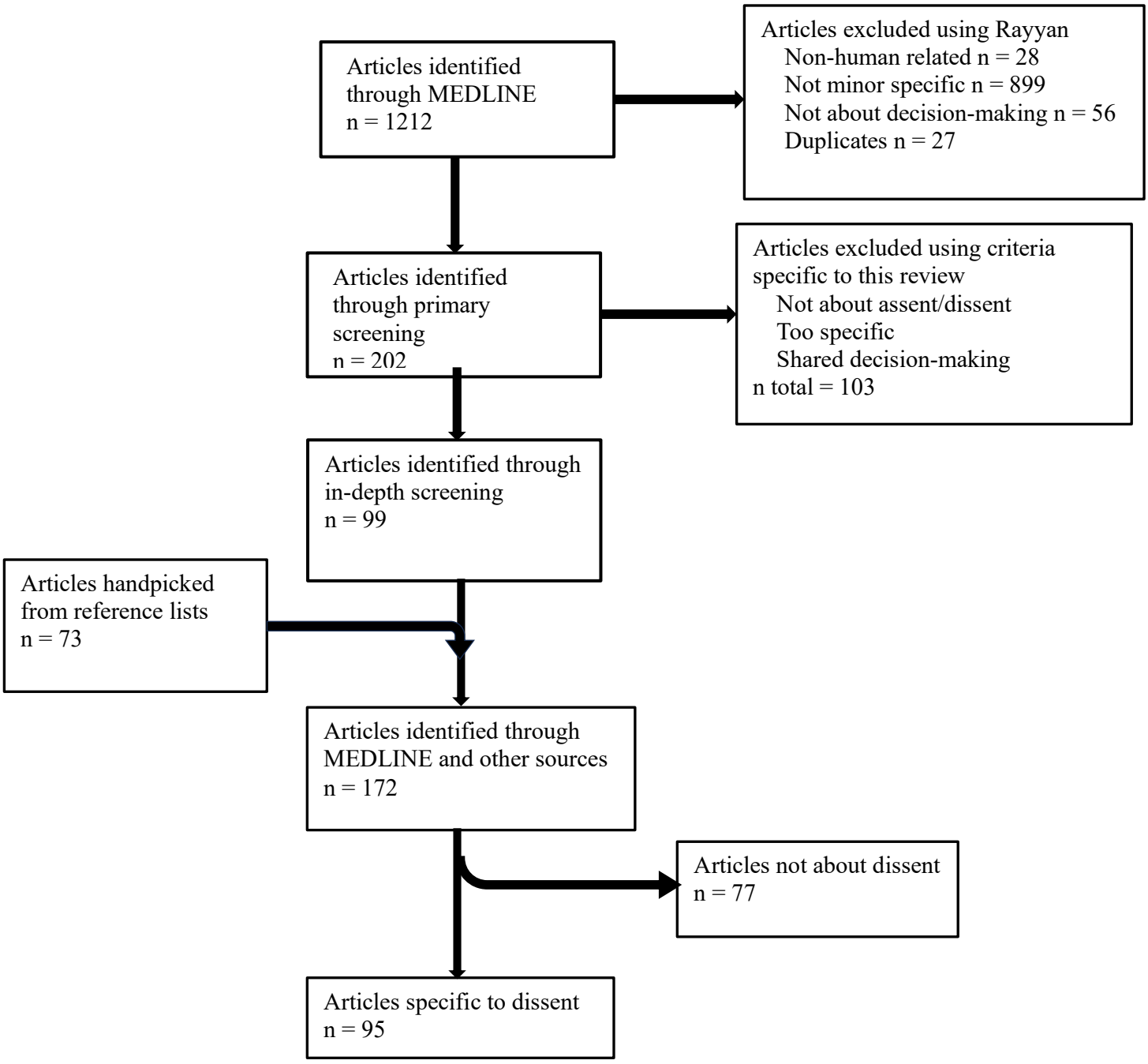
while reading through abstracts and articles. Texts were excluded if there was no mention of dissent. A total of 95 articles remained for further extraction (see Figure 2 for more details).

Data Extraction Organizing the data from the articles was done with spreadsheets. This allowed for separation of the categories for extraction, in this case, two out of the three were extracted: clinical and research context. The third category, legislative and regulatory frameworks, was extracted using a separate method. Both dissent in the clinical context and dissent in research had their respective spreadsheets. The data extracted included the reference, the date of publication, the country of publication, the thesis of the article, the main arguments and the ethical dilemma or discussions, as well as additional notes, where applicable.

Data Analysis Once the data was entered into the respective spreadsheets, a master spreadsheet was created and articles were thematically grouped (research, clinical, and case studies – a subcategory of clinical setting) by colour coding. The extracted data of this review is qualitative, as the goal of the search was to get a sense of the current views and ongoing discussions of dissent.

Presentation of Results

Figure 2:
Prisma Flowchart Depicting the Number of Articles Identified, Screened and Excluded for the Scoping Review



Targeted Search of the Legislative and Regulatory Frameworks for Minors' Consent to Treatment in Canada

The following question was posed to help guide the second search: what does current legislation and regulation surrounding pediatric dissent look like in Canada? A targeted search was done to identify the legislation and regulations in each province and territory regarding minors' consent to medical treatment.

Context The search was limited to jurisdictions in Canada to allow a comparative analysis of provincial laws and regulatory frameworks surrounding minors' decision-making with regard to medical treatment.

Types of Evidence Sources Secondary legal sources, provincial acts, and provincial policies were deemed acceptable sources to answer the question at hand.

Search Strategy As a starting point, secondary sources were used to help identify the provincial acts containing the relevant information. The acts pertaining to minor's medical decision-making of each province and territory were searched individually using Google. If information was missing, two things were done: first, a review of the reference list of the secondary literature already found or a review of other acts referenced in the legislature on the topic; second, an additional examination of the list of provincial acts that have been adopted on the provincial website. Provincial regulatory frameworks were limited to the College of Physicians and Surgeons of a given Province or Territory, or its provincial health website.

Evidence Screening and Selection Given that the search was targeted, minimal screening was necessary. Only the legislation and regulations pertaining to

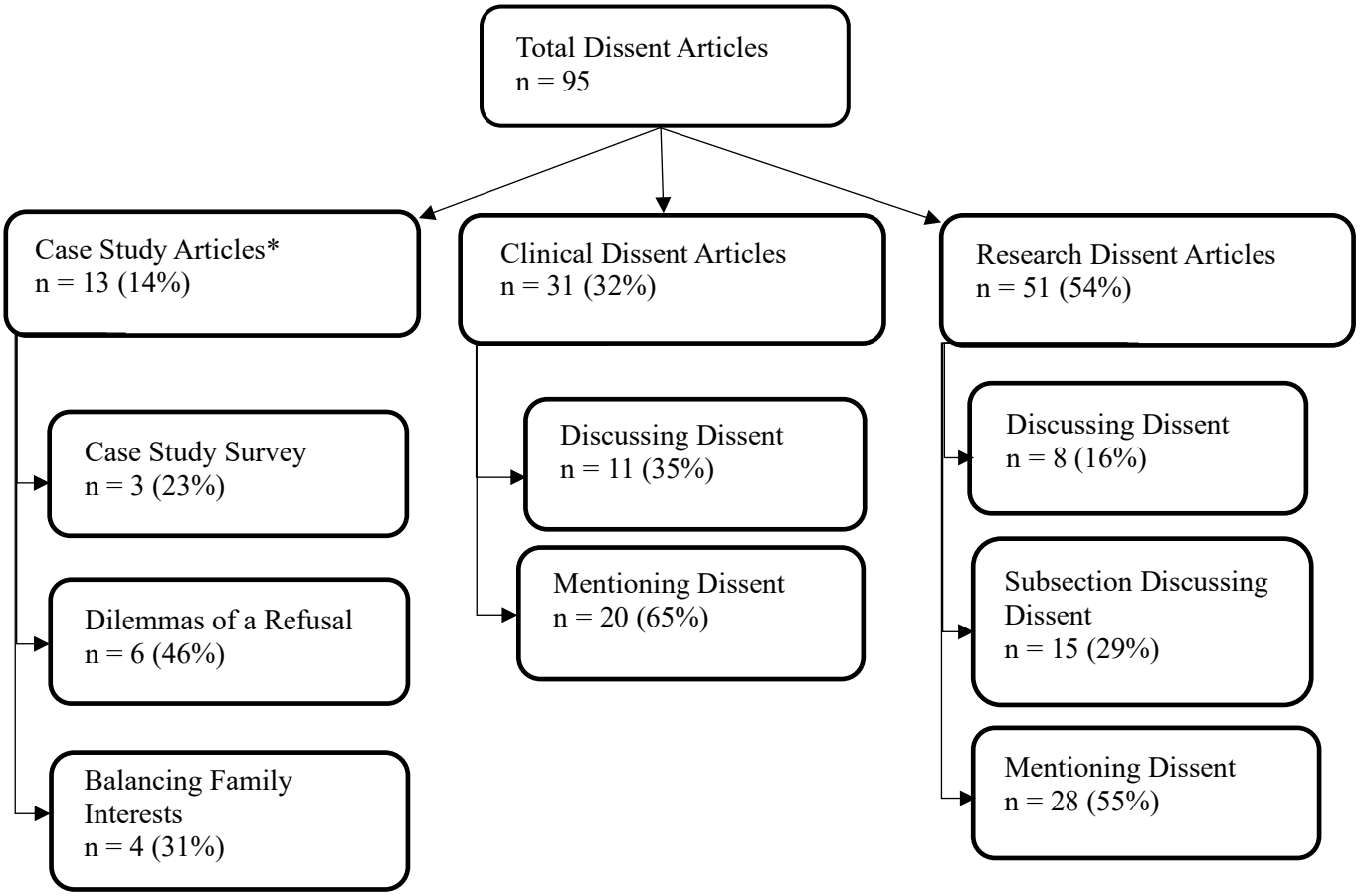
minors and medical decision-making was searched. The secondary sources were found on the Canadian Paediatric Society website, as well as in the review of its references. In total, 14 provincial and territorial acts were included, and 8 policies and regulations specific to the provincial healthcare system were included (see Table 1).

Data Extraction To organize the findings, a spreadsheet was created. The spreadsheet included the reference, the province, when the act/regulation was published and last updated, whether the definition of consent is included in the act/regulation, the age of majority in the jurisdiction, the medical age of consent for a minor in the jurisdiction, the legal framework related to capacity, and the legal framework related to the mature minor rule.

Chapter 3 - Results

The flow chart below (Figure 3) categorizes the number and types of articles about dissent retrieved in this review. There were 95 articles in total, 19 of which dealt directly with dissent and its ethical implications for clinical or research. In the rest of the articles, dissent was most often presented in relation to assent and was therefore not a direct focus.

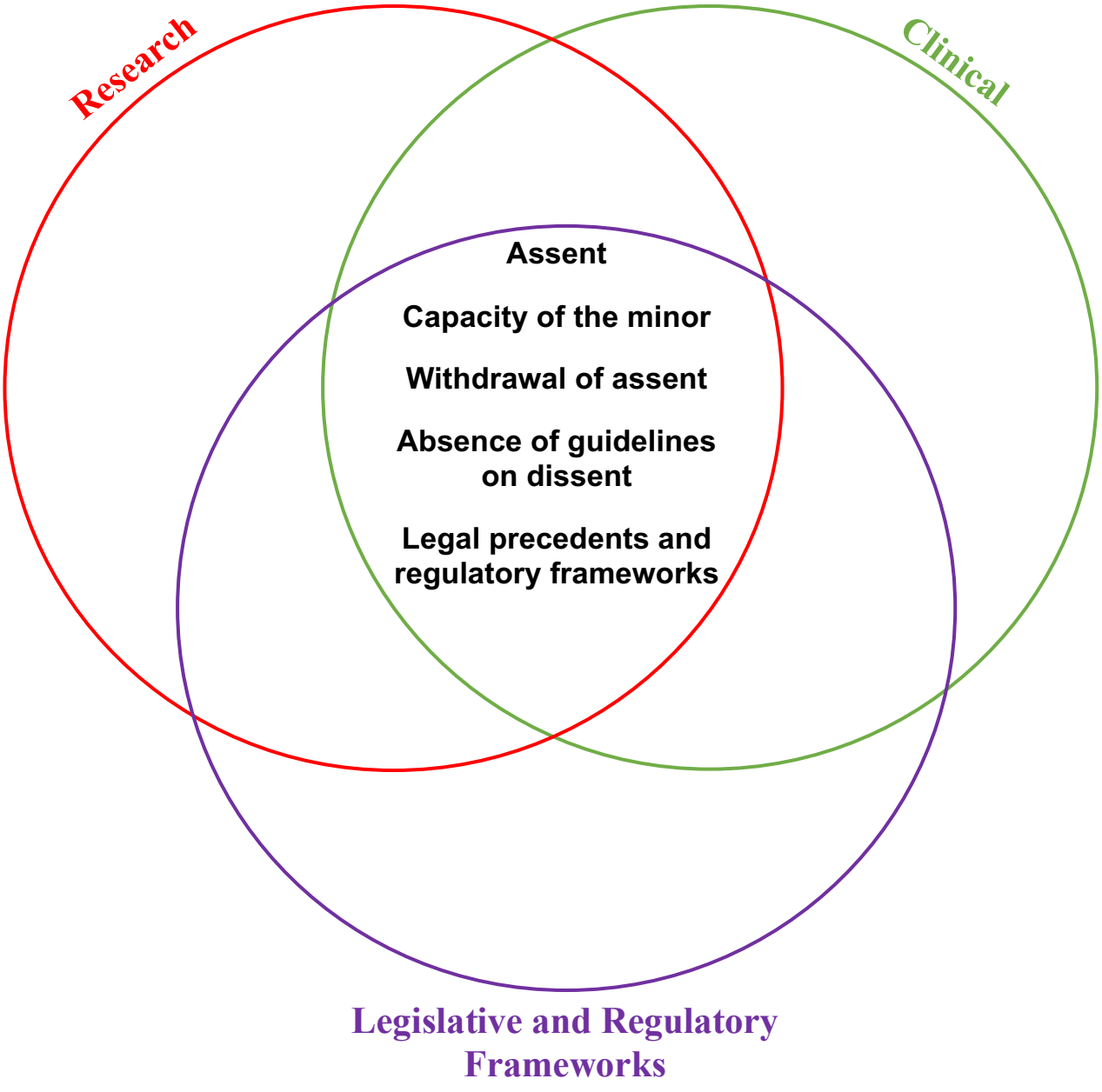
Figure 3:
Flow Chart Breaking Down the Discussion of Dissent Within Articles in this Review



*Many of the case studies were focused on highlighting significant complexities clinicians, patients, families, and the justice system face when presented with a situation of a minor refusing treatment

Figure 4 is a visual representation of the interrelatedness between research, clinical, and legislative and regulatory discussions surrounding dissent. Although all three could be standalone categories, they have all played an important role in shaping one another in the ongoing discussion about dissent. The subcategories seen inside the overlapping categories in the Venn diagram will be touched on in this review, and their role on dissent will be discussed in further detail.

Figure 4:
Venn Diagram Visually Representing the Interrelatedness of the Three Categories of Discussion on Dissent



As seen in Figure 3, there are variations in the number of articles regarding pediatric dissent in research (51), clinical (31), and case studies (13), and there are differences in how the research and clinical articles address the topic. The articles were broken down into two or three categories depending on how much they discussed dissent. In the 31 clinical articles, there were 11 articles that discussed dissent, while the remaining 20 did not elaborate on the subject. Of the 56 research articles, 8 were considered full-text discussions on dissent, 15 had a designated section of the article discussing dissent, and 28 articles did not elaborate on the topic. Out of a total of 95 articles on dissent, 76% used the wording 'dissent', while the other 24% did not mention the word dissent, but rather used words (referred to as 'dissent terminology' below) such as *refuse* or *refusal*, *object* or *objection*, *decline*, and *withdraw*. A review of where the words were located produced the following results: 67% of dissent terminology was only found in the body of the article. In 5% of the articles, dissent terminology was found in the title, abstract, and body, while in 7% of the articles, it was only found in the title and body of the article. Finally, in 20% of the articles, dissent terminology was found in the abstract and body[4]. Within the three main categories of this review on dissent: research, clinical, and Canadian legislation and regulatory framework, three subcategories emerged. The results of the three subcategories will be discussed below in the following order: 1) Current Views on Dissent; 2) A Minor's Capacity and its Complexity; 3) Lack of Guidelines and Clarity Regarding a Minor's Capacity and Dissent. Subsequently, the results for the Canadian legislation and regulatory frameworks will be discussed. These

[4] Values were rounded down for the purpose of the discussion. Exact values are 67.37; 5.26; 7.37; and 20.00 respectively.

results have been grouped in Table 1 and will be discussed separately from the literature review completed for the clinical and research settings.

1. Current Views on Dissent

There is a significant gap in the literature regarding pediatric dissent in both clinical and research settings. With a total of 95 articles found in this review, only 19 of them discussed dissent and its ethical implications for clinical settings or research with minors. Some of the research literature, 15 (29%) articles to be exact, carved out space to elaborate on dissent, but most articles, 28 (55%) of them to be specific, did not elaborate on dissent. Only 11 (35%) articles in the clinical section discussed dissent while the other 20 (65%) mentioned it, often only in passing as an addition to their assent discussion. This means a total of 19 (20%) out of 95 articles discuss dissent, its implications, and the related ethical considerations.

While dissent affects minors of all ages up to the age of majority, it is generally accepted that infants and very young children cannot make treatment decisions for themselves autonomously (American Academy of Pediatrics, 2016; Canadian Paediatric Society, 2018). Including young children and school age children in their care is recommended, although debate remains on how to do so. In research settings, assent requirements are “clearly mandated” while in clinical settings, assent is a recommendation for HCPs to follow, very little is actually written about dissent (American Academy of Pediatrics, 2016). Many researchers and clinicians are therefore left with little guidance regarding the age of dissent, whether a capacity assessment should be done before a minor can truly assent or dissent, and how differentiate true dissent from a minor simply having a bad day.

In the context of research, it is a "widely supported view that the dissent (or distress) of a [minor] should always be respected, at least when the research does not offer potential benefits directly to the [minor]" (Giesbertz et al., 2014). This statement is supported by many authors (Hammer, 2016; Kong et al., 2016; Lepola et al., 2022; Lind et al., 2003; V. A. Miller & Nelson, 2006). An essential component of ethical research is the ability to consent and to withdraw consent, or, in the case of minors, assent and withdraw assent. Withdrawl of assent is a form of dissent.

The Research Context Despite this widely held view, dissent in research settings, as shown in the data below, is not always well supported in practice. In 2013, Dove et al., (2013) did a review of Informed Consent Forms (ICF) in pediatric research in Canada and found that "fifty-six percent of the forms did not address a [minor]'s ability to dissent" (2013, p. 4). The same study found that some Informed Assent Forms (IAF) and Informed Consent Forms (ICF) "addressed the right to withdraw only to the parents and not to the [minor]" (2013, p. 4), but did not specify the number of documents for which this was the case. While this issue was found to be widespread within the consent forms in Canada, it does not only affect Canadian research and IAF/ICF (Johnston, 2006; Michaud et al., 2015; O'Lonergan & Forster-Harwood, 2011; Twycross et al., 2008; Unguru et al., 2010). Many studies have also shown that minors have felt that they could not withdraw from or decline to participate in research for various reasons. The authors of a study of pediatric oncology patients found that 38% of participants felt unable to dissent to participating in the trial (Unguru et al., 2010). Johnston (2006) found that although minors understood they could withdraw, they often were unsure of how to do so or felt they could not withdraw without disappointing others. Similar findings by Unguru et al.,

(2010), Twycross et al., (2008), and Michaud et al., (2015) suggest that physician and parental pressure, fear of disappointment, and uncertainty with regard to how one might express dissent or withdraw from the study are predominant issues in pediatric research.

The Clinical Context Dissent is often discussed simultaneously to assent. Therefore, the notion of assent will be included in this review to facilitate discussion of dissent. To begin with, there are two predominant assent models present in the literature. Which of these models one adopts directly affects decision-making surrounding dissent. The first, most prominent model is supported by Bartholome, (1989), Gilmour et al., (2011), Hickey, (2007), Wasserman et al., (2019), and others. This model is more widespread and is focused on ensuring minors feeling included in their care, empowering them, and building trusting relationships with healthcare providers. Although Bartholome (1989) argues that assent should always be sought, he does make it clear that if dissent cannot be respected, the physician should apologize to the minor "for the fact that the [minor] was 'forced' to undergo the intervention against [their] wishes" because it disrespects the minor as a developing person (1989, p. 264). Similarly, Wasserman et al., (2019) argues that despite a minor's dissent to a certain treatment, if that treatment is necessary and will proceed, assent should be sought. Seeking assent and expressing regret when a physician must treat the minor over their objections is believed to promote respect for minors (Hallström & Elander, 2004; Wasserman et al., 2019). The ideals for this model are great in theory, but in practice, they can lead to significant harms. This model is often criticized because it offers the perception of decision-making authority to minors without the intention of respecting that authority. For the purposes of further discussion, this model will be called *participation assent*.

The second model supported by the American Academy of Pediatrics, (2016), Leikin, (1983), Sisk et al., (2017), and others, operationalizes assent as an authorization given by the minor. In this model of assent, if a minor is recog nized to have the decision-making capacity to assent, they also have the capacity to dissent. This means the minor's dissent will be respected, with regard to the particular decision they are determined capable of assenting or dissenting to. Sisk argues that "not accepting dissent as a potential outcome of decision-making 'makes a mockery of the whole idea of assent'" (Sisk et al., 2017). Leikin (1983) agrees with this view, stating that "If assent is to be honoured, then dissent should be binding. If not, a promise has been broken, showing disrespect for the minor, which leads to mistrust of the physician or parents or both" (1983, p. 174). These authors believe that a minor should not be given the option to assent if the option to dissent will not be respected. For the purposes of subsequent discussions, this model will be referred to as *authorization assent*.

Because assent is so prominent a question in the treatment of minors in clinical settings, the Canadian Paediatric Society (CPS) and the American Academies of Pediatrics (AAP) have both published position statements on assent and the inclusion of minors in care. The CPS believes assent to be "essential [in] recognizing and respecting any young patient's intrinsic value" (2018, p. 139). According to the CPS and Hickey, (2007), seeking assent empowers minors (2007, p. 101), "reduce[s] patient anxiety, promote[s] trust between patients and HCPs, and acknowledge[s] a patient's developing autonomy" (2018, p. 143). However, the CPS cautions HCPs not to give minors the impression that assent and engagement in care give them more control or decisional power over their care (Canadian Paediatric Society, 2018). Similarly, the AAP supports

that no one should solicit a patient's views without intending to weigh them seriously, supporting an authorization model of assent. In situations in which the patient will have to receive medical care despite their objection, "the patient should be told that fact and should not be deceived" (2016, p. e8). These quotes reveal an uneven relationship between assent and dissent, in that the CPS still encourages assent for the participation of minors, but it is not necessarily an authoritative assent model being used. As a result, if a minor dissents, it may not be respected because the goal of obtaining their assent was the inclusion of the minor in the care process and not for decision-making purposes. The AAP, on the other hand, argues that if an adult is to solicit assent from a minor, the assent is authoritative and will be respected and, in turn, so will the dissent. It cautions, unlike the CPS, that if dissent cannot be respected, assent should not be sought.

Although dissent is not ignored according to the proponents of the participatory model of assent, it does not have equal standing as assent. According to the former view, if a minor continues to dissent even after attempts of negotiation or in the case of significant dissent, the CPS suggests "careful reconsideration of the medical necessity, risks and benefits of a proposed treatment [as] an essential step before continuing" (2018, p. 143). This suggestion is not unique to the Canadian Paediatric Society. Bartholome, (1989) and Gilmour et al., (2011) agree that persistent objection from a minor "demands respect" and "should be taken seriously" (1989, p. 263; 2011, p. S208).

This demonstrates how the two models of assent are applied in pediatric settings and how they affect dissent. Further discussion of these models of assent, and their implications with regard to dissent, will be included in the next chapter.

2. Minor's Capacity and its Complexity

Of the 95 articles, 88 (92%) discussed a minor's capacity to some extent. Out of those 88 articles, 78% of them discussed the minor's ability to make treatment decisions using the words capacity or competence, while 22% of them used the term *understand*. Only 5% of the articles solely used the term capacity, and 74% used a combination of the words *capacity* and *understand* to explain a minor's ability to make treatment decisions for themself. In this section, the difficulty of assessing a minor's capacity will be discussed, followed by a rebuttal of the misconception many hold that minors are incompetent. Finally, the challenge faced as minors develop more decision-making capacity vis-à-vis treatments will be discussed.

Assessment of a Minor's Capacity Tools have been created or adapted for minors' capacity assessments such as "the Competency Questionnaire, the Hopkins Competency Assessment Test, the MacCAT-T and MacCAT-CR and the Structured Interview for Competency and Assessment Testing and Ranking Inventory" (Hein, Troost, et al., 2015). However, for the assessment of a minor's ability to make treatment decisions, these tools have been deemed inadequate by some authors. (Hein et al., 2012; Hein, Troost, et al., 2015). These tools have been developed to assess an adult's competence, and even when adapted for minors, which they rarely are, they are still insufficient. Hein, Troost, et al., (2015) describe the absence of a "clear definition and operationalization of children's competence" and say the focus of future studies should aim to improve the assessment of minor's competence, i.e. understanding, appreciation, reasoning, and expression of a choice (2015, p. 4). There is also limited knowledge on the

applicability and reliability of these tools for minors[5] as "only one study confirmed feasibility of the MacCAT-CR in [minors] and MacCAT-T has only been applied in adolescents" (Hein et al., 2012; Hein, Troost, et al., 2015).

Minors as Capable Decision-Makers Reportedly, some children as young as five years old are capable of assent (Roth-Cline & Nelson, 2013; Waligora et al., 2014), although a greater number of studies have shown that "school age" children, i.e. those of 7 to 12 years of age, have the ability to "participate meaningfully" (Weithorn & Campbell, 1982) in treatment decision-making (Abramovitch et al., 1991; Geller et al., 2003; S. Miller, 2000; Weithorn & Campbell, 1982).

There is still debate as to when a minor has sufficient capacity for their assent to be considered equivalent to informed consent, particularly for older and mature minors. The major issue at play is when does a minor develop the capacity and/or become old enough to refuse the treatment that adults believe to be in their best interest. It would be logical, as De Lourdes Levy et al. (2003) have said, to "assume that if [minors] are competent to consent to a procedure, they are also competent to refuse it" although this seems to pose additional issues.

One issue lies in the assumption that children, especially young children, lack capacity. Some authors such as O'Hearn et al., (2018) believe that "[t]o provide dissent, the individual must have capacity to understand the implications of their decision" (O'Hearn et al., 2018). Many authors share this view, saying minors must comprehend (Cotrim et al., 2021), understand, or that one should "consider [a minor's] competence to

[5] At the time of this review, no capacity assessment tools have been standardized or found to be reliable for younger children.

refuse or dissent"(Hein, De Vries, et al., 2015). Roth-Cline & Nelson (2013) argue that "by assuming a lack of capacity among young children, the potential arises to dishonour and disregard a minor's wishes by failing to solicit meaningful assent or dissent" (Roth-Cline & Nelson 2013). Cotrim et al., (2021) also point out that information should be presented in an age-appropriate manner in order for the minor to understand the information provided to them and therefore have the ability to provide meaningful assent or dissent. Authors such as Alderson et al., (2006), Hallström & Elander, (2004), and Loeff & Shakhsheer, (2021) have argued that minors are not mature enough and lack life experience;, they invoke the minor's specific cognitive development and capabilities for decision-making as well as their health condition as reasons why minors are not well placed to make life-altering treatment decisions such as treatment refusal. However, according to these same authors, if a minor does not demonstrate sufficient capacity to make treatment decisions, it is still important to include them in the care process and take their dissent seriously (Alderson, 2007; Alderson et al., 2006; Hallström & Elander, 2004; H. Harrison, 1993).

Challenges When Minors are Competent Decision-Makers The concern with capacity and refusal becomes more challenging when the minor is older and demonstrates a higher capacity level for decision-making. Comparative studies on minors' decision-making with adults have been done and several authors in this review agree that "adolescents have the capacity to understand important informational elements in a research study in a manner similar to adults" (Roth-Cline & Nelson, 2013). If many adolescents have similar decision-making capacity to adults, they are, ipso facto, capable of deciding on certain treatment options for themselves (Dickey & Deatrick, 2000;

Mercurio, 2007; Weithorn & Campbell, 1982). Dickey & Deatrick, (2000) have said that "although many health care providers believe that the ability to make reasonable informed consent decisions is based on abstract thinking and formal operations as described by Piaget in 1972, Dickey, (1992) found that an adolescent need not possess formal operational, abstract thought to participate in valid health care decision-making"[6] (Dickey, 1992; Dickey & Deatrick, 2000; Piaget, 1972). Furthermore, in a study by Weithorn & Campbell (1982), adolescents age 14 and above demonstrated comparable decision-making capacity as adults on the condition that all the information was provided to them. According to Mercurio, (2007), pediatricians have recognized that some adolescents are capable of making treatment decisions and could therefore make them just as well as adults.

Over half (61%) of the authors agree that the lower the risk and the higher the capacity (generally the older the minor), the more weight their opinion should have on the final decision. In other words, if the risk is low, the capacity requirements will also be lowered for that decision. For example, any minor may choose the placement of a catheter, or which arm they would like to have their blood drawn from in a non-emergency. When the risk and benefit ratio increase, the requirements for capacity increase. Arguments for accepting the refusals of adolescents who show higher decision-making capacity are more complex. Organizations such as the American Academy of Pediatrics, (2016) support limiting an adolescent's short-term autonomy to preserve "long-term autonomous choice and an open future" (2016, p. e12). That is to say, in cases

[6] Dickey's (1992) study sought to address the relationship between gender, age, developing operational thoughts, and the ability of adolescents to make healthcare decisions. While it was believed that competency and the ability to reason formally were mutually dependant, his study showed no significant relationship between the two.

of life-saving treatment, the AAP maintains that is ethically justifiable to limit a minor's autonomy and not accept their treatment refusal. However, Ross (2009) underlines how, in practice, the justice and medical systems tend to undermine adolescent autonomy. The author spells out a few possibilities, one being that "the mature adolescent's autonomy is overridden when [their] actions are against [their] parents' perception of what is in [their] best interest" and the second is that the "mature minor's doctrine is only invoked when the parents concur [with the minor's decision], which makes one question whether the courts' decisions are truly being based on respect for adolescent autonomy" (L. F. Ross, 2009). That being said, it seems that when lifesaving treatment is available, there are arguments to undermine the family or the adolescent's refusal (e.g., the best interest of the child, the right of the minor to an open future), current trends suggest that adolescents are being given more decisional power over their care, especially if their parents are supportive of a refusal.

Ethical challenges arise in cases where the capacity of minors is misjudged. On the one hand, a minor may not possess the capacity to make a decision but may be deemed to have capacity and therefore given the option to assent or dissent to care. In this case, adults unknowingly make a minor responsible for a decision they are not ready to make. If the decision is a refusal, the refusal may be respected, which could lead to considerable harm in terms of clinical outcomes if the decision does not align with their best interest. Or, the refusal could be rejected, and the autonomy of the adolescent would be disrespected under the pretext of the best interest standard. In other cases, a minor may have decision-making capacity, but be judged to lack it and will be denied the

opportunity to make decision for themselves (Leikin, 1983). In this case, once again, moral harm is done by disrespecting the minor's agency.

Talati et al., (2010) studied the reaction of pediatricians to refusals of treatments by minors and the results have proven to be ethically challenging. Duncan and Sawyer (2010) relate Talati et al., (2010) findings perfectly, explaining that "[t]he more important finding from an ethical perspective is the fact that paediatricians' views also depend on the prognosis of treatment. When the prognosis of treatment is good, 72% of paediatricians would ignore a 16-year-old's refusal when the parents are in favour of treatment. When the prognosis is bad, only 35% of paediatricians would ignore the refusal when parents are in favour." In this scenario, the minor's capacity did not change, the prognosis did, supporting Ross's argument that adolescent autonomy is not truly a treatment or the justice system's goal. On the other hand, the scenarios described by Talati et al., (2010) align with the commonly held view supported by the AAP and described earlier that a minor's short term autonomy can and/or should be limited in the interest of their right to an open future.

3. Lack of Guidelines and Clarity Regarding a Minor's Capacity and Dissent

Research is often voluntary and does not provide direct benefits to the participants. Therefore, the risks of stopping any procedure when the minor dissents are quite low. This is not the case in clinical settings. Although there is a need for more guidelines on how to assess a minor's competence, since this seems to create a sort of bottleneck for respecting their dissent, authors such as Duncan & Sawyer (2010) and Hein et al. (2015) believe there also needs to be a consensus within the discussion of assent, dissent, capacity and the creation of guidelines. Hein et al. (2015) states the

following: “The current situation has been referred to as a ‘hodgepodge of practices’: there is no gold standard and no hard empirical data. [T]he MacCAT tools have ranked the highest and are considered the best choice for measuring capacity to consent to treatment and clinical research in adults, nonetheless, assessing competence to consent in minors, even with adequate tools such as the MacCAT, is still lacking” (2015, p. 4).Other authors in the research field have echoed Hein et al., (2015), saying, “[t]he definition, purpose or scope of assent (like the interpretation of dissent) remains woefully ill-defined” (Tait & Geisser, 2017). In many cases for research, parents are asked to help interpret their child’s behaviour, statements, and whether their child is assenting or dissenting to the research (Waligora et al., 2014). Some authors such as Giesbertz et al., (2014) have commented on the difficulty of differentiating between valid dissent, a young minor’s silence, or a young minor simply being unhappy because they wanted to play on the playground. To add to this complex issue, when researchers are asked to evaluate the minor’s capacity to assent or dissent to research, very little guidance is generally given. (Waligora et al., 2014).

Unlike within the context of research, when a minor dissents to care, the risk and benefit ratio changes significantly, so the ability of a minor to withdraw from the care plan at any time is not usually an option. Many healthcare providers find themselves in a complex ethical dilemma when facing a dissenting minor. Not only do they have to take into consideration the risks and benefits of the proposed intervention, the timeline of the intervention at which the dissent happens, the age of the minor, their capacity, the wishes of the family, and the minor’s wishes, but also their own biases that may be influencing their judgment (De Lourdes Levy et al., 2003; Dell et al., 2008; Grady et al., 2014). In

Canada, few provinces have established a minimal age for minors to consent to medical treatment (Hesson et al., 1993), while other provinces do not have a specific age requirement, but rather specify that the minor needs to demonstrate capacity (See Table 1 for a more detailed provincial breakdown). The Confederation of European Specialists in Paediatrics supports the obtention of assent while treating minors, although they specify in their policy statement "that all [minors] have a right to give their assent or dissent and that they may effectively refuse treatment or procedures that are not necessary to save their lives or prevent serious harm" (Lee et al., 2006). Duncan & Sawyer (2010) comment on the "difficult position [of health professionals]; charged with the task of assessing competence in young people but lacking the adequate resources to do so" (2010, p. 113). Overall, there seems to be a lack of guidelines and resources to help HCPs assess a minor's capacity to assent or dissent, as well as a lack of clarity on how to handle a minor dissenting.

Canadian Legislative and Regulatory Landscape Results

Table 1:

Legislative and Regulatory Frameworks Across Canada Related to a Minor's Consent to Medical Treatment

Province	Consent Definition Present in Reviewed Acts	Consent Definition Present in Reviewed Regulations	Age of Majority	Medical Age of Consent	Capacity Framework in Legislation and Policy	Mature Minor Provincial Framework
British Columbia	Yes[a,b]	Yes[c]	19[a,d]	Under 19[b,c,d]	A[a,b,c] D[c] E [c]	Individual capacity assessment[b,d]
Alberta	No	Yes[e,f]	18[d]	"mature minor"[e]	A;D;E[f]	Individual capacity assessment[d]
Saskatchewan	No	Yes[g]	18[d]	16[g,h]	A[g,h] E[g,h] D [g]	Individual capacity assessment[d]
Manitoba	Yes [i]	N/S	18[d,i,j]	16 [d,i,j]	A;E[i,j] B[i]	Mature minor at 16 years old Under 16 years old → individual capacity assessment[d,i]
Ontario	Yes[k,l]	Yes[m]	18[d]	16[k,l]	A;C;E[m]	Individual capacity assessment[d]
Quebec	Yes [n]	N/A	18[d,n]	14[d,n]	N/S	N/A
Newfoundland	No	Yes [o]	19 [d]	16[d,o]	A;E[d,o] C [p]	Legal Age at 16 **Under 16 years old → presumed to lack capacity[d]
New Brunswick	Yes [p]	N/A	19 [d]	16 [p]	A;D;E [p]	Mature minor at 16 years old Under 16 years old → individual capacity assessment [d]
Nova Scotia	No	Yes [q,r]	19 [d,r]	N/S	A[q,r] B[q] D[q,r] E[q,r,s]	Individual capacity assessment[d]
Prince Edward Island	Yes[t]	N/A	18[d]	16[t]	A;C;D;E[t]	Individual capacity assessment[d]
The Yukon Territory	Yes[u]	N/A	19[d]	16[u]	A;D;E[u]	Individual capacity assessment[d]
The Northwest Territories (NWT)	No	N/S	19[d,v]	N/S	E[v]	N/S
Nunavut	No	N/S	19[d,w]	N/S	A;E[w]	N/S

Notes:
[a] (*Health Care (Consent) and Care Facility (Admission) Act*, 2023)
[b] (*Infants Act*, 1996)
[c] (*The Infants Act, Mature Minor Consent and Immunization | HealthLink BC*, 2022)
[d] (Canadian Paediatric Society, 2018)
[e] (College of Physicians & Surgeons of Alberta, CPSA, 2016)
[f] (Alberta Health Services, 2020)
[g] (College of Physicians and Surgeons of Saskatchewan, 2022)
[h] (*Health Care Directives and Substitute Health Care Decision Makers Act, 2015, H-0.002*, 2015)
[I] (Manitoba, 2004)
[j] (*The Health Care Directives Act, C.C.S.M. c. H27*, 1992)
[j] (Manitoba, 2004)
[k] (*Health Care Consent Act, 1996, S.O. 1996, c. 2, Sched. A*, 1996)
[l] (*Substitute Decisions Act, 1992, S.O. 1992, c. 30*, 1992)
[m] (College of Physicians and Surgeons of Ontario, 2001)

[n](*Chapter CCQ-1991 CIVIL CODE OF QUÉBEC*, 1991)
[o] ("Standards of Practice and Practice Guidelines-Consent to Treatment," 2019)
[p] (Government of New Brunswick, 1976)
[q] (NS Health & IWK Immunization Working Group, 2021)
[r] (Standards & Guidelines College of Physicians & Surgeons of Nova Scotia, 2016)
[s] (*Personal Directives Act*, 2008)
[t] (*CONSENT TO TREATMENT AND HEALTH CARE DIRECTIVES ACT*, 1988)
[u] (*Yukon Legislation - Care Consent Act*, 2022)
[v] (*PERSONAL DIRECTIVES ACT S.N.W.T. 2005,c.16*, 2005)
[w] (*CONSOLIDATION OF GUARDIANSHIP AND TRUSTEESHIP ACT S.N.W.T. 1994,c.29*, 1994)

*Capacity legend:
A - Treatment specific
B - define different levels of capacity
C- Capacity can change over time
D- individual assessment needed
E- capacity is defined
**Newfoundland and Labrador : a person under 16 years of age is presumed to lack capacity but this may be rebutted (Canadian Paediatric Society, 2018)

Table 1 represents a synthesis of the results of the Canadian legislature and regulations regarding dissent. A review of the results presented in Table 1 summarizing the key differences between the provinces and territories will be done, followed by a contrast of the common law mature minor doctrine in Canada and the United States.

In this review, there was very minimal interpretation of the legislation conducted and no articles describing different interpretations were used for this review. The goal was to compare the current legislative and regulatory frameworks in place in different provinces on a surface level. The first thing to note is that this table is not exhaustive of list all acts and regulations regarding healthcare or minors, but includes those relevant to minors' decision-making in healthcare contexts. An important detail regarding Canada's legislation is that only three provinces of the thirteen provinces and territories had regulations enacted specifically concerning minors and medical treatment decision-making at the time of this review: Quebec's[7] Chapter CCQ-1991, British Columbia's Infants Act, and New Brunswick's Medical Consent of Minors. The second thing to note

[7] Quebec, unlike the rest of Canada, uses the Civil Code. The remainder of Canada and the USA uses common law, therefore it will be the assumed legal system in which the discussions in this review will take place.

is that nothing in Table 1 is about dissent; all legislative and regulatory frameworks at the time of writing this review are in reference to consent and nothing was available that was specific to dissent. The lack of results on dissent is significant and demonstrates the second knowledge gap found in this review pertaining to the Canadian legislative and policy framework regarding minors' decision-making in healthcare.

Canadian Legislative and Regulatory Landscape As identified in the first and second columns in Table 1, not all acts and regulations defined consent within the document (only 7 acts and 6 policies). The age of majority is relatively uniform from one province to another, but the age at which a minor can make medical decisions for themselves varies. Alberta does not impose an age limitation, but rather specifies a capacity standard for mature minors, while other provinces and territories such as Nova Scotia, the Northwest Territories (NWT) and Nunavut have no age or capacity limitations set officially. The capacity framework did vary slightly; three provinces and territories stood out amongst the rest: Quebec, the NWT, and Nunavut. Unlike the rest of the provinces, Quebec has the lowest age (14)[8] at which a minor can make legal decision for themselves, including medical decisions (Canadian Paediatric Society, 2018; *Chapter CCQ-1991,* Civil Code of Québec, 1991). Every province and territory, with the exception of Quebec, defines *capacity* in their regulations. The Quebec civil code Chapter CCQ-1991 (Chapter CCQ-1991, Civil Code of Québec, 2023), has many passages about capacity, yet the term itself is not defined within the document. Nunavut

[8] Other provinces and territories may allow a minor younger than 14 years old to make treatment decisions for themselves if they are deemed a mature minor.

has a brief framework of capacity laid out with some specificities while the NWT had the broadest framework. The NWT defines capacity as the ability to understand the information and appreciate "reasonably foreseeable consequences" (*PERSONAL DIRECTIVES ACT S.N.W.T. 2005,c.16*, 2005). Nunavut adds that capacity is the ability of a person to understand by themselves or with assistance, information relevant to "making decision[s] concerning [their] own healthcare" (*CONSOLIDATION OF GUARDIANSHIP AND TRUSTEESHIP ACT S.N.W.T. 1994,c.29*, 1994). All other provinces and territories had capacity definitions that were more specific because of the inclusion of one or more of the following details: there are different levels of capacity and each level is defined; a person's capacity can change over time and therefore needs to be continually assessed; a person's capacity must be assessed on an individual level.

Mature Minors Finally, in Canada, the mature minor doctrine is recognized by most provinces and territories, but not applied equally. Some provinces use a specific age as a determining factor, while others use capacity assessment as the mature minor regulatory framework. In Quebec, starting at the age of 14, an individual is considered capable of making medical decision for themselves, but the term *mature minor* is not recognized (*Chapter CCQ-1991 CIVIL CODE OF QUÉBEC*, 1991; Council of Canadian Academies, 2018). In Manitoba and New Brunswick, a mature minor is recognized at the age of 16, and if the minor is under 16, a capacity framework is used to determine whether or not they are a mature minor (Canadian Paediatric Society, 2018; Government of New Brunswick, 1976; Manitoba, 2004). A similar minimum age is found in Newfoundland and Labrador, but the language used for minors under 16 years of age

changes to a person presumed to lack capacity; this presumption can also be rebutted (Canadian Paediatric Society, 2018).

The mature minor doctrine is applied slightly differently in the United States (US) than in Canada. In Canada, the mature minor doctrine is not officially defined in the federal legislation. Rather, the courts recognize certain "individuals with the capacity to make an informed healthcare decision but who have not yet reached the age of majority" (Council of Canadian Academies, 2018). Many factors are at play such as voluntariness, understanding, severity of the illness, risks and benefits of the treatment or alternatives, and more specific provincial stipulations that may come into play. Once a minor is declared to be a mature minor in Canada, they are legally recognized to have the competence to make their own medical decisions, be it to accept treatment or refuse it. In the US, the mature minor is not recognized as able to make all medical decision for themselves (Coleman & Rosoff, 2013). As Hickey, (2007) puts it "[t]his 'maturity' authorizes the minor to make decisions regarding his or her medical treatment. It does not, however, provide carte blanche permission for minors to make decisions regarding medical treatment without parental consent" (Hickey, 2007). The major constraint to a mature minor's ability to make medical decisions is when they are making life-limiting decisions about their care. While this review is focused on the Canadian system, many articles included are written from an American perspective, and consequently, the mature minor doctrine is often discussed with this constraint in mind.

Chapter 4 - Discussion

The dissent literature, although sparse, raises some interesting dilemmas. In the research setting, the bottleneck is found in HCPs wanting regulations and more guidance regarding dissent. In the clinical setting, the two models of assent run the risk of disrespecting a minor's preferences, as well as minimizing their capacity to participate in their care, which can cause moral harm. When looking at a capacity standard, the risk of excluding younger minors from dissent because they lack sufficient capacity is elevated in both settings. Since assent is required in research, guidelines have been created to help navigate the issue with minors. Little has outlined the management of dissent in non-therapeutic and therapeutic research for varying age groups. Finally, the regulatory frameworks in Canada do not seem to offer a clear consensus on managing a refusing younger minor or adolescent, as cases of precedence are very individualized and most laws pertaining to medical treatment and decision-making are still focused on the paradigmatic case of adults and only consider consent, not dissent.

A select few of the results will be discussed in greater detail to allow for adequate development of each topic. First, the impact of the two models of assent on an understanding of dissent will be explained. Second, the influence of capacity on the models of assent and dissent will be discussed. Finally, this section will conclude with a examination of the challenges and reasons underlying the lack of regulatory guidance related to dissent in Canada.

Assent Models

Assent Requirements As discussed in the previous chapter, there are two predominant models of assent that appear in the literature. Each of these has different requirements, and different implications for how one might understand dissent. Bartholome, (1989), who supports the participation assent model, offered the following as the requirements of assent, with subsequent definitions being very similar:

1. One must assist the child or adolescent in developing an age or developmentally appropriate awareness of the nature of the illness;
2. One must disclose to the child/adolescent the nature of the proposed treatment and what they are likely to experience;
3. One must solicit the child's or adolescent's expression of willingness to undertake the proposed treatment.

This definition is still used for participation assent models.

In newer requirements for assent, particularly for authorization assent models, there is a fourth requirement, that is a capacity or understanding assessment[9]. For example, “making a clinical assessment of the patient’s understanding of the situation and the factors influencing how he or she is responding (including whether there is inappropriate pressure to accept testing or therapy)” (American Academy of Pediatrics, 2016). It will be shown below, using an example, why this fourth requirement makes a difference in care.

[9] In many circumstances, the requirement for assisting a minor in understanding the information given to them and assessing their understanding of the information presented is done simultaneously. Because of this, it is common to see only three assent requirements instead of four.

Why are these assent requirements essential? It is because they set a guideline for clinical and research settings on what is expected when acquiring assent from a minor. These requirements are crucial for acquiring a minor's *authorization*, i.e., giving them decisional authority to assent or dissent. The additional fourth requirement, which assesses capacity, tells the assessor whether or not the child is capable of understanding what they are assenting to.

Below a presentation of the participation assent model will be given, followed by a discussion of its strengths and limitations. One limiting factor of this model is the risk of disrespecting of a minor's true preferences are higher due to the minors not being given true decision-making authority. Following this, arguments supporting the authorization assent model will be presented. Two of the reasons given in support of this model are that adults will only seek assent or dissent when they intend to respect the minor's decisions and this model respects the minor as a moral agent.

Participation Assent In the participation assent model, assent could be replaced by participation, inclusion in care, shared decision-making, or similar synonyms. When assent becomes any of those other things, adults risk of disrespecting a minor's preferences and therefore causing harm. The participation assent model is criticized because of the dilemma faced when assent is respected, but dissent is not (American Academy of Pediatrics, 2016; Leikin, 1983; Sisk et al., 2017). Participation assent does not use assent as a way to solicit and respect a minor's true preferences according to their ability to understand. This makes the assent meaningless. Assent should be a way for the minor to authorize something, but in the case of participation assent, the assent is no longer solely to authorize, but to give the minor a sense of autonomy and control. It is

used to simply give the minor a perception of empowerment (Hickey, 2007) by having their preferences heard, when ideally, assent should empower the minor because their preferences will be respected (Canadian Paediatric Society, 2018).

Minor's inclusion in care is an important care goal that continues to evolve and that adults should continue to strive for, but assent may not be the ideal tool achieve inclusion. In the case of participation assent, a minor's assent will always be supported. The minor is "going along" with the adult's care goals for the minor. The decision-making abilities of the minor, in other words, the minor's agency is not actually respected in these cases, because a refusal would not be respected. If adults only approve of a minor's acquiescence because it mirrors what they believe to be in the minor's best interest, but would not respect differing opinions from the minor, it demonstrates inconsistency in the treatment of the minor as a moral agent. This causes moral harm. As mentioned earlier, this view of assent is common and may help create a trusting relationship between the minor and the HCPs. If decision-making authority were given to the minor and then revoked, the opposite may happen. In such a case, the minor is not respected as a developing person whose growing autonomy must be cultured, and the trusting relationship between the patient and HCPs may be threatened. In cases where participation assent is promoted, it is often argued that a minor will assent or dissent without fully understanding the circumstances (Canadian Paediatric Society, 2018). As seen in the Results section, authors such as Bartholome, (1989) and Wasserman et al., (2019), argue that overriding a minor's dissent is acceptable as long as the HCPs apologize for disrespecting the minor. The following example illustrates why participation assent is problematic.

Scenario: Juliette is nine years old and hurt her hand when she fell off her bike. Her parents have her seen by her pediatrician. Juliette is cooperative and allows the pediatrician to examine her. The pediatrician sees swelling and bruising, which they explain to the parents, as well as to Juliette, and indicates they would like to do an X-ray. When Juliette is asked if it would be "Okay if we took a 'picture of the bones in her hand,'" she says "no". When her parents and her pediatrician attempt to explain that she may have broken bones, Juliette is adamant that she does not want pictures of her bones taken.

In this scenario, Juliette is refusing care she needs. The issue here is that the pediatrician went through the steps of participation assent, i.e. they sought Juliette's preferences, giving her the impression she had authority but did not have the intention of respecting those preferences if they did not align with the adults' goals of care. They helped Juliette understand what was happening to her hand in an age-appropriate manner, they explained to both her parents and Juliette the next part of the treatment plan, in this case the need for diagnostic imaging, and they solicited assent or dissent. All her preferences have been met, but the doctor and her parents are about to disrespect a preference of hers by forcing her to have an X-ray. With participation assent, HCPs and caregivers run the risk of disrespecting the minor often by offering assent, which gives space for dissent, while having no intention of respecting the minor's dissent. In Juliette's case, it would have been preferable to include her in her care in a multitude of different ways (clear explanations of the injury and treatment plan, active listening to her needs, etc.) without offering the option of assenting to the x-ray if dissenting was not possible. There are plenty of reasons Juliette may be refusing an x-ray that could potentially be

worked through before having to get to the point of breaking a trusting relationship. It could be argued that if the minor assents or dissents while not fully understanding the nature of the situation, the minor should not have been given the option to assent or dissent in the first place, as per the fourth requirement for assent.

As seen in Juliette's case, participation assent is not necessary for the inclusion of minors in their care. In fact, inclusion of minors should always happen. However, HCPs ought to be aware that soliciting assent also gives space for dissent. Despite this, under the model of participation assent, dissent will often be overruled if the adults believe that what is being proposed is in the minor's best interest. Why then use assent as a participation tool, rather than what assent is truly meant to be, that is a tool to acquire a minor's authorization, and not develop a separate one for participation? A suggestion proposed for this limitation by Roth-Cline & Nelson, (2013) is one should only seek assent from minors when it comes to simple preferences to avoid having to deal with potential dissent when the stakes are high (American Academy of Pediatrics, 2016; Roth-Cline & Nelson, 2013). This suggestion aligns with the authorization model of assent.

Authorization Assent The authorization assent model is compatible with the practice of respecting dissent and supporting minor's dissent to care and research, though it still has limitations. The authorization model is most similar to the current understanding of informed consent; a patient can give their permission for or authorize a test, treatment or medical procedure and the patient can also refuse any of it. Similarly, on the authorization assent model, if a minor is given the option to assent, they are also given the option to dissent, and both must be respected. As reason would suggest, if one is to be honoured (assent), so should the other (dissent). This means that, under the

authorization model of assent, dissent is given as much decisional space and authority as assent in pediatric care and research. In a clinical setting, this would mean that a minor who is judged capable of assenting to something, be it some test, treatment, or procedure, is also capable of dissenting to those same things, and the adults must respect that dissent.

Although this model of dissent seems to give minors more power over their care (i.e., being able to assent or dissent), it does have its limitations. The biggest limitation is that it depends on a minor's capacity entirely, as highlighted in the fourth assent requirement mentioned above. When a clinical assessment is done on a minor's capacity to understand, the clinician or investigator would then also assess the level at which the minor is capable of making decisions. This results in minors who have lower decision-making capacity not being given the opportunity to assent or dissent to a particular decision. For example, a 10-year-old may have the capacity to choose how to treat a minor skin infection, either with a single local dose of injected antibiotic or an antibiotic ointment applied over the following two weeks. However, this minor will not be given the option to have the infection treated or not. That decision will be made for them. However, given differences in capacity, a 16-year-old judged to understand the consequences of refusing any antibiotic course of treatment may be given the option to assent or dissent to the treatment options. These two scenarios show that depending on the capacity of the minor, the physician may include a minor in the decision-making relative to their care, but not whether they will receive care; in other cases, a minor will be involved in both. While the 16-year-old has much more autonomy and control over their care because they have shown a higher level of capacity, the 10-year-old was not given the choice of being treated but did get decisional authority on how the treatment

was being administered. This does pose a problem for younger minors because it means that they do not have the option to dissent in many instances in their care if the adults believe that they lack sufficient capacity to make a decision about their care.

In instances where a decision related to care can be life-limiting, most agree that a minor's short-term autonomy should be limited in order to preserve their long-term autonomy (American Academy of Pediatrics, 2016). Under the authorization model of assent, in such contexts, a younger minor, with a lower decision-making capacity, would not be given the option to either assent or dissent. Since younger minors have a lower decision-making capacity, they would not be given the option to assent nor to dissent. They should, however, be included in their care and participate in a multitude of other, less significant, decisions regarding their health. It must be asked whether removing the option of assenting and dissenting until minors show a higher level of capacity could potentially be of detriment. Ideally, the wishes of a young minor who does not want something to be done to them are respected. The participation assent model attempts to resolve these issues unsuccessfully since it results in giving the minor the impression of decision-making authority when they do not have any. Although the participation assent model's ideals are still what the goal of inclusion in care should be, especially to fill the gaps that the authorization assent model cannot achieve, there are other methods of doing so that are potentially more beneficial to minors. Something that is becoming clear is that assent should only be called *assent* when used in the model of authorization assent, but if one wants to include minors in their care, the word *assent* may be misleading and make it sound as though minors have more decisional authority than they are truly given.

Suggestions for the inclusion of minors in their care to use as an alternative to assent will be discussed in Chapter 5.

Should dissent be respected in all cases? Yes. In cases in which a minor is asked what they would like to do, their response should be respected, regardless of whether it is assent or dissent. This means, however, that the adults caring for the minor should only offer the option of assent and dissent if they intend to respect the choice the minor makes. In the case of participation assent, the moral wrong involves offering a choice to the minor, and then retracting that choice if the minor makes the "wrong" choice. If the adults had no intention of respecting the minor's choices in the first place, the choice should not have been offered. This is often the case for necessary treatments or lifesaving treatment for a minor. In the case of Juliette described in the participation assent section, she needed an x-ray to determine the severity of her injury. Had she refused the x-ray and the adults accepted that decision knowing it was not in her best interest, further injury could have been sustained to her hand. Consequences, especially long-term ones, can be difficult for minors to consider, as discussed by Alderson et al., (2006), Hallström & Elander, (2004) and Loeff & Shakhsheer, (2021) in the Results section (p.33).

Research Setting

In this section, the application of the assent models in research assent is a requirement in research, unlike in clinical care, where it is a recommendation. The AAP clearly states this dissimilarity saying, "Informed consent and assent obtained from children involved in research are clearly mandated, in contrast to the 'recommended' guidance in place in clinical care" (2016, p. e12). The reason for this is that the intent in research is to learn, and not to provide direct therapeutic benefit to one individual, as is

the case in clinical practice. Clinical care provides individualized treatments that have already been proven safe and effective, keeping in mind the patient's best interest. Research settings, both therapeutic and non-therapeutic, cannot provide individualized treatment plans to patients as they are testing for the safety and effectiveness of a novel intervention. The best interest of the patient is no longer the primary concern; in research, the goal is generalizable knowledge. One could argue that a patient may gain some benefits from a therapeutic trial, such as a Phase 1 cancer trial, but as Ross argues, the primary goals of the trial are not in favour of the patient, but rather of science. Ross argues, "Phase I research is done to determine toxicity; the possibility of direct benefit is secondary to the objectives of the study. … Focusing exclusively on whether Phase I trials could be interpreted as offering the prospect of direct benefit fails to acknowledge the moral relevance of the researchers' intent"(L. Ross, 2006). The risk and benefit ratio must also be considered for such a trial; if the therapeutic benefits are only a possibility, are the risks worth taking against the patient's wishes (in the context of this discussion, a minor)? Therefore, if a minor is able to assent to research, just like in a clinical situation, then the minor should be able to dissent to it and their dissent should be respected.

Research Assent and Dissent Guidelines Many authors have voiced their concerns regarding the lack of guidance on dissent in clinical research and on how it should be incorporated within research settings (De Lourdes Levy et al., 2003; Dell et al., 2008; Duncan & Sawyer, 2010; Giesbertz et al., 2014; Hein, Troost, et al., 2015; Tait & Geisser, 2017; Waligora et al., 2014). A challenge presents itself when a minor dissents to research because 1) there are very few, if any, guidelines to help investigators navigate this situation; and 2) if the minor dissents when investigators followed the participation

assent model, then forcing a minor to participate in research is in direct contradiction with the "voluntary" principle of research. Given that assent is already written in the requirements and routinely assessed in pediatric research, it seems only logical to have dissent written in as regulation for investigators to respect. This could involve explicitly stating in the assent form that the minor can withdraw at any point. Having dissent explicitly stated in the IAF/ICF form would encourage a more robust use of the authorization assent model in research. This would also help investigators recognize and respond appropriately to dissent by having clearer guidelines to follow. As mentioned in the Results section, research by Dove et al., (2013) has shown that over half of IAF/ICF do not include the minor's right to withdraw from the trial. Including this information in the IAF/ICF would clarify that dissent can be proactive or retroactive once the minor familiarizes themselves with the research.

Decisional Authority of the Minor in Research Another important consideration is that therapeutic research would need to consider a minor's decision not to participate as final. Ross, (2006) suggests "that assent should be dispositive" and "[parents] should not be authorized to compel their child to participate in Phase 1 research because the research is not intended to provide direct benefit" (Ross, 2006). This is true for all clinical research. As mentioned earlier, a fundamental difference between a minor participating in research and receiving treatment in a clinical setting is that in a clinical setting, the minor will be receiving proven effective treatment supported by existing data. In a research setting there is no treatment proven to be effective, because one is in the process of being proven safe and effective. Asking a minor to participate in these trials when the risk is elevated, the potential therapeutic benefits are not the primary

goal, and the minor does not want to, is inherently wrong. This would never be done to an adult; a minor should never therefore be asked to do the same for the benefit of others.

Older Minors

The older minors become, the more decision-making capacity they have, making it more likely that they will be able to refuse care. This becomes ethically challenging for adults attempting to balance the minor's agency with their best interests. This section will discuss the additional challenges of treating minors with increased decisional capacity and argue that the authorization assent model is the best for showing respect for their growing autonomy. A second argument will be made to reinforce the importance of only presenting a choice of assent or dissent to a minor when the adult truly intends to respect the minor's choice.

Respecting A Minor's Increasing Decision-Making Capacity

Capacity in refusing care plays an increasingly important role for older minors. The model of authorization assent should therefore be used, which in practice means only allowing an adolescent to assent if their dissent will be respected. This is because typically, the more decision-making capacity a person has, the more decision-making authority that person should be given. More often than not, in practice, participation assent i.e., inclusion, shared decision-making, and building a trusting relationship, over this idea of true authorization from the minor, is encouraged under the guise of assent, especially in adolescent care (Canadian Paediatric Society, 2018; Gilmour et al., 2011; Hallström & Elander, 2004; Hickey, 2007; Wasserman et al., 2019). Dissent then becomes a very ethically challenging situation because the model of participation assent does not give any decisional authority to the minor. Some authors have even commented

that physicians may judge adolescents as having decisional capacity when the adolescent agrees with the decision at hand, but if there is disagreement, their capacity will be questioned (Alderson, 2007; Duncan & Sawyer, 2010). As argued above, if an adolescent is considered capable of assenting, they should also have the capacity to dissent. Yet, in practice, refusal seems to require a higher standard of capacity.

Uneven Respect of Dissent in Older Minors The Talati et al. (2010) study showed that dissent seemed to be held to uneven standards and that this is a common bias among healthcare professionals. Ultimately, the study found that pediatricians were more likely to respect dissent from an older minor and when the prognosis was poor, and they were more likely to respect dissent if both parent and minor agreed (Talati et al., 2010). An interesting finding is that 72% of pediatricians would disregard an older minor's dissent or refusal if the prognosis was good (Talati et al., 2010). What is noteworthy about this study is that the older minors used in the scenarios for the study presumably did not lack or gain any more capacity between their refusals in the poor prognosis situation and those in the good prognosis situation (Duncan & Sawyer, 2010), yet refusal for one prognosis required a higher level of capacity. While it is a generally accepted view that as risk/benefit profiles shift, requirements for assent and dissent do as well, in this case, it can be assumed that for some pediatricians, assent would have been an acceptable choice, but refusal would not have been, regardless of the prognosis scenario. The older minor would therefore have had sufficient capacity to assent, but not to dissent, furthering this imbalance of requirements. It is worth mentioning that the study surveyed pediatricians with fictional scenarios; it is therefore difficult to judge whether these numbers represent how one would truly react when faced

with a similar situation, a limitation noted in the study. This study shows how in practice, higher levels of capacity can make dissent more challenging. Not only are older minor capable of more authoritative decision-making, but they should also be respected as moral agents. This can be particularly challenging when the decision at hand is a life-limiting decision. Practising the authoritative assent model does reduce the risk of accidentally giving a choice to a minor when they do not truly have decision-making authority.

Legislative and Regulatory Frameworks

In Canada, the mature minor is a federal doctrine applied independently in the provinces and territories. Unfortunately, very little guidance exists for HCPs to help them determine who should be considered a mature minor and what to do in the case of a minor refusing life-limiting treatment. Below, a discussion of the application of the mature minor doctrine in Canada with two examples of court cases are presented, followed by an exploration of why dissent is such a difficult topic to regulate.

Mature Minors and Life-Limiting Treatments

Federal legislation in Canada does not specify what should be done in the case of refusal by a minor. It only states that a minor is deemed a mature minor if they are considered to have sufficient decisional capacity. In certain jurisdictions, such as the US, the mature minor doctrine does not always allow a mature minor to refuse certain treatments, such as life-saving treatments (Coleman & Rosoff, 2013; Hickey, 2007). This is because the state, as well as the adults in charge of the minor's care, may believe that treatment is in the minor's best interest and that beneficence ought to outweigh (or perhaps limit) autonomy. Oddly, a similar argument is made for assent. Assent is meant to increase trust, promote the

developing autonomy of the minor, and allow the minor to choose what is best for them. If the state and the adults know what is in the best interest of the minor, but assent is also promoted as a means of allowing a minor to choose what is in their best interest, those interests can sometimes conflict. This is why authorization assent should be prioritized as the assent model, because only when true decisional authority is given will the minor be permitted to assent or dissent and have their decision respected.

In Canada, it is not specified whether the mature minor doctrine applies to life-limiting decisions of a minor; therefore, very little guidance exists for medical professionals faced with a mature minor refusing a life-saving treatment. In some cases, courts have allowed mature minors to refuse life-saving treatments, especially when the parents support the minor's decision. However, in other cases, a different decision is made. In the 2014 Makayla Sault case in Ontario, 11-year-old Makayla was diagnosed with leukemia and given a 75% chance of survival with further chemotherapy. She was given the right to refuse more chemotherapy in favour of more traditional and alternative healing methods (Mitchell et al., 2015). Another case from 2009 involved A.C. v. Manitoba (Director of Child and Family Services), in which a 14 year old who was a devout Jehovah's Witness wanted to refuse a life-saving blood transfusion, which was supported by the parents, but was forced to receive treatment (Supreme Court of Canada Decision, 2009). These cases illuminate interesting dilemmas but do little to help healthcare professionals navigate minors' refusals of care because they do not provide consistency or a regulatory framework.

Why Are There So Few Dissent Guidelines? Some may be wondering at this point why we do not have well-defined regulations regarding dissent considering the

difficulties discussed above. Unfortunately, there is no clear answer to that question. One possible answer is that just like assent, there is still some confusion about when dissent should and should not be, and unless we find a more widespread agreement on this, writing regulations may prove difficult. Another is that pediatric care is very individualized. The capacity of one minor may be very different from that of another, making it hard for policy and lawmakers to either standardize, assign an age at which a minor can consent or refuse care, or create a capacity-specific regulation. Policy and law makers are also lacking resources specific to dissent to help guide them, as they are not the ones handling these dilemmas on a regular basis. This review is just one illustration of the lack of discussion surrounding dissent in the literature. As seen in the discussions above, ethically, dissent is a difficult subject to navigate. Adults who care for a minor, including the state, want to do what is in the best interest of the minor, while permitting the minor to participate, building a trusting relationship, respecting the minor's developing autonomy and truly respecting the minor as a person with all the dignity they are owed, all while preventing harm. The lack of regulatory frameworks that healthcare professionals and experts can rely on when trying to untangle dilemmas surrounding dissent compounds the issue (De Lourdes Levy et al., 2003; Dell et al., 2008; Duncan & Sawyer, 2010; Grady et al., 2014). As a result, dissent guidelines and regulations are trapped in a predicament where healthcare professionals and experts are hoping for more policies and laws for guidance, and policy and lawmakers may also be waiting for the current dissent discussions to grow.

Review of Discussion

To review, this chapter offered a presentation of two models of assent: participation assent and authorization assent. The participation assent model is the most widely used model for the inclusion of minors in their care and is promoted to build trusting relationships and empower minors. Under the authorization assent model, minors would only be given the option to assent if the option to dissent would be equally respected. Following this, a critical review of how both models apply to dissent was offered. An argument was made in favour of authorization assent over participation assent.

Next, the issue of dissent in pediatric research was discussed. Although it is generally accepted that dissent should be respected in research, clear guidelines are missing, and the ability to withdraw from research is not present in most IAF/ICF forms. Since research is fundamentally different from care, in that research does not provide proven effective treatment, but rather is done to discover new ones, the risk and benefit ratios are different from practice. That being said, a minor should have final say on their participation in research, more closely following an authorization assent model.

Older minors were discussed next, including the challenges brought on by an increase in decision-making capacity. Once again, the authorization assent model was proposed in order to avoid accidentally giving the minor a false sense of authority, then taking it away, thereby disrespecting the minor as a moral agent.

Finally, a critical examination of the Canadian legislative and regulatory framework revealed the lack of consensus and guidelines regarding dissent. Dissent is an ethically challenging subject that still needs further clarification before any formal regulatory framework can be drawn up. Moreover, minors are continuously developing,

making it difficult to create standardized age-based guidelines for HCPs. All things considered, additional research and further discussion on the implications of and the integration of assent/dissent models in pediatric care are still needed.

Chapter 5 – A Potential Avenue to Pursue?

To help navigate difficulties related to dissent, a promising avenue is the relatively new approaches in interdisciplinary studies of childhood ethics, including a few of their key concepts. First and foremost, it would be worthwhile to stop thinking of a minor's ability to contribute to care in a binary way, i.e. assent and dissent. Secondly, setting aside some of the main principles that help guide adult ethics, but that are more difficult to adapt for minors is a promising avenue to pursue. These ideas will be discussed below.

Assent and Dissent: A Binary Approach to Paediatric Care In the field of childhood ethics, many argue that minors are moral agents, with agency being present in all minors (Carnevale, 2020; Carnevale et al., 2017; Montreuil, Noronha, et al., 2018; Montreuil & Carnevale, 2016). Childhood ethics is a particularly interesting field to further investigate in lieu of the binary view of assent and dissent for minors, as it calls for a different, more nuanced conceptions of minor's voices. The binary model of assent and dissent can be an oversimplification of a minor's capacity to be involved in their care in a meaningful way. When using models in which minors can either possess sufficient capacity to be recognized as having decision authority or not, minors who do not have sufficient capacity may be left behind. Carnevale (2020) discusses the importance of having a "thick" conception of the minor's voice, meaning that the adult must relate a minors voice as "relationally, socially, culturally, and politically embedded—including generational embedment … children's expressions are agential expressions of their aspirations and related concerns, which also inform our understandings of their best interests; the latter being the ethical standard that should orient all actions involving children" (2020, p. 2). Montreuil & Carnevale (2016) also explain what minors' voices

can sound or look like, how they can be understood, and how adults can be better partners to minors in healthcare settings. By setting aside the terminology of assent and dissent and prioritizing the minors' voices, there is also an important recognition of the minor's dignity and their agency. Another way of categorizing these models is to only use the terms *assent* and *dissent* when a minor has true decisional authority. This would mean setting aside the model of participation assent and replacing it with the concept of a minor's voice for their inclusion in care. As seen in the majority of the views on minors discussed above, "[minors] are not recognised as fully autonomous agents capable of moral reasoning or assuming full responsibility for their choices and conduct.… They are perceived to acquire agency gradually, as they mature and become adults" (Carnevale 2015). Often, the exclusion of minors from discussions regarding their care is said to be for their own good, because it is in their best interest, or even because they would not be able to understand (Carnevale 2017), furthering the embedded view that a minor either has or does not have the capacity to assent or dissent, to participate in the decision-making process of their care. As mentioned earlier, listening to minors' voices would be a potential alternative to the participation assent model. This is because it is a more holistic approach to minors' care and would reduce the risk of misleading the minor into thinking they have decision-making authority. As a result, adults would only seek a minor's assent or dissent when the minor has decision-making authority, but the minor would be included in their care in various other ways, showing respect to the minor as a moral agent

Minors as Moral Agents Respecting minors' voices and leaving behind these binary views avoids excluding minors from being heard. It also allows them to be

recognized as moral agents, especially when minors do not have decisional authority over many of the care decisions being made. The recognition of agency in minors is becoming more prominent (Montreuil & Carnevale, 2016); there are recognized tensions between the best interest standard and agency (Carnevale et al., 2015). The best interest standard was also the argument used to refuse a minor's dissent to treatment discussed earlier (p. 32-35). In other words, if a minor's decision to refuse treatment was not in line with what the adults believed to be in the minor's best interest, the minor's capacity to make decisions for their care was often put into question. A minor's agency has been defined as follows: "Children's capacity to act deliberately, speak for oneself, and actively reflect on their social worlds, shaping their lives and the lives of others. This definition entails that multiple forms of expression can be used to speak for oneself, including speech and bodily expressions, and that the capacity of children to enact agency is not dependent on adults as facilitators of agency" (Montreuil & Carnevale, 2016). The tension between the best interest standard and agency in minors stems from the idea that minors are in a vulnerable population and in need of , yet they have "capacity for moral reasoning as human agents" (Montreuil, Noronha, et al., 2018). This tension is present in the assent-dissent pair for similar reasons. Authors in childhood ethics argue that this duality between needing protection and having agency does not in fact need to be in opposition, but can coexist in a person. Montreuil et al., (2018) argue that "children are considered both vulnerable and moral agents: They do need a form of protection based on their vulnerability but are agents with moral outlooks and experiences whose perspectives should be recognized." The difficulty of recognizing this may be related to the pre-eminence of the principle of autonomy, which, as shown in earlier discussions, is difficult

to apply and adapt to minors, yet is a guiding principle in the field of bioethics, which mostly focuses on adults.

Taking a look back at Juliette's case (p. 48-49), the application of childhood ethics' listening to the minor's voice would be an acceptable way to avoid Juliette's dissent to x-ray while including her in care. In the last scenario, participation assent was used, and the pediatrician asked Juliette to assent to the x-ray as a means to include her, but not to give her true decisional authority. In this alternative, while Juliette would not be given the option of getting an x-ray or not, she could be included in other ways. One suggestion would be to assess Juliette's understanding of an x-ray. If this is her first time, there could be some anxiety surrounding the idea of such a procedure. Showing her how an x-ray is done and what it does might help. Explaining to Juliette how bones are fixed and heal, and answering any questions that may come up during that conversation, could facilitate her inclusion in her care. Another important factor is understanding that Juliette is a minor in a complex social environment. She may feel anxious about the idea of having an injury that is visible to others, such as in school. Taking this into account is very important. Juliette could also have reservations about the duration of the proposed tests or treatment. Sometimes children have agendas and schedules of their own that are just as important as adults', and it is essential to recognize the role this can play in how a minor may think about their own care. Addressing any of the issues listed above, although not an exhaustive list, is significant in the inclusion of a minor in their care while still providing them the care they need.

All in all, should discussions about assent and dissent continue? Yes. They are important topics in pediatric care. Currently, minors are not sufficiently included in the

discussions or in the healthcare legislation and regulations surrounding decision-making. Writing into the legislation and regulations something that cannot be measured (e.g., age, type and severity of illness) or that does not have a specific threshold (e.g., maturity, capacity, vulnerability) increases the difficulty of standardization and is often difficult to enact. Although the dissent conversation should not be put aside, getting entangled in the terminology and broad principles such as autonomy and best interest can cloud other more holistic approaches for the true inclusion of minors in their care and research such as the childhood ethics approach described above.

Conclusion:

The aim of this thesis was to conduct an interdisciplinary scoping review on current discussions of pediatric dissent in clinical and research settings as well as the legislative landscape of Canada. Overall, few articles were found that discussed dissent in depth, and the gap in knowledge was evident. The following three subcategories were identified: Current Views on Dissent; A Minor's Capacity and its Complexities; and Lack of Guidelines and Clarity Regarding a Minor's Capacity and Dissent. The results showed that a significant number of authors held varying views regarding dissent, how it should be and is included in care or research, and why dissent is important. Many more authors were in accordance regarding the complexity brought on by a minor's age and level of capacity with regard to dissent. The vast majority of articles (92%) discussed capacity and were in agreement that a higher level of capacity is required when the risk of the decision increases. Finally, many authors took issue with the lack of guidelines both in research and clinical settings regarding dissent and how to recognize, manage, and respond to it. An overview of regulatory approaches across Canadian provinces and territories in relation to consent and capacity was also offered. This systematic legislative search found another significant gap surrounding minor's ability to dissent to medical treatment in Canada; no acts on medical decision-making were found regarding minors refusing or dissenting to care, although the search did show varying differences between provinces in consent laws concerning minors.

Three arguments were offered in the discussion. The first held that participation assent does not allow for a minor to be adequately included in discussions about their care and leads to their capacity not being taken seriously. As a result, when this model is applied to dissent, minors are disrespected, and moral harm is caused. The alternative

model of authorization assent allows minors to have more decisional authority but limits the decisions they have sufficient capacity to make. In the research context, assent is required prior to a minor's participation. Because all research is ultimately done for the benefit of furthering scientific knowledge, minors who are asked to participate should have final authority on whether to participate or not. The second argument in the discussion maintained that when dealing with older minors, it is increasingly important to utilize the authorization model of assent. Older minors have a greater decision-making capacity as compared to younger minors. If adults do not intend to respect the decision made by the minor, then the choice should not be presented in the first place. It was shown that for older minors, the application of standards for assent and dissent were uneven. While this may seem logical due to the risk and benefit calculations, it is disrespectful to the minor when the choice is offered, but the minor's decision is not respected by the adults, and this can cause moral harm. Finally, legal precedents and bioethics literature have shown that there is very little consensus regarding how to respond to a minor's refusal of care. Because of the lack of guidelines on dissent, there is very little for HCPs to use as reference to help them navigate difficult situations both in care and in research settings. Two legal cases presented, that of Makayla Sault and Manitoba v. A.C., had contrary results, resulting in very little direction given to HCPs. It is possible that lawmakers are looking to experts in the field of pediatrics for guidance on what is the best way to handle refusals in the pediatric population to help create regulations, while experts are looking to lawmakers, leaving both sides at a loss.

In the end, childhood ethics studies have shown great advances in the inclusion of minors in their care without getting caught up in the terminology or principles typically

used for the adult population. Childhood ethics support a more holistic approach to pediatric care and research and encourage the respect of minors as moral agents. This allows for minors' voices to be heard and better understood, which in turn leads to respect for the minor and higher-quality care.

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