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Understanding Children's Best Interests for Healthcare Decisions: A Critical Interpretive Review

Micaela Nicole Forte, *Western University*

Supervisor: Smith, Maxwell J., *The University of Western Ontario*
Co-Supervisor: Shelley, Jacob, *The University of Western Ontario*

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Abstract

‘Best interests’ is a key ethical norm for children’s medical decision-making. While intended to guide parents and healthcare practitioners (HCPs) in their decisions, it has been criticized for its ambiguity and inconsistent application. In the context of childhood vaccination, ‘best interests’ faces unique challenges due to parental vaccine hesitancy, their preventative nature, and their dual benefits to individuals and the public. I employed critical interpretive review (CIR) methodology to analyze 58 empirical and non-empirical publications on children’s best interests and healthcare decisions, including vaccination. I identified five themes that furthered understandings of children’s best interests and healthcare decisions. ‘Best interests’ was not uniformly conceptualized among the reviewed works. The factors that make up a child’s ‘best interests’ were influenced by the various interpretations of ‘best interests’. This thesis provides insights into HCPs’ interpretations of best interests, highlighting areas for further consideration, namely, how to navigate the subjectivity of these decisions.

Keywords

Best interests, children’s best interests, the best interests standard, healthcare practitioners, healthcare decision-making, vaccination, parents, parental vaccine hesitancy, critical interpretive review.

Summary for lay audience

Background: ‘Best interests’ is an important ethical principle for making decisions on behalf of a child who is mentally incapable of making their own medical decisions. It is intended to guide decision-makers, such as HCPs and parents, to make the ‘best’ decision for the child. However, this standard is often criticized for being unclear and applied inconsistently. When it comes to childhood vaccination, decisions become more complex due to factors such as a parent’s reluctance or refusal to vaccinate their child, the precautionary nature of vaccines to protect from an illness that may not seem like a clear threat, and the dual benefits of protecting the individual and contributing to protecting others. This thesis begins to address these matters by exploring the perspectives in both empirical and non-empirical literature on ‘best interests’ and children’s medical decisions including vaccination.

Methods: This thesis employed critical interpretive review (CIR) methodology to review the literature on children’s best interests and healthcare decisions. 58 publications were reviewed, analyzed, and interpreted.

Findings: The findings were organized into five themes or descriptions of important trends and patterns that described how children’s ‘best interests’ were understood and applied. The concept was not consistently conceptualized or applied among the reviewed publications. The factors that made up a child’s ‘best interests’ appeared to be influenced by the varying conceptualizations.

Conclusions: This thesis provides insights into how HCPs interpret the best interest standard in the literature. The findings point to key areas in children’s healthcare decision-making that require further consideration, particularly how to handle the subjective nature of these decisions. This research can help improve the ethical integrity of medical decisions for incapable children.

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Chapter 1

1 Introduction

There is no legally defined age for consent to healthcare decisions in Ontario (Coughlin, 2018). A presumption of capacity for patients under the age of majority (18 years of age) exists until evidence suggests otherwise (Coughlin, 2018). Suppose a clinician deems a patient incapable of making a particular decision, and the child does not have previously expressed capable wishes. In that case, a substitute decision-maker (SDM) is charged with the responsibility to make ethically justified treatment decisions for the incapable patient (Ontario, 1996). Best interests is a key concept in medical decision-making among incapable children and their SDMs. Ontario law requires the best interests standard to be used to help SDMs make medical decisions, grounded in the values and preferences of the patient (Ontario, 1996). Some scholarly work has taken up understanding the above (Bester, 2019; Diekema, 2011; Kopelman, 1997; Salter, 2012).

Medical decision-making for pediatric patients is complex, as there remains room for interpretation and application of the best interests standard (Kopelman, 1997). Decision-making for incapable children with respect to prophylactic interventions, such as vaccination, adds another layer to the complexities of substitute decision-making since these are preventative interventions rather than therapeutic interventions. Regarding vaccination, there remains a clear threat (disease); however, what differentiates prevention from treatment is that the child already has a disease or condition with the latter, whereas in the former, they do not. Both present a threat, but this distinction may pose challenges in determining the best interests. Less work has gone into understanding this.

Vaccine hesitancy among parents stems from various factors (Canadian Paediatric Society, 2018; Rellosa, 2022; Smith et al., 2017) and has contributed to the hesitant uptake of COVID-19 and other childhood vaccines, which in turn has led to the re-emergence of VPDs leading to increases in illness, hospitalization, and death among children (Doherty et al., 2022). Parental vaccine hesitancy has also triggered court cases arising from familial conflicts around the COVID-19 vaccine (Braley-Rattai, 2021; Powell, 2022). Considering pediatric COVID-19 vaccine decision-making in the context of best interests provides a novel setting to explore how best interests are understood in the literature. This focus is particularly pertinent given the heightened public scrutiny surrounding COVID-19 vaccination decisions for children, and the unprecedented nature of the rapid development and implementation of the vaccination. These factors uniquely influence parental decision-making and highlight the necessity for an examination of how best interests are determined in this specific and contentious context.

Clinical guidance for addressing parental vaccine hesitancy is available from various Ontario medical Colleges, associations, and the provincial government, and some guidance mentions ethical considerations for vaccinating children (Rus & Groselj, 2021). Guidance that informs practitioners about the best interests standard exists, although it does not provide discussion on navigating ethical tensions practically (Taylor, 2014). Healthcare practitioners (HCPs) are a trusted source for parents to receive health information and therefore play a key role in affecting parental vaccine attitudes (Public Health Agency of Canada, 2022; Shen & Dubey, 2019). This suggests that HCPs are important individuals to converse with parents regarding their vaccine choices for their children. A considerable amount of research has focused on understanding parental vaccine hesitancy and how HCPs can address it through conversations (Politis et al., 2023). However, this research has not thoroughly explored the morality of these approaches. Therefore, an exploration into the best interests standard and vaccination could provide valuable insights into how HCPs can use ethical norms to navigate parental vaccine hesitancy.

This thesis set out to explore how the best interests standard is understood by HCPs in the context of COVID-19 vaccine decision-making for children. This chapter provides an overview of vaccine hesitancy, the COVID-19 pandemic and vaccine, best interests, and the research objective that guides this thesis.

1.1 Ethical dimensions of vaccine hesitancy

Ethical tensions can arise when healthcare practitioners (HCPs), distressed when treating vaccine-preventable diseases (VPDs) (Klitzman, 2022), discuss vaccination with vaccine-hesitant parents. How clinicians utilize ethical reasoning and decision-making when speaking to patients and their parents about what is in the patient’s best interests is important to support conversations that respect patients and their autonomy while addressing conflict.

Ethical reasoning can help clinicians navigate complex situations where medical facts alone might be insufficient in aligning the understanding and agreement among the clinician, child, and parent/family triad regarding the child's medical decision. When parental beliefs and values conflict with medical recommendations, such as in some cases of childhood vaccine decision-making, ethical reasoning may be beneficial. In these scenarios, employing an ethical norm such as best interests may ensure that the varying or conflicting perspectives are scrutinized and founded on ethical principles.

Moreover, ethical decision-making may lead to greater transparency and trust, facilitating a collaborative relationship between the triad. This may be particularly crucial for discussing contentious topics such as vaccination, resolving conflicts, and ensuring that the provided care aligns with the child's well-being.

1.2 Background on the COVID-19 pandemic and vaccine

The coronavirus (COVID-19) pandemic is a global outbreak of severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2). Initially detected in China in December 2019, COVID-19 is an infectious disease with varying symptoms and degrees of severity depending on one's age, the variant, and other factors (Canada, 2024a). COVID-19 can spread from an infected individual when they breathe, speak, cough, sneeze, etc., through respiratory droplets and aerosols (small droplets that linger in the air). The virus can also survive for a certain amount of time on objects, which, if touched, can cause infection if it reaches the mouth, nose, or eyes with unwashed hands (Canada, 2024a).

COVID-19 is highly contagious through the air and surfaces. Its infection rate in children fluctuated throughout the pandemic. Infection rates may have been modified through national vaccination programs and mandates, mask mandates, quarantine mandates, travel bans, community outbreaks, and the emergence of new variants. COVID-19 epidemiology for children poses challenges for establishing, due to the high prevalence of asymptomatic infections and testing rate discrepancies for children compared to adults (Hyde, 2021; Wald et al., 2021). Despite this, the Canadian government updates the incidence of COVID-19 cases and, as of May 2024, incidence is currently described as ‘low’ (4.9 million cases with a weekly positivity of 7.4%) but showing signs of increase[1] (Canada, 2024b).

COVID-19 infection in children can cause no symptoms or mild symptoms, but can also lead to hospitalization for breathing difficulty or multisystem inflammatory syndrome (MIS-C), long-term effects (post-COVID-19 condition), or death (Canada, 2021). Children with underlying health conditions are at higher risk of severe illness, including those who have immunocompromising conditions, Down syndrome, neurological disorders, conditions that require substantial medical care, or ongoing lung problems (Canada, 2021).

In Canada, a state of emergency was declared on March 23, 2020 (Canadian Institute for Health Information, 2022). In response to the COVID-19 pandemic, many public health measures, including novel vaccinations, were implemented in Canada. Health Canada approved the Pfizer-BioNTech[2] COVID-19 vaccine for use in people aged 16 and older in December 2020, and 5 months later, for ages 12-15. In November 2021, a lower dosage was approved for children aged 5-11 (Canadian Institute for Health Information, 2022). Finally, in July 2022, a quarter dosage of the Moderna vaccine was approved for children aged six months to 5 years (Boisvert, 2022). There is little, if any, Canadian guidance for receiving and administering COVID-19 vaccines for children under 6 months[3]. This population relies on others being vaccinated to be protected from COVID-19 infection (Ontario, 2024).

Public Health Ontario states that the COVID-19 vaccine is not 100% effective at preventing infection (Public Health Ontario, 2021). Side effects of vaccination in children include redness, soreness, or swelling at the injection site, as well as chills, joint pain, tiredness, headache, mild fever, and muscle aches (Canada, 2021). While serious reactions are extremely rare in children, myocarditis and pericarditis are potential adverse reactions to the COVID-19 vaccination but resolve quickly after seeking medical care (Canada, 2021).

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[1] As of May 2024

[2] The Pfizer-BioNTech vaccine was the first to be approved by Health Canada, followed by other available vaccines in Canada including AstraZeneca and Moderna. Vaccine names have since been updated (Canadian Institute for Health Information, 2022).

[3] The United States Food and Drug Administration (FDA) has not approved or authorized a COVID-19 vaccine for children under 6 months (Centers for Disease Control and Prevention, 2024)

Vaccine hesitancy[4] is difficult to define as it can be complex and context-specific, and can stem from varying levels of trust, complacency, misinformation, and many other factors (World Health Organization, 2015). For the sake of this investigation, it may be referred to as the refusal or hesitation to obtain a vaccination, despite the availability of vaccine services (World Health Organization, 2015). Parental vaccine hesitancy is the refusal or hesitancy of vaccinating one's child(ren) who is (are) deemed incapable of consenting to vaccination themselves. Since the advent of vaccines, vaccine hesitancy has existed (Fisher, 2024). The since-retracted publication of Andrew Wakefield's study on the correlation between the measles-mumps-rubella (MMR) vaccine and autism development in children was a cornerstone of parental vaccine hesitancy (Jarry, 2023), and the COVID-19 pandemic represents another key moment in time where parental vaccine hesitancy has peaked (He et al., 2022). Academic experts in vaccine hesitancy have theorized a multitude of reasons for this phenomenon, including news outlets and social media platforms fraught with mis- and dis-information about the COVID-19 vaccination, a scientifically ignorant society, or a severe breakdown of the public's trust in medicine and public health (Goldenberg, 2021)[5].

1.3 Conceptualization of the term 'best interests'

The best interests standard is a norm for medical decision-making for patients who lack medical decision-making capacity. Parents[6] of children deemed legally incapable are responsible for making decisions in the best interests of their children. As per the *Health Care Consent Act* (1996) of Ontario (HCCA), capacity (and 'capable') refers to the ability to "understand the information that is relevant to making a decision about the treatment […] and able to appreciate the reasonably foreseeable consequences of a decision or lack of decision" (1996, c. 2, Sched. A, s. 4 (1)). As a general rule, patients must give their informed consent prior to any healthcare treatment (Ontario, 1996). It is the duty of the healthcare provider to determine the capacity of the individual, and their SDM if they are deemed incapable. Decisional capacity and consent are determined and required for the specific

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[4] I recognize that vaccine hesitancy and refusal are mutually exclusive events, however, my thesis is concerned with any form of non-vaccination which includes both hesitancy and refusal. I will henceforth refer to vaccine hesitancy and refusal as 'vaccine hesitancy'.

[5] There are surely myriad reasons for parental vaccine hesitancy, but an explanation or analysis of these reasons is beyond the scope of this thesis.

[6] I use the term parents throughout this thesis, but other individuals such as grandparents, caregivers, legal guardians, etc. may also act as SDMs. They are henceforth included in the term 'parents'.

intervention of concern and can change depending on the treatment and the time. For instance, a patient may be deemed capable of consenting to one treatment, but incapable of consenting to a different treatment. Additionally, a patient may be capable of consenting to any given treatment at one point, but due to disease progression or deterioration, they may be incapable of consenting to treatment at a later date or if their condition improves, they could be deemed capable when they were previously deemed incapable (Ontario, 1996). While this thesis does not aim to assess insights about determining decisional capacity, it is important to preface my results by clarifying the role it plays in considering the best interests of the child.

The best interests standard is widely accepted as relevant for making decisions for incapable children (and adults) (Kopelman, 2007). Therefore, it is presumed that a child must be deemed incapable to consider and employ the standard, as a capable child would make the decision for themselves. For most childhood vaccines, administered in infancy, presuming *in*capacity seems reasonable, as it is unclear whether infants can understand or appreciate the risks and benefits of vaccination (Dawson, 2005). When it comes to youth and adolescents, there exists guidance for HCPs detailing that capable youth can provide consent to COVID-19 vaccination (Chris & Orkin, 2021). In this case, it would be unnecessary to enact the best interests standard as the child is legally able and responsible to decide for themselves.

The best interests standard is a legal and ethical one, and there are distinctions on how it should be used as a *prima facie* duty to guide choices (Buchanan & Brock, 1986) versus how the best interests of the child test are employed to make judicial decisions regarding a child's wellbeing in custody decisions (Kopelman, 1997). This thesis will explore the ethical dimensions of the best interests standard, and will include discussions contextualized by the legal application of the standard, justified by a recent court case regarding COVID-19 vaccination of children (*J.N. v. C.G.*, 2022).

In order to explore the ethical dimensions of the best interests standard, it is important to acknowledge the confusion around the meaning of 'best interests' (Kopelman, 1997). The term 'best interest' may colloquially refer to thoughts or actions in concern for someone's wellbeing, so as to benefit them (Merriam-Webster, n.d.). In pediatric healthcare, the concept has faced criticism for being vague, applied inconsistently, and subject to abuse (Kopelman, 1997; Salter, 2012).

Determining what constitutes the child's best interests can vary widely among HCPs, parents, and other stakeholders. Many reasonable interpretations of the child's 'best interests' may arise when considering complex issues (Salter, 2012). Medical 'facts', relational, emotional, and other relevant factors in individual cases may be interpreted and weighed differently, leading to inconsistent and sometimes conflicting decisions (Salter, 2012). This inconsistency may stem from 'biases'; some relevant ones for pediatric medical decision-making are cultural backgrounds, personal values, and education (including medical training).

Some conceptions of best interests may fail to account for the complexities of these biases, family dynamics, and cultural contexts (Salter, 2012). In pediatric medical decision-making, the child's best interests may be solely dependent on medical facts and considerations and de-prioritize factors beyond the child's medical benefits such as family dynamics, financial health, and cultural considerations. This conception is criticized as too narrow and failing to respect 'the family' (Salter, 2012).

Clearly, there are various understandings of 'best interests' and thus many applications, leading to a confusing and inconsistent body of literature. Salter argues that 'best interests' arguments are overly obscure and open to so much interpretation that they cannot offer any guidance for pediatric decision-making (Salter, 2012). She calls for a more 'adequate' standard of decision-making that is more consistently applied, where similar cases result in similar outcomes. Given this gap in the literature, this lack of clarity necessitates further investigation into how HCPs understand best interests in the context of pediatric medical decision-making. By exploring the intricacies of how 'best interests' are understood and applied in pediatric medical decision-making, we may better understand the various perspectives and challenges that are considered and faced by HCPs, respectively, and take a step towards developing a more coherent and applicable standard in pediatric healthcare contexts. This is crucial for improving its application in practice and ensuring better health outcomes for children, or considering the possibility of replacing the standard with an alternative framework, depending on the findings from this thesis.

This thesis was interested in understanding HCPs' perspectives of children's best interests. I initially attempted to interview HCPs, but had challenges with recruitment. This led me to conduct a critical interpretive review of empirical and non-empirical literature, to be discussed further in Chapter 2. In light of these challenges, this thesis aims to investigate the literature on HCPs' perspectives on how best interests are understood and navigated in the context of childhood vaccination decision-making. To preface this investigation, it is worth noting that vaccine decisions are often considered in the child's and public health interests. While vaccinations are a prophylactic measure to protect the public, they will almost always have a beneficial effect (even if marginal) on the child. As noted, per the HCCA, parents are required to make decisions in the best interests of their child (Ontario, 1996). Parents may also feel justified in exercising their parental autonomy to make decisions for their children based on their own beliefs and wishes for raising their children. Unique to vaccination, parents also have an ethical (and in some cases legal, i.e., when vaccines are mandated) responsibility to contribute to public health measures by vaccinating their children (Nihlén Fahlquist, 2023). Vaccination is more than a child's/parent's responsibility. It is also a public health responsibility. Can vaccination for public health purposes ever be considered in the 'best interests' of a child, or is it simply an additional justification for vaccination? Where other healthcare decisions may concern and affect the child and their family, for example, a blood transfusion or resuscitation, freedom to do whatever one wishes may be valued differently than when one considers vaccination. Vaccination may be viewed as a moral practice, where healthy individuals who are not contra-indicated to vaccination hold a moral obligation to be vaccinated. When an incapable child is considered, their parents hold that moral obligation. This is perhaps a reason, in and of itself, for parents to vaccinate their children, aside from other arguments such as the best interests of the child.

Thus, vaccination provides a unique case to examine children's 'best interests', given these factors. With the dearth of scholarly literature written on how we do and ought to understand this, I set out to conduct a critical interpretive review of existing best interests literature to explore what insights might be gleaned about the case of vaccination.

1.4 Research question

The purpose of this thesis is to explore the perspectives of HCPs in both empirical and non-empirical literature on the best interests standard for childhood vaccination decisions. Specifically, rather than presuming that perspectives from theoretical works influence clinical interactions reported in the literature, or that clinical perspectives inspire theorizations of these encounters, this study explores all these perspectives together to identify areas of alignment and areas of dissonance. The overarching aim of this thesis is to inform how best interests is considered in contexts of vaccine decision-making for incapable children, in the hopes of improving children's healthcare decisions.

The research question that guides this study is: "How are best interests for children's health decisions understood by HCPs in empirical studies and how ought best interests be understood by HCPs in non-empirical articles?"

1.5 Previous work

Originally, I intended to pursue semi-structured qualitative interviews with HCPs to explore their experiences with vaccine hesitancy. However, I ran into serious challenges in the recruitment stage. Despite keeping recruitment open for six months and reaching out to all 187 Ontario Family Health Teams and all 34 Ontario public health units, I did not receive any responses to my recruitment emails or posters. My recruitment materials reached well over 200 potential participants, yet no one volunteered to participate, even after expanding the target group from primary care practitioners to nurse practitioners, public health nurses, and other HCPs involved in vaccination.

After I exhausted all methods for recruitment within my ability, I pivoted the methodology to focus on a critical interpretive review of existing research since, based on my past experiences researching children's best interests (see: Positionality), it was apparent that there were insights to glean from this disparate literature. This review will elucidate important aspects of how the best interests of children are understood and applied in healthcare decision-making and could lay the groundwork for future research, which may be able to incorporate elements of my original proposed methodology. Below is a description of my previous work.

My initial goal was to ascertain how HCPs discuss how they navigated COVID-19 parental vaccine hesitancy through the use of the best interests standard. Traditionally, routine vaccinations in childhood are administered by a child's HCP (i.e., primary care provider) or by public health nurses in school. However, during the COVID-19 pandemic, COVID-19 vaccinations have been more commonly provided by other HCPs such as public health nurses and pharmacists as well as primary care practitioners, as school vaccination programs halted when schools closed.

I received Research Ethics Board (REB) approval from the Western Health Sciences REB to conduct one-hour semi-structured interviews with 8-10 HCPs in Ontario over Zoom. I attempted to recruit participants by emailing healthcare organizations with my recruitment e-mail script and virtual study poster. Potential participants were directed to a survey where they could review the letter of information and consent form, as well as a pre-interview demographic survey to ascertain their job (physician, nurse practitioner, public health nurse, etc.), location of practice, etc. While my recruitment materials reached hundreds of HCPs, no participants were recruited. Many organizations and HCPs responded stating they felt my research was important but they did not have the capacity to participate in my study at the time. My recruitment was open from November 2023 to the end of April 2024, and due to feasibility reasons, I could not extend recruitment any longer. During this time, Ontario was experiencing a mild resurgence of measles, and a significant delay in childhood vaccinations (DeClerq, 2024). The COVID-19 pandemic reduced in-person healthcare appointments and placed school immunization programs on hold due to school closures (Lee et al., 2022). When schools and clinics re-opened, most Ontario public health units did not resume childhood immunization programs right away (DeClerq, 2024). This may provide some justification for the inability for HCPs engaged in vaccination to participate in my study, as they were preoccupied with ensuring children were catching up with their routine vaccinations.

We might also consider the possibility that HCPs did not wish to participate in this study because they did not engage the best interests standard with vaccine-hesitant parents, even though they may have believed it was an important ethical standard. When HCPs are faced with vaccine-hesitant parents, perhaps their approach is to avoid confrontation or persuasion and accede to the parent’s wishes. For example, one study demonstrated that most HCPs spent 1 to 5 minutes discussing immunization with parents, but indicated that this duration is insufficient (Saitoh et al., 2022). It is unlikely, however, that this is enough time to provide vaccination education and address a hesitant parent’s fears, concerns, and values, while also persuading them to vaccinate their child.

Whatever the reason, HCPs did not agree to participate and thus it was necessary to pivot my investigation. I was interested in exploring the novel bioethics literature review methodology introduced by Rosalind McDougall, the critical interpretive review (McDougall, 2015). This will be discussed further in Chapter 2.

Conceptualization, and therefore application, of the best interests standard is not uniform in my introductory review of the literature. So how is decision-making in the best interests of the child understood and approached by HCPs, especially when it comes to vaccination? Drawing on critical perspectives, I undertook a critical interpretive review of the empirical and non-empirical literature to shed light on this question.

1.6 Outline of this thesis

The first chapter of this thesis was used to introduce the relevant concepts to my research question: pediatric medical decision-making, best interests, and vaccination. The prevalent issues and gaps in the literature were also introduced. The second chapter outlines the methodology and methods employed to guide this literature search, data collection, and analysis. The third chapter presents the findings of the analysis. The fourth chapter discusses the findings as they pertain to the research question, and implications for policy, practice, and theory. The fifth chapter presents future research directions, limitations, and a summary of this investigation.

Chapter 2

2 Methods and Methodology

This study employed a critical interpretive review (CIR) methodology to answer the research question: "How are best interests for children's health decisions understood by HCPs in empirical studies and how ought best interests be understood by HCPs in non-empirical articles?" CIR methodology was developed by Rosalind McDougall, who drew on concepts from Dixon-Wood's critical interpretive synthesis (CIS) (Dixon-Woods et al., 2006; McDougall, 2015). CIR employs a thorough and thoughtfully designed literature search to illuminate and analyze key ideas in the field, rather than systematically collating instances of arguments. It differs from a 'systematic' approach, as the identified literature does not necessarily capture every single article or viewpoint relevant to the research question but is a substantial research endeavour to identify the literature that best answers my research question. While systematic literature reviews necessitate retrieving all literature that affects an argument (either strengthens or weakens), rigorous bioethics reviews work differently – bioethical justifications are not necessarily strengthened or weakened by additional papers with the same argument (McDougall, 2014).

2.1 Positionality

As an advocate for public health measures and vaccination programs, I recognize that my circumstances and personal beliefs may influence my interpretation of the data. I am a white woman, living in a high-income country, and have been vaccinated and boosted against COVID-19. These factors have shaped my point of view on best interests and vaccination, as I was privileged to have prolific access to vaccines and information to help me make informed decisions about vaccines.

Additionally, I am privileged to have a university-level education, and my previous research and exposure to bioethical discourses surrounding the best interests standard, as well as the knowledge and training I have gained from my supervisors, who specialize in bioethics and healthcare law, have shaped and influenced my perspectives and therefore analysis. This background allows me to critically engage with the ethical considerations that underpin vaccine hesitancy and public health policies. This pre-existing knowledge can be both an asset and a potential source of bias. On one hand, it enables me to identify and analyze nuanced ethical arguments effectively. On the other hand, it may lead to an inclination towards certain interpretations of data that align with projects in which I have previously been and currently am involved. By making my positionality explicit, I aim to transparently preface my approach to this review, as well as my analysis and interpretation of the reviewed works, allowing readers to understand the lens through which I approached this research.

2.2 Critical interpretive review methodology

McDougall (2015) proposed a methodology for approaching critical interpretive reviews as a novel research study. She suggested six features of a ‘good critical interpretive review’:

1. Answers a specific research question, which may have been refined through a literature review,
2. Analyses the literature as a whole as well as analyzing individual findings and arguments within that literature,
3. Does not utilize rigid quality assessment criteria, but comments within the review itself on quality issues,
4. Generates theory and puts forward an argument about the literature,
5. Captures all of the key ideas in the existing literature that are relevant to the research question, and
6. Records and reports the search strategy (McDougall, 2015).

Key ideas are “ideas that are influential in the discussion to date and/or uniquely insightful in relation to the research question” (McDougall, 2015). CIR methodology proposes that the researcher determines which ideas are ‘key’, and that what is key may differ between individuals depending on their context and their conception of what constitutes a key idea. I determined key ideas as those that have importance in answering my research question, namely, how the authors of a publication framed and discussed the best interests standard and medical decision-making, particularly in relation to childhood vaccination.

As CIR relies heavily on the positionality of the researcher within a particular community of practice, it is essential to explicitly report the literature search strategy as well as the quality issues that may be evident in the review. ‘Quality’ is subjective where qualitative and commentary-type publications are considered, and there is a risk of researcher subjectivity with individual judgment on the researcher's part (McDougall, 2015). Subjectivity arguably inherently exists in qualitative research, given that methodologies often ask the researcher to interpret the literature and imbue their presence in the research process (Eakin & Gladstone, 2020). Rather than this being a limitation, as it is in the quantitative paradigm (Galdas, 2017), I wish to acknowledge that my positionality affects my interpretation, arguments, and analysis, and another researcher might produce alternate interpretations, arguments, and analyses. CIR proposes that publications should not be assessed for quality as a limit for inclusion in the review, but quality issues should be reported in the findings. While I did not exclude articles based on any quality criteria, I aimed to comment on concerns regarding weaknesses in the publications.

During analysis, I drew on non-empirical ideas to view the empirical work and compared the non-empirical work with the empirical data to bring forth new insights and knowledge about best interests and vaccine decision-making. Empirical and non-empirical (largely comprised of what could be considered 'normative') articles were included in this literature review, as descriptive empirical studies restrict themselves to providing empirical knowledge on an ethical topic without necessarily further referencing to or interacting with the normative debate, both of which this investigation is concerned (Salloch et al., 2012). The research question for this study, concerning how best interests are understood by HCPs in empirical studies and how best interests ought to be understood by HCPs in non-empirical articles, can be, and ought to be, answered through both empirical and non-empirical research to glean perspectives about how best interests are theorized and applied in practice. Empirical articles rest on observational and measurable phenomena generated from experience, rather than theory (Borry et al., 2006). Empirical articles may include quantitative or qualitative studies that use observations, questionnaires, focus groups, interviews, systematic reviews, etc., presenting data to provide a descriptive claim. Non-empirical articles are generally all other scholarship other than grey literature, including investigations of a normative claim or abstract concept.

Along with implications about the findings I generated through the critical insights from the literature, I also drew important insights about employing this novel methodology to answer my question. Through this thesis, I explored an innovative methodology with few publications detailing guidance for researchers: Dixon-Woods and colleagues (2006) offer a substantive description of the CIS, McDougall (2015) provides a theoretical interpretation and refinement of the methodology for the bioethics field, and a handful of researchers have embarked on CIR.

The ill-suited nature of systematic review methods to bioethics literature necessitated this nascent methodological approach. It also broadens the type of literature that may be analyzed together, where a systematic review or a CIS aims to analyze one type of ‘evidence’. Given the dearth of empirical literature regarding best interests and pediatric vaccine decision-making, I expanded my research question to incorporate both empirical and non-empirical literature in this review.

For this body of literature, a CIR was the most fitting method to answer this question, as it enables its users to capture and analyze the key ideas from both empirical and non-empirical publications. A systematic review is ill-suited to this project as it focuses on interrogating either empirical or non-empirical literature (McDougall, 2014). A systematic review of reasons (asking an empirical question of what reasons have been given when the ethical question is addressed in the normative literature), another nascent methodology in bioethics, may have been suitable but poses challenges with the identification of appropriate search terms, the time-consuming nature of identifying a significant amount of irrelevant articles in the generated searches, and the ambiguity of assessing the quality of ‘good arguments’ (McDougall, 2014). Systematic reviews require a specific quality assessment of the publications; however, the assessment of the quality of empirical studies may not apply to theoretical studies with moral reasoning (McCullough et al., 2007). Additionally, my research question is better suited to this approach of literature reviewing, as I aimed to investigate the ethical justifiability of empirical and normative arguments.

Dixon-Woods and colleagues state the iterative nature of a critical review, where research question generation, literature searching and selection, data extraction, and analysis are “interactive, dynamic and recursive” rather than predefined steps for the researcher to follow, and the findings of the search may determine the research question. This resonates with my review process, where my research question was refined throughout the data extraction and analysis process.

Ethics approval was not necessary for this study as the publications analyzed were available on public databases.

2.3 Data collection

The research question I sought to explore was: “How are best interests for children’s health decisions understood by HCPs in empirical studies and how ought best interests be understood by HCPs in non-empirical articles?” After trial and error with various search term combinations, as well as meeting with a research librarian at Western University, the search strategy was chosen to include three dimensions: ‘best interests’, children, and health. This was expanded considerably following an initial search for ‘best interests’, children, and vaccination, which failed to identify relevant studies. The other dimensions of the research question (vaccination and COVID-19) were excluded, given the limited results from the initial search. These dimensions were then incorporated into the discussion of my findings.

MEDLINE, Embase, CINAHL, and Scopus were searched using a combination of broader terms and keywords pertaining to ‘best interests’ and ‘pediatric ethics’, ‘children’, ‘teens’, ‘adolescents’, and ‘health’. Medical Subject Headings (MeSH terms), a standardized vocabulary of biomedical- and health-related terms to describe the subject of a journal article, were applied when the databases prompted their use. MeSH terms in these searches include ‘child’, ‘infant’, ‘minors’, and ‘adolescen(ts/ce)’. Certain terms were exploded to encapsulate all MESH terms in the category, as well as references indexed to any narrower term(s): in MEDLINE, Embase, and CINAHL, the terms ‘child’, and ‘infant’ were exploded. Searches included functions to find keywords with proximal concepts. In MEDLINE and Embase, the functions ‘adj3’ and ‘adj5’ (adjacent 3 and 5) were utilized to include articles that discussed the separate terms ‘best interests’ and ‘child’ or ‘pediatric’ and ‘ethics’ within 3 and 5 words of each other, respectively. This function was also utilized during the search of CINAHL, indicated by the terms ‘W3’ and W5’ (within 3 and 5, respectively). The search of the database Scopus uses ‘N3’, as in ‘near 3’. Searches of MEDLINE and Embase searched the keywords specifically in the titles and abstracts by using the function ‘.tw.’. The use of the asterisk ‘*’ in the middle or at the end of a term included articles with all possible spellings and endings of the terms. Articles were limited to the English language in MEDLINE, Embase, and Scopus (CINAHL does not have this function). The Scopus search strategy is simple compared to the other three databases, as some of these functions are not applicable since it is a strictly ‘keyword interface’. Search terms related to vaccination were removed to broaden the scope of the best interests discussions in order to capture literature from other disciplines. A total of 4146 articles were retrieved across the four databases: 817 from MEDLINE, 1093 from Embase, 1058 from CINAHL, and 1178 from Scopus. It was essential to broaden the search strings to capture more empirical studies, without limiting by discipline or type of healthcare decision. The table below shows the search strings from each database, along with the number of results:

Table 1: Search strategy

Database	**Keywords**	**Hits**
MEDLINE (Ovid)	best interest*.tw. OR (best interest* adj5 child*).tw. OR (best interest* adj5 standard*).tw. OR (p*ediatric adj3 ethic*).tw. AND adolescent/ OR exp child/ OR exp infant/ OR minors/ OR p*ediatric*.tw. OR (child* OR teen* OR youth).tw. AND “health” AND limit to English language	817
Embase	(best interest*.tw. OR (best interest* adj5 child*).tw. OR (best interest* adj5 standard*).tw. OR (p*ediatric adj3 ethic*).tw. AND adolescent/ OR exp child/ OR exp infant/ OR minors/ OR p*ediatric*.tw. OR (child* OR teen* OR youth).tw. AND “health” AND limit to English language	1093
CINAHL	"best interest*" OR "best interest* W5 child*" OR "best interest* W5 standard*" OR "p*ediatric* W3 ethic*" AND (MH "Child+") OR (MH "Infant+") OR (MH "Minors (Legal)") OR (MH "Adolescence") OR p*ediatric* AND “health”	1058
Scopus	(TITLE-ABS-KEY ("best interest*" OR "p*ediatric* n3 ethic*") AND TITLE-ABS-KEY (child*OR teen* OR youth OR adolescen* OR infant* OR minor*) AND TITLE-ABS-KEY health)) AND (LIMIT-TO (LANGUAGE , "english"))	1178

The articles were uploaded to Covidence, where 1670 studies were identified by the software as duplicates, and 18 were manually identified as duplicates. After duplicates were removed, 2476 articles were screened by title and abstract. The title and abstract screening process identified studies that did not fit the inclusion and exclusion criteria. The inclusion and exclusion criteria are as follows:

- Studies must be in English.

- Studies must include the term ‘best interests’ in terms of children.
- Studies must be regarding ‘healthcare’ decision-making.
- Studies may be empirical or non-empirical (normative).

Studies had to include the term ‘best interests’ in relation to children, as this was the central and most important concept of this review. Studies that did not use this term explicitly were excluded. Studies that mentioned this term but did not engage with the term beyond a passing mention were excluded, as they did not add anything to the discussion. Studies that used the term to discuss the interests of the public, an adult, an organization, etc., were also excluded. Studies that discussed the best interests of an unborn fetus or a pregnant adult (over the age of 18) were also excluded. Other publications that only referred to relevant terms in understanding the best interests standard without mention of the standard (such as beneficence, non-maleficence, substitute decision-making, or the harm principle) were not included, as it was unclear whether studies that did not mention the specific term would advance a discussion on how the best interests standard is conceptualized and applied in healthcare decisions without being explicit. These terms may have been used by scholarly literature to refer to the principles of interest in this investigation and could provide relevant insights into how HCPs navigate pediatric medical decision-making in the best interests of the child but go beyond the scope of this review.

Studies were included if they pertained to the best interests standard for ‘healthcare’ decisions. A healthcare decision is defined as a decision regarding treatment that a health practitioner has proposed (Ontario, 1996). Health practitioners are considered in Canada as “a person lawfully entitled under the law of a province to provide health services in the place in which the services are provided by that person” (Canada Health Act, 1985). Decisions regarding healthcare included treatment and withholding treatment. Treatment is defined as interventions or non-interventions for a health-related purpose and includes a course of treatment, plan of treatment, or community treatment plan (Ontario, 1996). Certain aspects that are tangential to treatment were excluded such as capacity assessments, restraint, participation in research, information sharing or withholding, teaching, child abuse reporting, etc., as conceptualization and analysis of the best interests of the child differ in these decisions (other actions that are not included in “treatment”, as defined by the HCCA, were not included in this list as they did not arise in the literature).

Both empirical and non-empirical literature that explores the ethical contours of how HCPs did or should navigate vaccine hesitancy with the best interests of the child were relevant to this study. As previously mentioned, empirical articles use data to provide a descriptive claim and may include quantitative or qualitative studies that use observations, questionnaires, focus groups, interviews, systematic reviews, etc. Non-empirical articles included those that discussed the authors' own theoretical positionings, arguments, experiences, or beliefs.

No inclusion or exclusion criteria specified a year range – although this study is interested in COVID-19 vaccination, if specifications were made to restrict literature from the beginning of the COVID-19 pandemic (2020) until the present, this would severely limit the number of articles, thereby potentially excluding papers with key ideas.

Some conference abstracts seemed to describe an empirical study but were ultimately excluded as the full study would have been picked up by the search strategy if it had been published. Manual searching of these abstracts on Google, and checked in Covidence, confirmed this.

2325 articles were deemed ineligible based on the inclusion and exclusion criteria during the title and abstract screening. 151 articles were screened by full text, of which 99 articles were removed during the full-text screening as they lacked focus on best interests and pediatric medical decision-making. Many studies were excluded for containing an insufficient discussion of the standard. Even though these articles included the term 'best interests', they did little to engage with the concept or explain how the standard was used beyond merely mentioning the term in passing. For instance, many publications included sentences in their abstracts and a handful of times in their body that X was 'in the best interests of the child' without explanation of the analysis behind how this was arrived at. This falls short of the conceptual relevance and depth required of included articles given the nature of the research question.

Data was extracted from more than 58 articles, and while I was immersed in the data, I found that some papers repeated ideas and theories that had already been forwarded by other publications and did not contribute any new key ideas. These papers were removed from the final 58 included articles. While this process does not reflect 'true' theoretical saturation, CIR methodology does not seek to analyze all publications that present, for example, measles vaccination and best interests. During this immersion process, it only became evident during data extraction and analysis that certain papers were not contributing any novel insights.

38 empirical and 14 normative articles were deemed suitable for this study. Citation searching and hand-searching the journals retrieved 3 more relevant empirical and 3 normative publications. All 58 articles were included in the review and extracted data from all. The PRISMA diagram is presented in the following figure:

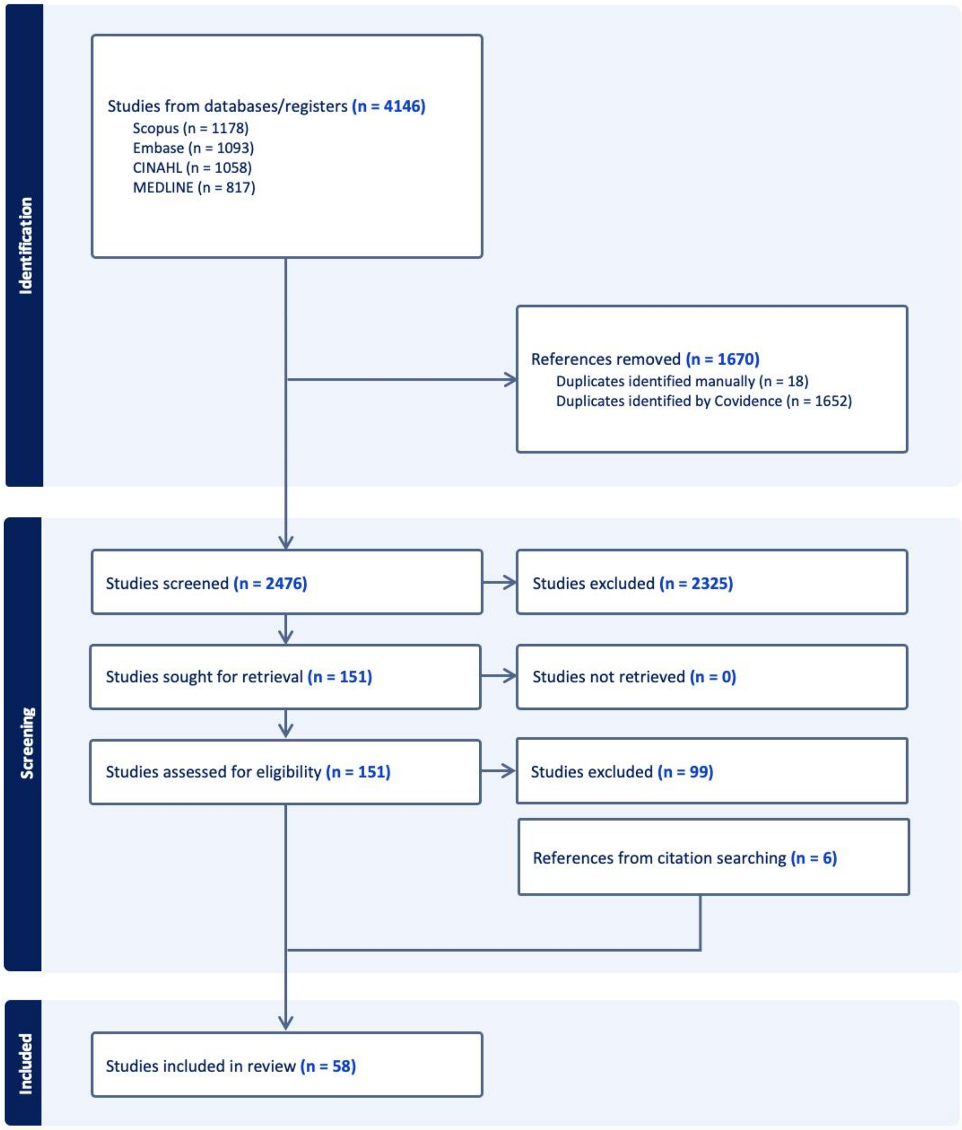

Figure 1: PRISMA diagram

This review aimed to capture the relevant key ideas to best interests decision-making for childhood vaccination, and due to the lack of literature, those that discussed the best interests standard within other healthcare decision-making domains were deemed relevant to answer my research question. Determinations of key ideas were informed by the research question. This included literature that discussed and advanced a normative ethical argument or an empirical ethical discussion. I was particularly interested in how the best interests standard was understood in this way. I was not as interested in the normative legal perspectives of the best interests standard. Though relevant, this was beyond the scope of my project and research question. The normative domain of the best interests literature includes ethical and legal inquiry, among others. Concerning normative literature, this investigation is primarily interested in the literature of a normative ethical nature, as in articles that discussed the ethical contours of what ought to be, what is morally permissible, etc. (Vogelstein et al., 2019). The normative legal literature focuses on discussions of legal norms and jurisprudence, and the court's interpretation of the best interests standard. As previously discussed, the best interest standard is used in legal proceedings to provide legal analysis for substitute decision-making concerning custody or family disputes, a child's education, and welfare. Literature that discussed the best interests in the legal context outside of healthcare decisions was less relevant to answering my research question. While this literature could provide insights, they were beyond the scope of my investigation. Normative legal papers were therefore excluded.

While these steps are explicitly outlined in this chapter to be transparent for the reader, I wish to emphasize that this process was iterative and non-linear.

2.4 Data analysis

This entire process was immersive and iterative; the former meaning becoming deeply familiar with the data through creative outlets such as mind maps and narrative description memos, and the latter meaning the non-linear process of moving back and forth from data and analysis to compare and deepen the results (Charmaz, 2014). I was the only researcher involved in data analysis, which helped deepen immersion in the data, thus increasing the rigour of my analysis (Green et al., 2007).

My analysis began with charting the 58 articles. Data extraction took place in Covidence. A Data Extraction template was created, inspired by Dixon-Woods and colleagues' (2006) systematic data extraction pro forma, to include these headings: Study ID, Title, Country in which the study was conducted, Aim of study, Treatment/Intervention/Decision, Study design, Year, Sector, Possible conflicts of interest, Population description, Institution, Inclusion criteria, Exclusion criteria, Method of recruitment of participants, Total number of participants, Primary finding(s), Codes, and Key quotes with page #s. Not all publications had data to extract for some of these categories, namely the normative commentary pieces that did not have participants, therefore extraction consisted of summaries of key ideas relevant to the critique of the literature (Dixon-Woods et al., 2006).

To each publication, I ascribed various 'codes', as in the rudimentary aspects of elements of the data that stood out (to me) as relevant in furthering understandings of how HCPs conceptualize and approach best interests in medical decision-making. Some codes were ascribed to many publications, and other codes were only ascribed to one. A total of 54 unique codes were recorded across all 58 publications. When a code was recorded, key quotes from the publication that provided context and description of the code were copied into the data extraction template. The following table demonstrates a charting example:

Table 2: Charting example

#	Reference	Country	Objective	Study design	Participants	Context	Codes
1	Abdin et al. 2022	United Kingdom	To explore factors that influence professionals in deciding whether to withdraw treatment from a child and how decision making is managed.	Semi-structured interviews	15 Health professionals	Treatment withdrawal for children with life-limiting illnesses	Parental role of determining BIS/working with parents; State intervention; Relationship building/trust; Child's voice/assent; Other: Competence, severity, parental denial, negotiation, Charlie Gard, Tafida Raqeeb, culture
2	Albersheim et al. 2010	Canada	To assess the attitudes of Canadian neonatologists towards the authority of parents to make life-and-death decisions for their babies.	Semi-structured interviews; Standardized scenarios/ Vignettes; Survey	164 Neonatologists	Life-and-death decisions for sick neonates	Definition of BIS; Parental role of determining BIS/working with parents; Other: Uncertainty, harm principle, survival, personhood
3	Armstrong et al. 2011	Ireland	To determine whether healthcare providers apply the best interest principle equally to different resuscitation decisions.	Survey	148 Consultants, trainees in neonatology, paediatrics, obstetrics and 4th medical students.	Resuscitation of critically ill patients	Definition of BIS; Other: Age, your own child, medical student vs physician, prognosis, QoL, disability
4	Bahus and Førde 2011	Norway	To understand whether the attitudes of Norwegian doctors regarding surrogate decision power in end-of-life care conform to legal rules.	Survey	640 Doctors: internal medicine, paediatrics, surgery, neurology, and neurosurgery	End-of-life care for critically ill children	Parental role of determining BIS/working with parents; UNCRC; Bioethical principles; Other: Criticism of BIS, futility, BIS not upheld, time
5	Belcher 2013	United States	To understand the perceptions and lived experiences related to futile care and moral distress of nurses who provide care to extremely immature newborns.	Semi-structured interviews	10 NICU Nurses	End-of-life care for critically ill children	Parental role of determining BIS/working with parents; UNCRC; Bioethical principles; Other: Criticism of BIS, futility, BIS not upheld, time

Charting of all articles is available in Appendix A: Reviewed articles.

Codes were then typed out to be viewed in entirety, which contributed to the recognition of patterns, areas of agreement, areas of contention, areas for further clarity, etc., in the literature. Codes and key quotes were collated by the similarity of topics and arguments, influenced by the data corpus and my positionality to explore and identify potential themes. Themes were iteratively identified, refined, and named to capture important aspects including relevant perspectives, factors, tensions, and ethical considerations to my research question. I generated themes in three ways: by organizing and categorizing codes, by reflexively considering the presented arguments and patterns within the data and discussing with my supervisors and advisory committee, and by posing all questions in my analytic guide (see: Table 3: Analytic guide) to each text. Key quotes were recorded directly from the texts, along with memos about how they related to previous arguments or prospective themes. Additionally, relationships between codes, key quotes, and developing themes were considered as a whole to identify further patterns and arguments relevant to the research question and categorize hierarchies of themes, sub-themes, and codes.

Dixon-Woods and colleagues propose the development of a ‘sampling frame’ to retrieve articles within boundaries specific to the interpretive methods and research question (Dixon-Woods et al., 2006). Rather than relying on narrowly defined inclusion criteria to find publications that answer a research question defined at the outset of the investigation, CIR methodology suggests an interpretive boundary in order to include insights across relevant fields. This does not require the inclusion of all literature in these fields, so for feasibility reasons, Dixon-Woods and colleagues suggest using purposive sampling to limit publications to those concerned with relevant topics (in this case, best interests and pediatric medical decision-making), and later employing theoretical saturation to iteratively focus the emerging analysis (Dixon-Woods et al., 2006). CIR methodology treats saturation differently than has previously been articulated by scholars like Glaser and Strauss, who contended that theoretical saturation is an iterative process, where publications are constantly compared for recurring theories and themes (Glaser & Strauss, 1967). They proposed an exhaustive, or ‘true’ form of theoretical saturation in which the benchmark for quality is achieved when no additional theories, themes, ideas, or understandings arise from constant comparison within the data (Glaser & Strauss, 1967). More recently, qualitative scholars have challenged this benchmark that analysis must reach to be considered high-quality analysis (Sebele-Mpofu, 2020). ‘True’ theoretical saturation has been more recently re-conceptualized as an ‘ideal’ for qualitative researchers to aspire towards – a subjective and practical judgement made by the researcher once new ideas or arguments do not seem to arise. Of course, these ideas may well exist. This is particularly relevant for CIR, where quality assessments do not strive to be ‘rigid’, and rather comment within the review on ‘quality issues’ (McDougall, 2015).

In considering this critique, I approached the venture of theoretical saturation in my analysis with the purpose of focusing concepts and themes (Dixon-Woods et al., 2006). I acknowledge that my role in conducting analysis as a critical researcher bears subjectivity; if another researcher were to undertake analysis of the same data, new ideas, arguments, and themes would likely emerge. As previously stated, this is an integral feature, rather than a deficit, of CIR.

The process of reviewing and analyzing the articles was critical: each publication was questioned on how parental views on the best interests standard were represented, and prioritized, and what this said (and did not say) about the norm. Simultaneously, I was critical of the entire body of literature, interrogating key justifications provided and generating a critical argument about the literature. The following table depicts the questions I used as a guide to critically analyze the articles individually, as well as in their entirety:

Table 3: Analytic guide

Guiding questions:	**Sub-questions:**
What values are evident in this text?	○ How are the values expressed? ○ How do those values work together or create tension in this text? ○ What values are missing?
Whose voices are prominent in the text?	○ How are the HCP’s voices represented? The child’s? The parents’? ○ Who is considered an ‘expert’ on the best interests of the child and how does this occur?
How are the voices and values elicited?	○ Are the children’s voices being elicited? ○ If so, how and where are the children’s voices being elicited? ○ What guidance, if any, is provided about eliciting the views of the child?

How are the voices and values prioritized?	○ Whose voices are missing? • Is the child's voice missing? • Is the parent's voice missing? • Both?
Who benefits from the representation of the best interests of the child presented in this text?	○ Who (or what) is left out of this representation?
Which interpretations of the best interests of the child are evident in this text?	○ Which interpretations are limited or challenged (i.e., biomedical, bioethical, legal)?
What does this text 'do' to represent determinations of the best interests of the child?	
What does this text assert (implicitly or explicitly) about how HCPs do or ought to navigate the best interests of the child?	

As this review was critical and interpretive in nature, themes were generated interpretively from the literature and my own interpretation of what they meant against my understanding of the greater field of pediatric medical decision-making. Dixon-Woods and colleagues (2006) report the use of a large multi-disciplinary team and constant dialogue (called "checks and balances") to ensure there were multiple perspectives framing the analysis. Rather than including a second reviewer, I reported my positionality and constant reflexivity through memoing throughout the review process.

I also employed a form of "checks and balances" with two supervisors with expertise in this area, meeting weekly for dialogical reflexivity sessions to discuss emerging ideas and critiques within the literature. As McDougall (2015) reflects, CIR must acknowledge the interpretation involved in defining 'key ideas' and seek to explicitly report the review process to enable readers to engage critically with the critique produced.

This extraction process helped me identify key ideas and themes relevant to my research question to develop a critique of the literature: there are several contrasting perspectives, decision-makers, factors, and ethical considerations discussed in relation to the best interests of the child and medical decision-making. Once all information was extracted from the full texts, data was downloaded as a Microsoft Excel file. Themes were then developed to explain this trend, compared constantly against the publications in this review, to refine the categories and the relationship between them. Memoing was employed to remind me of personal reflections that arose during the analysis process.

2.5 Conclusion

In conclusion, this chapter described the methodology and methods used in this thesis. After recruitment challenges, I employed CIR methodology to investigate the literature regarding HCPs' perspectives on children's best interests and healthcare decision-making. Both empirical and non-empirical literature were included to explore the ethical contours of how HCPs did or ought to navigate the best interests of the child in the context of healthcare decisions. The next chapter presents the findings of my review.

Chapter 3

3 Results

This chapter describes the findings from my critical review of the literature regarding best interests and children's healthcare decisions. The themes explored in this chapter speak to the ideas I identified as 'key': the relevant dimensions of best interests that can deepen how it is understood in relation to children's medical decision-making. The findings presented below involved analysis and interpretation on my part (as discussed in Chapter 2), however, Chapter 4 provides a refined analysis of my research question: "How are best interests for children's health decisions understood by HCPs in empirical studies and how ought best interests be understood by HCPs in non-empirical articles?"

In the following, I set out to report findings from empirical and non-empirical articles separately, in order to reflect on the similarities and divergences of how best interests are understood. The non-empirical literature discussing how 'best interests' for children's health decisions *ought to be* understood by HCPs is discussed first, followed by the empirical literature on how 'best interests' *are* understood. Then, both are discussed together, including reflections based on my interpretations and positionality. All themes were represented in each type of literature. Therefore, these overarching reflections from both literatures were reported at the end of each sub-section. The organization of my findings in this way seemed advantageous, as direct comparison revealed consistencies, discrepancies, gaps, etc., on understandings of best interests from both empirical and non-empirical research.

To preface the description of themes, I wish to return to the concepts of capacity and decision-making presented in Chapter 1. Individuals who are capable of making medical decisions have the right to make any medical decision they wish, as per the bioethical principle of respect for autonomy (codified in law), even if these decisions carry the potential for great risk or severe harm. For those who are incapable of making their own medical decisions, SDMs cannot make any medical decision they wish – they are responsible for making a decision in the best interests of the incapable person. In most medical decision-making, navigation of what is 'best' may not be necessary as the principle of respect for autonomy entails deferring to the individual's expressed wishes, or if they are incapable, deferring to their previously expressed wishes. However, for those who have never expressed capable wishes, it is important to interrogate what is ‘best’ for the incapable patient, which may not be so straightforward. This raises a number of questions:

1. What are the conceptions of ‘best interests’?
2. What existing ethical dimensions instruct us to determine ‘best interests’?
3. What factors are relevant to determine ‘best interests’?
4. Whose perspectives are relevant to ‘best interests’?
5. Who gets to decide what is in the child’s ‘best interests’?

These questions helped me explore overall patterns in the literature and organize my findings according to main themes.

The search of the literature yielded 41 empirical publications and 17 non-empirical publications. I identified 5 main themes in the literature that can further understandings of how best interests are understood by HCPs in empirical studies and how best interests ought to be understood by HCPs in non-empirical articles regarding medical decision-making for children. They include: 1) How are ‘best interests’ conceptualized? 2) what ethical dimensions are at work within ‘best interests’? 3) what factors influence ‘best interests’? 4) whose perspective is ‘best’? 5) who decides what is ‘best’?

To briefly summarize each theme, the first theme, “how are ‘best interests’ conceptualized?” explored the various conceptions and definitions of ‘best’ interests presented in the empirical and non-empirical literature. The theme “what ethical dimensions are at work within ‘best interests’?” explored relevant ethical dimensions to ‘best interests’, including respect for autonomy, beneficence, non-maleficence, justice, the harm principle, proportionality, the ‘double effect’, herd immunity, etc. The theme “what factors influence ‘best interests’?” explores the many factors including medical factors such as prognosis, quality of life, futility, and suffering, as well as other relevant factors such as culture, religion, socioeconomic factors, etc. The fourth theme, “whose perspective is ‘best’?” explores who does or ought to inform ‘best interests’ decisions, including HCPs, parents, children, and families. Finally, the fifth theme “who decides what is ‘best’?” explores who ultimately has the power to decide what the child’s ‘best interests’ are. The fourth and fifth themes do not aim to provide a determinate answer to who is in fact ‘best’, and rather, to reflect on the agreement or competing ideas of what is ’best’ in relation to children’s medical decisions.

All the reviewed publications stated that substitute decisions *should be* made in the child's best interests. In other words, no one seemed to disagree with the starting point that best interests ought to guide decision-making, however that may be interpreted.

3.1 How are ‘best interests’ conceptualized?

Firstly, there seemed to be difficulty defining how the child's best interests were conceptualized in both the non-empirical and empirical literature. This insight was not surprising, given the description in Chapter 1 of the conflicting and uncertain ideas on what ‘best interests’ constitutes.

3.1.1 Non-empirical literature

Chervenak and colleagues (2016) illuminated the distinction between the best interests standard as an ‘ideal’ or a ‘norm’:

> As an ideal, it sets a goal toward which pediatricians and parents should strive, knowing that in some cases they may fall short. In its 1995 statement on parental permission, the American Academy of Pediatrics invokes the standard as a norm that creates ethical obligations of both pediatricians and parents when there is effective treatment that protects the health of children. (Chervenak et al., 2016, p. 305)

Concerning childhood vaccination, falling short of vaccinating all children without medical contraindications was deemed ‘acceptable’ if the best interests standard was viewed as an ideal, but not as a norm. Chervenak and colleagues (2016) stated that from the ideal conception, the health of children may not have been effectively protected and, therefore, the standard ought to be understood as a norm. Additionally, Chervenak and colleagues (2016) stated one should consider best interests ‘biopsychosocially’ to avoid biomedical reductionism and narrow diagnostic and therapeutic reasoning. However, they also proposed that the patient’s parents’ interests should not be included in the HCP’s determination of best interests, as they are not the patient.

These authors seemed to promote a conception of the child’s best interests that is most meaningful when viewed as a common practice rather than something for HCPs to strive for, particularly when considering vaccination decisions. Interestingly, these authors propose a ‘biopsychosocial’ conception of a child’s best interests while simultaneously excluding the interests of the parents. This may raise questions about the possibility of excluding parents’ interests while including the child’s biopsychosocial environment, as these two aspects seem closely intertwined.

In non-empirical publications theorizing how to conceptualize ‘best interests’, I became attuned to conceptions that suggested best interests could be understood ‘objectively’, and ‘not objectively’ or ‘subjectively[7] (Dawson, 2005; Pierik, 2020). Dawson used the term ’subjective’ to describe a view of ‘best interests that is determined by “what the individual themselves does choose, or if they are incompetent, what they would be expected to choose if they were able to do so” (2005, p. 80).

Dawson (2005) and Pierik (2020) used the term ‘objective’ to describe best interests conceptions as the maximization of the person’s ‘welfare, well-being, or good’ (Dawson, 2005; Pierik, 2020). Both Dawson (2005) and Pierik (2020) stated that objectively, best interests were judged as the decision that brought about the maximum ‘welfare’ in a medical situation was in the person’s best interests. Dawson (2005) described that, on this view, best interests could be “ determined independently of what the relevant individual themselves might believe or desire to be relevant to the production of their good” (Dawson, 2005, p. 79), signaling that this conception of ‘best interests’ did not restrict itself to ‘what the person believes is in their best interests’. Dawson (2005) also concluded that, in the case of young children who do not have decision-making capacity nor prior expressed wishes, vaccination decisions can only be made objectively. In his view, these decisions are made by balancing the benefits and harms of a particular vaccination and non-vaccination. Conversely, Pierik (2020) proposed that the objective conception of best interests failed to provide sufficient guidance for making decisions on prophylactic treatments like vaccination as these situations may not involve ‘clear and present danger’. He argued that other medical and non-medical considerations could be helpful in determining what is ‘best’ for a child.

These conflicting views in the non-empirical literature intrigued me, as both authors seem to be interpreting the objective account similarly but applying it to the vaccination case differently. In my interpretation, these authors mean to say that objective accounts of best

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[7] This is a simplification of a complex and nuanced concept for the purposes of this discussion.

interests weigh the harms and benefits of a proposed treatment, such as vaccination, based on the available empirical evidence of said vaccination. This raises questions about what counts as a benefit and a harm, and how these are chosen when weighing best interests objectively. The term ‘objective’ may be problematic as empirical evidence is not necessarily objective, and the very selection of what empirical evidence is included is unclear and subject to judgment. While there may be value in this kind of approach to determining a child’s best interests, there seems to be plenty of subjectivity inherent in what these authors have presented as ‘objective’, which renders the distinction between ‘objective’ and ‘subjective’ perhaps less helpful in gaining clarity on the best interests standard and its application. Additionally, Pierik's (2020) argument that VPDs do not involve ‘clear and present danger’ was interesting to me, as while the illness may not seem ‘present’, the risk of being exposed exists. Regardless, other non-medical considerations may still help determine a child’s best interests, to avoid decisions that do not take into account the child’s broader relational environment.

Furthermore, non-empirical publications present ‘best interests’ as an obligation for physicians to protect their pediatric patients (Chervenak et al., 2016), and simultaneously, publications indicate that the best interests standard is meant to guide parents to make medical decisions on behalf of their incapable child (Lara Carrion & Bramstedt, 2023). Hester and Salter suggest the best interests standard ought to be used as a moral guide for parents, as they hold decision-making authority (Hester & Salter, 2022). While parents are legally responsible for making decisions based on their child’s best interests in Canada, they do not hold ultimate or absolute decision-making authority, and when clinicians feel that the best interests of the child are not being upheld by the parents, they may seek to use the best interests standard to justify intervention by the courts. The best interests standard has been used as a threshold for indicating the need for state intervention in pediatric medical decision-making (Bayefsky, 2018; Dawson, 2005).

3.1.2 Empirical literature

Views about how best interests were conceptualized arose in empirical publications. Some publications suggest that given its varying interpretation, the standard ought to be considered as a guide, rather than as a strict framework for decision-making (Cavolo et al., 2021), while others show how HCPs use the standard more narrowly to answer specific treatment questions (Streuli et al., 2021). Many other publications state simply that the best interests of the child are difficult to determine (Deligianni et al., 2023). This resonates with the conflicting definitions within the non-empirical literature but does little to advance the concept to use in practice.

Some of the reviewed publications detailed that HCPs' determinations of best interests relied on 'objective' medical information (e.g., prognosis and quality of life) while others describe how HCPs relied on broader factors about the parents' influence, familial factors, and the HCP-patient-parent triad relationship. For instance, some publications proposed that an HCP's expertise was prioritized in best interests decisions as they could be 'objective' and 'rational', whereas the child's parents cannot (Cavolo et al., 2021; Street et al., 2000). This seems to indicate that some HCPs strive for 'objectivity' when making best interests decisions, but again, the use of the term 'objective' seems to better signal that HCPs can make judgments that exclude the emotions that parents bring to determining their own child's best interests.

The empirical literature described contrasting conceptions of how HCPs considered the child and their family in best interests. For example, one publication described how some HCPs felt the best interests of the child were tied closely, if not equivalent to, the best interests of the child and their family (Birchley et al., 2017). Another publication purported that best interests were reliant on the perceptions and values of the 'stakeholders' (Cavolo et al., 2021). Another publication reflected on this conception, stating: "BIS really means that the child is at the centre, with all its aspects [...] The BIS means to be raised and to flourish in a biological, psychological, social and economic environment where all aspects are optimally available" (Streuli et al., 2021, p. 762). This directly contrasted other empirical viewpoints where the child alone was the focus of the assessment of best interests, and the benefits and the burdens for the family, physicians, or others were not the priority (Armstrong et al., 2011; Janvier et al., 2008; Laventhal et al., 2017).

The excerpts mentioned above may reflect the varying and sometimes directly conflicting views on how HCPs conceived of best interests. HCPs seemed to be divided on whether the 'objective' approach is 'best'. This raises questions surrounding how HCPs can truly be 'objective' when weighing the harms and benefits of a proposed treatment, since these sorts of things generally involve human interpretation, raising questions about whose interpretation matters, morally speaking. This appears to be reflected in the empirical literature, where some HCPs considered the benefits and burdens of the child and other stakeholders in their environment, while other HCPs excluded the child's greater social interests from their decisions.

Reflecting on the insights from the non-empirical and empirical reviewed works regarding how 'best interests' were conceptualized by HCPs, there are some agreements and differences worth noting. Both literatures highlighted 'objective' accounts of best interests, which raises similar concerns about what this term represents, and perhaps more importantly, what it obscures. In my interpretation, these authors are pointing towards a harm-benefit analysis of best interests based on empirical evidence of a given treatment. This conception of best interests may require further explication of how HCPs can or ought to approach harm-benefit analyses 'objectively', or if this is truly possible. Additionally, this analysis of harms and benefits may be one way of determining best interests. This approach seems to align with consequentialist ethics, which adds up the consequences (or harms and benefits) of a certain treatment to determine its ethical permissibility. Other theoretical approaches in ethics, such as deontology and virtue ethics, might evaluate a treatment's ethical importance based on one's duties or virtues, perhaps even irrespective of the treatment's consequences. This is not to say that a harm-benefit analysis is not important but to demonstrate that there are other ways of evaluating an ethical 'best interests' decision. Accepting an 'objective' approach to determining best interests, understood as weighing benefits and harms, may entail (or require) the acceptance of a consequentialist ethic, which should not be taken for granted.

Disagreements between the non-empirical and empirical literature included the way biopsychosocial considerations were conceptualized. Interestingly, both literatures reflected this as a centring of the child in best interests decisions; however, non-empirical papers excluded the parents' interests while empirical studies did not specify how to navigate these considerations.

3.2 What ethical dimensions are at work within 'best interests'?

This next theme explores the ethical dimensions expressed in the non-empirical and empirical literature surrounding best interests. Under this theme, I included ethical principles, frameworks, and models. As such, I used the term 'ethical dimensions' so as to not limit this discussion to any one of these dimensions. I first discuss my findings and reflections on Beauchamp and Childress's bioethical principles, comparing the non-empirical and empirical literature, and then discuss the remaining dimensions, including herd immunity, the harm principle, altruism, and other principles and standards. I structured this analysis in this manner due to the extensive findings from the first category. By keeping the comparisons of each type of literature closely integrated, I aim to ensure the reader retains a clear understanding of the distinctions and commonalities presented. The following table summarizes the ethical dimensions and their influence on best interests:

Table 4: Ethical dimensions of 'best interests'

Ethical dimension	**How 'best interests' is influenced**	**References**
Beauchamp and Childress' bioethical principles	Beneficence, non-maleficence, respect for autonomy, and justice were important in identifying and weighing factors in the child's best interests.	(Cavolo et al., 2021; Chervenak et al., 2016; Clark et al., 2020; Dawson, 2005; Diekema & Bioethics, 2005; T. W. R. Hansen et al., 2013; Hodges et al., 2002; Janvier et al., 2008; Laventhal et al., 2017; Mack et al., 2024; McDougall & Notini, 2014; Richards et al., 2018; Rus & Groselj, 2021; Sieg et al., 2019; Valdez-Martinez et al., 2014)
Herd immunity	Relying on herd immunity is not in the best interests of children, for a number of reasons.	(Bester, 2017; Braley-Rattai, 2021; Chervenak et al., 2016; Diekema &

		Bioethics, 2005; Malm & Navin, 2020)
Harm principle	Parental decisions may be permissible so long as they do not place the child at 'substantial risk of serious harm'.	(Clark et al., 2020; Diekema & Bioethics, 2005; Jivraj et al., 2016; McDougall & Notini, 2014)
Reasonable interests framework	HCPs and parents should treat each other as 'epistemic equals' by considering and responding to each other's reasons in deliberations of the child's best interests.	(Hester & Salter, 2022)
Altruism	If a child is capable of appreciating altruism, and it is believed that they would want to pursue a decision that provides benefits to others (such as vaccination and organ donation), these ought to be offered.	(Curley et al., 2007; Malm & Navin, 2020; Sarnaik et al., 2013)
The 'double effect'	If an action has both a helpful and harmful outcome, the action may be permissible provided that the harmful outcome, while expected, is not the primary one	(Sieg et al., 2019)
The 'not unreasonable' standard	If a certain treatment was recommended by an HCP, a parent's refusal of such treatment could constitute an unreasonable decision, therefore disqualifying them as the pediatric patient's SDM	(Clark et al., 2020; Janvier et al., 2008; McDougall & Notini, 2014)

The ‘shared optimum approach’	Decision-makers may adopt various positions while attempting to find an optimum for the pediatric patient and limit state intervention.	(Streuli et al., 2021)
The ‘expertise’ and ‘negotiated’ models	The ‘expertise’ model privileges physician expertise in determining the best interests of the child based on their medical knowledge and neutral involvement, and the ‘negotiated’ model acknowledges a subjective component to best interests by mediating between the values of the physicians and parents.	(Cavolo et al., 2021)

3.2.1 Beauchamp and Childress’ bioethical principles

The empirical and non-empirical literature often discussed Beauchamp and Childress’s bioethical principles for medical decision-making (2001), including beneficence, non-maleficence, respect for autonomy, and justice. These principles have become a ‘canon’ for bioethics because of these authors’ (important and pioneering) work. It is important to note that these principles are heavily criticized in bioethics, as many more principles are relevant to medical decision-making (Huxtable, 2013), but arose frequently in the reviewed literature.

3.2.1.1 Non-empirical literature

In the non-empirical literature, beneficence and non-maleficence were recorded as guiding ethical principles for determining the best interests of medical interventions, including childhood vaccination (Rus & Groselj, 2021). Observed data supporting vaccination seemed to be useful in determining the benefits and risks of vaccinating or not (Chervenak et al., 2016; Dawson, 2005). Where there was ‘clear’ evidence about the harms and risks to treatment, and they may be weighed straightforwardly, this provides a compelling argument to provide (or withhold) the treatment (although it is unlikely that empirical evidence can be conclusive) (Dawson, 2005). Vaccination requires us to also consider the likelihood of contracting the VPD and the potential resulting harm. For instance, Dawson (2005) stated that a judgment that weighs the empirical evidence of the risks and benefits was a necessary part of determining how to serve the child's best interests. While vaccinations posed risks from the physical prick of the needle and possible side effects, Chervenak (2016) suggested that these constituted "negligible risk" as they were offset by the risk of infection without vaccination. These authors seem to be representing a beneficence-based clinical judgement, where clinical benefits outweigh clinical risks. Some believed there was different ethical weight given to beneficence, or seeking maximal good, compared to non-maleficence, or seeking to minimize harm (Dawson, 2005).

Additionally, Rus & Groselj (2021) reflected that beneficence may extend to the child and society when determining the best interests of the child with respect to vaccination. These authors stated that vaccination has a double beneficial effect, protecting the individual and indirectly safeguarding the community. This perspective seems to add another layer of complexity to best interests determinations, where beneficence may include direct and indirect benefits. Returning to earlier reflections on weighing harms and benefits 'objectively', this raises questions of which benefits HCPs do or ought to consider and whether this includes greater benefits (or harms) to society.

The non-empirical literature also discussed the bioethical principle of respect for autonomy in relation to best interests. For childhood vaccination, one author suggested that parental autonomy should be "exercised under the constraint of the best interests of the child", where HCPs should seek parental permission, rather than consent, for childhood vaccination unless otherwise contraindicated (Chervenak et al., 2016, p. 306). They stated that on this basis, parental refusal of childhood vaccines is not ethically sound. Hodges and colleagues discussed the principle of respect for autonomy in terms of the growing societal acceptance that children "have rights to autonomy and deserve special legal protections" (2002, p. 1). Interestingly, while Hodges and colleagues (2002) emphasized that an incapable child's 'autonomy' be respected until they are able to 'express an opinion' on a treatment, I feel both Hodges and colleagues (2002) and Chervenak and colleagues (2016) could be reflecting similar understandings, in different words. As 'respect for autonomy' entails one's right to make decisions about their own health, this cannot directly apply to children deemed incapable of making their own medical decisions. Thus, the child's rights are arguably respected through the best interests principle, where SDMs are responsible for upholding the child's best interests.

Finally, non-empirical publications discussed the bioethical principle of justice and childhood vaccination. Some publications used justice to emphasize one's duty to contribute to herd immunity and protect vulnerable individuals (Diekema & Bioethics, 2005; Rus & Groselj, 2021). These publications raise questions around both respect for autonomy compared to justice, and family interests versus civic responsibility. In both cases, these publications seem to be signaling that childhood vaccine decisions have ethical implications for both the individual and the community and that perhaps best interests ought to be extended to address both of these aspects.

3.2.1.2 Empirical literature

In the empirical literature, the four bioethical principles of respect for autonomy, beneficence, non-maleficence, and justice were often mentioned along with the best interests of the child. One publication stated that Beauchamp and Childress stipulated no principle is preemptive, nor are the decision-making powers of the clinicians, parents, or children (Valdez-Martinez et al., 2014). The perception that the bioethical principles were at work within the best interests of the child standard emphasized in one publication the HCPs' obligations to uphold beneficence and non-maleficence by promoting maximal 'good' and minimal harm (Cavolo et al., 2021). This involved HCPs conducting a harm-benefit analysis, which entailed a variety of considerations depending on the treatment (Cavolo et al., 2021). This understanding seems to align well with non-empirical views on weighing the harms and benefits of potential actions and inactions to determine best interests (Dawson, 2005).

In my interpretation of the empirical literature, HCPs seemed to consider the possible harms and benefits or proportionality of treatment to the child to support medical decision-making. Some authors stated this was a step in determining the best interests of the child (T. W. R. Hansen et al., 2013; Mack et al., 2024; McDougall & Notini, 2014; Richards et al., 2018; Sieg et al., 2019), and others found that minimizing harm was a separate norm from the best interests standard (Janvier et al., 2008; Marcello et al., 2011). Proportionality was found to be a *prima facie* duty and key ethical factor in guiding best interests determinations, where the HCPs were responsible for balancing the burdens and benefits of proposed interventions (Mack et al., 2024; McDougall & Notini, 2014). When weighing the burdens and benefits of an intervention, for example, withdrawing life-sustaining treatment, HCPs considered whether the treatment options could achieve the desired outcome (prolonging life), or whether the prognosis was so poor that suffering and eventual death were certain (Richards et al., 2018; Sieg et al., 2019). Proportionality was not always expressed as purely clinical, where prognosis and recovery were critical factors amongst other familial and contextual factors (Mack et al., 2024; Sieg et al., 2019). While the option that maximizes benefits and minimizes burdens seemed to be the 'ideal' for HCPs, there were often resource limitations and conflicting opinions within the child's network of relationships that HCPs were inclined to consider (McDougall & Notini, 2014). Other factors included the emotional and psychological consequences to the child and their family. In the previously mentioned case, if the family members expressed that additional treatment would be more than they and their child could bear, some HCPs argued it was ethically permissible to withhold or withdraw life-sustaining treatment (Sieg et al., 2019).

Conversely, while some HCPs viewed proportionality as a part of best interests determinations, others viewed them separately. One publication used a case example of vaccination to demonstrate how in the face of parental vaccine hesitancy or refusal, although vaccination is in the child's best interests, it is more harmful to the child to be removed from their parents through state intervention than to go unvaccinated (Janvier et al., 2008). This was then applied to a case of life-sustaining treatment, where the harm of withholding care is death, which must be balanced with the 'harm' of possible lifelong disability (Janvier et al., 2008).

Again, these publications seemed to signal that benefits and harms could extend to the child's greater social environment, as well as emotional and psychological implications. Many of these publications seem to suggest that best interests can be 'best' determined in terms of consequences, but as previously mentioned, which consequences matter is of some debate, and there exist other ways of determining the ethical permissibility of a decision.

In this review, I found that empirical articles discussed the bioethical principle of respect for autonomy. Cavolo and colleagues (2021) stipulated that HCPs were obligated to evaluate the capacity of parents or other SDMs to make autonomous decisions in the best interests of their children and uphold those decisions. The principle of respect for autonomy arose in the empirical literature in parallel with the best interests standard, where HCPs attempted to respect the child's 'autonomy' as well as address their best interests (Clark et al., 2020). When a child was vocal and clear about their treatment preferences, ethical issues were expressed by HCPs concerned with respecting a pediatric patient's autonomy despite instances where it is unclear whether the child is capable of weighing the pros and cons of a proposed treatment: "I don't want to harm him by not starting as well, and I also don't want to harm him by starting. […] It's really the edge of harm and help" (Clark et al., 2020).

Interestingly, it seems as though 'respect for autonomy' may be referring to the agency of the child here, since when the best interests standard is discussed, this (should) preclude a determination that the child is incapable of making their own medical decisions and therefore respect for their autonomy is operationalized through the best interests standard. It is curious that the term 'autonomous' was used to reflect parents' decisions on behalf of their children, which seems to signal the view that best interests are purely determined by what the parents want.

The bioethical principle of 'justice' was discussed in one empirical publication as an ethical concern for trans youth accessing healthcare. Trans youth whose parents were 'unsupportive' (presumably of their child seeking hormone therapy) were described as facing challenges in accessing healthcare due to a "lack of system navigation, transportation, financial, and decisional support" (Clark et al., 2020, p. 174). These authors seem to be signaling that concerns about justice were considered in HCPs' determinations of a child's best interests, who strived to lessen inequities in their determinations.

In empirical publications, upholding the bioethical principles of respect for autonomy, beneficence, non-maleficence, and justice were shown to set moral limits on HCPs' actions to promote beneficence (Valdez-Martinez et al., 2014). Some HCPs experienced uncertainty and distress when these principles conflicted with each other to cause ethical tensions, as HCPs wished to avoid morally wrong interventions (Deligianni et al., 2023; Weiner et al., 2022). For instance, one publication reported how respect for autonomy clashed with non-maleficence in the context of vaccine hesitancy and refusal, where the decision to not vaccinate had harmful implications for the child and others, including increased risk of VPDs (Wiley et al., 2023). The principles were also shown to conflict with the best interests standard when parental autonomy threatened the best interests of the child (Laventhal et al., 2017). Parental autonomy has been shown in the non-empirical and empirical literature to clash with the best interests of the child, which will be examined later in this chapter. In my reflections, I found that this took for granted the exclusion of parents from a child's best interests. This only reflects one view of best interests, as others may believe that parental autonomy is an important, even essential, aspect of determining a child's best interests and thus would not view parental autonomy as 'clashing' with best interests.

Both the non-empirical and empirical works discussed the four bioethical principles, agreeing and disagreeing on some aspects. They seemed to agree that the principles were important in determining best interests, including balancing harms and benefits (beneficence and non-maleficence), respecting autonomy (within the constraints of best interests), and considerations of justice extending beyond the individual to the community. Those publications that discussed harms and benefits were not in agreement on which ones to weigh their determination on. In the non-empirical literature, harms and benefits may or may not have extended to the community's interests of herd immunity, and in the empirical publications, harms and benefits may or may not have extended to the family's interests. This represents an area for further interrogation to understand how best interests may navigate these differences. Interestingly, non-empirical and empirical publications reflected 'respect for autonomy' similarly but, in my view, requires further clarification when considering best interests. These publications raise questions about how 'autonomy' can be exercised by parents and respected by HCPs while making substitute decisions. Finally, justice concerns arose in both types of literature, where best interests included consideration of the broader social contexts of the decisions, including protecting others through herd immunity and protecting the individual from unfair medical treatment.

3.2.2 Other ethical dimensions

3.2.2.1 Non-empirical literature

In the non-empirical literature, the ethical consideration of 'herd immunity' was discussed to justify parental refusals of vaccination on behalf of their children. Herd immunity was expressed as the reliance on high vaccination rates in a community to protect the unvaccinated (Bester, 2017). It seemed to be an important goal for vaccination programs as the individuals (children and adults) in the community who were unable to be vaccinated because they were immunocompromised or for whom the vaccine was contraindicated may have received protection from herd immunity. For these individuals, vaccination is not an option. For the parents whose child can receive the vaccine but is refusing, they wish to rely on herd immunity as well to protect their child. Some publications expressed this as the 'free-rider' problem, where parents and the child benefit from the public good without contributing, and actually undermine public efforts (Braley-Rattai, 2021; Diekema & Bioethics, 2005). Bester (2017) cites many reasons why it is unethical for parents to rely on herd immunity, rather than vaccination, to protect their children. Firstly, herd immunity is not a stable construct, as some argue it is threatened by the dynamic changes of populations in any given area that can lead to decreasing rates of vaccination in the community. Additionally, if the number of parents relying on herd immunity increases, the number of children who are vaccinated decreases, thus threatening herd immunity (Bester, 2017). It would be unethical to allow one parent to rely on herd immunity and disallow another child from doing so to maintain herd immunity (for equally healthy children). Therefore, it is in the best interests of children, generally, to rely on vaccination to protect them, rather than herd immunity. In this view, one publication indicated that HCPs have a responsibility to protect all of their pediatric patients, thus they may rely on compelling the parents to vaccinate their children to protect herd immunity (Chervenak et al., 2016).

Parents who rely on herd immunity may be viewed as gambling with a child's health, thus neglecting their responsibility to uphold the best interests of the child (Bester, 2017). A clear case of not attending to the best interests of the child is when parents rely on the 'exogenous boosting hypothesis' (EBH), holding 'Pox Parties' to intentionally infect their child with varicella to protect the older community from contracting shingles, among other reasons (Malm & Navin, 2020). Parents who consider the benefits of others while deciding whether to protect their children from the harms of the disease may be viewed as 'perverse', and suggests the parent assumes altruism on the child's part (Malm & Navin, 2020).

There seem to be ethical *and* public health implications when parents believe it is in the best interests of their child to be protected by herd immunity rather than vaccination. Interestingly, there were no publications that argue it is in the child's best interests to contribute to public health measures to curb disease spread. I interpreted this as suggesting that, due to children's increased vulnerability, it is less controversial to argue that parents should protect them through vaccination. Rather, these publications seem to be showing how the ethical and public health duty to uphold herd immunity is placed on *parents* to vaccinate their children in the interests of public health and protecting the immunocompromised. This ensures the best interests of the child lie at the center of vaccine decision-making, rather than the interests of the public.

Additionally, I considered the harm principle a key ethical dimension in the non-empirical literature. The harm principle was first conceived by John Stuart Mill and proposed for pediatric decision-making by Douglas Diekema to justify state intervention when significant but preventable harm is imminent to a pediatric patient (Diekema & Bioethics, 2005; Mill, 1993). Diekema stipulated eight conditions that must be met before considering state intervention (Diekema & Bioethics, 2005). In his view, parental decisions may be permissible so long as they do not place the child at ‘substantial risk of serious harm’. In comparison, Hester and Salter (2022) presented the ‘reasonable interests framework’ for children’s medical decision-making that considered the relational aspects to best interests. Their framework attends to the system of relationships and dynamics that exist in children’s medical decision-making. Additionally, they encourage HCPs and parents to treat each other as ‘epistemic equals’ by considering and responding to reasons in deliberations of the child’s best interests (Hester & Salter, 2022).

Both the harm principle and the reasonable interests framework aim to protect the well-being of children but do so through different lenses. In my reflection, the former principle relies on clarifying which risks and harms are ‘substantial’ to the determination, and results may vary from one HCP to another. This may lead to differing interpretations of what constitutes significant harm. In contrast, the latter framework emphasizes the importance of balancing power dynamics and promoting shared decision-making but may cause challenges when there is significant disagreement between parents and HCPs. Additionally, I am uncertain about the time and resources this framework seems to assume are available for HCPs, and how it would be operationalized in situations where these are limited.

3.2.2.2 Empirical literature

The harm principle also arose in the empirical literature (Clark et al., 2020; Jivraj et al., 2016; McDougall & Notini, 2014). Although ‘harm’ was not defined clearly, one publication suggested that “relevant harms go beyond the physical, including the domain of the child’s future autonomy” (McDougall & Notini, 2014, p. 450). Clark and colleagues suggested that HCPs could use the harm principle to initiate treatment when patients are incapable of making treatment decisions and the parents are unsupportive of the proposed treatment by determining whether this course of action would 'cross the harm threshold' (Clark et al., 2020). They also suggested that the harm principle could be "a practical alternative to the best interests standard" for HCPs, when determining the risks of harm from withholding, delaying, or initiating a proposed treatment and whether the treatment would cross the harm threshold (Clark et al., 2020, p. 172). The harm principle was also adapted differently for pediatric organ donation, where an intervention 'not *against* a child's best interests' may have been deemed ethically acceptable (Jivraj et al., 2016). When applied to pediatric organ donation after death (DND), HCPs were ethically permitted to offer a child's organs in benefit to the recipient, as this was not necessarily 'medically indicated' in the donor child's best interests, but not directly 'harmful' either (Jivraj et al., 2016).

The empirical publications that discussed the harm principle as an alternative also critiqued the framework as problematic due to the subjective nature of determining 'harm', the 'harm threshold' and challenges in consistent judgements (Clark et al., 2020; Jivraj et al., 2016; McDougall & Notini, 2014). One author suggested that the harm principle was only relevant when HCPs conflicted with parental treatment decisions (McDougall & Notini, 2014).

In empirical publications, HCPs considered the concept of altruism in organ donation cases, where if a child was likely to wish to be an organ donor for themselves, there was a benefit to the child through the altruistic act of helping others (Curley et al., 2007; Sarnaik et al., 2013). Some HCPs believed that parents could not presume altruism on the part of a child (Curley et al., 2007). Others questioned whether the inability of the child to appreciate the altruistic act removed any benefits of altruism to the donor (Sarnaik et al., 2013). Alternatively, one publication hypothesized that withholding offering donations after cardiac death to children who are capable of understanding and appreciating altruism may be a violation of autonomy (Sarnaik et al., 2013).

Upon reflection, this conception of altruism and the harm-benefit analysis may apply to non-vaccination, as the child may be considered 'harmed' in the process of protecting another person's interests. Some empirical publications argued it was more acceptable, however, to assume a child's altruism when they were dying than when they were healthy:

one child will certainly die and thus ‘harming’ them by accelerating death through organ protection drugs was not viewed as severe as potentially harming a healthy child by exposing them to disease solely to potentially protect others (Curley et al., 2007). Altruism was also exhibited in the context of childhood vaccines and VPDs. Parents who bring their children to Pox Parties are deemed ‘perverse’, as there is a lack of empirical evidence that they are more effective than vaccines at decreasing the incidence of shingles, especially when there exists a shingles vaccine (Malm & Navin, 2020). The use of ‘harm’ and ‘altruism’ seems to assume that best interests are best determined using the harm-benefit analysis, which, as I explored earlier, raises questions about other ways to understand best interests.

The doctrine of “double effect” arose in one publication to similarly balance harms and benefits (Sieg et al., 2019). The use of opiates and anxiolytics in palliative care is known to alleviate pain and suffering, while potentially hastening death. The “doctrine of double effect” states that if an action has both a helpful and harmful outcome, the action may be permissible provided that the harmful outcome, while expected, is not the primary one (Sieg et al., 2019).

The ‘not unreasonable’ standard, put forward by Rhodes and Holzman, has also been proposed to supplement the best interests standard (Clark et al., 2020; Janvier et al., 2008; McDougall & Notini, 2014). This involves HCPs evaluating both the capacity of a parent as the SDM and the reasonableness of their decision. For example, if a certain treatment was recommended by an HCP, a parent’s refusal of such treatment could constitute an unreasonable decision, therefore disqualifying them as the pediatric patient’s SDM (Clark et al., 2020). Parents are therefore only entitled to be the primary decision-makers when the HCP believes they are committed to the pediatric patient’s well-being and a minimally appropriate level of concern (McDougall & Notini, 2014). If parents fail to meet this standard, the HCPs are entitled to seek state involvement to appoint an alternate SDM for the patient (McDougall & Notini, 2014).

In my interpretation, these principles and standards seem to imply that ‘harm’ and ‘reasonableness’ are defined by the HCP, therefore limiting decision-making input and power to the HCP’s discretion. This raises questions about whether what is ‘reasonable’ or ‘not harmful’ to an HCP is ‘best’ for a child, and vice versa. Or, if the conception of what is ‘best’ for a child is up to the discretion of the HCP, then how are ‘reasonableness’ and ‘harm’ operationalized in practice? If best interests are dependent on the HCP, this could place more decision-making power on HCPs which could lead to inconsistencies and the potential for bias to seep into children's medical decisions.

One publication put forward the Shared Optimum Approach (SOA), a framework that combined the best interests standard and shared decision-making approaches (Streuli et al., 2021). The framework was stipulated as an umbrella term to allow decision-making stakeholders to adopt various positions while attempting to find an optimum for the pediatric patient. It attempts to limit state intervention and emphasizes HCP's responsibilities to support pediatric patients and their parents without striving for a singular "best" treatment option (Streuli et al., 2021). My interpretation led me to understand that this approach differs from the 'harm' and 'reasonableness' standards as decision-makers other than HCPs are considered. However, like Hester and Salter's (2022) reasonable interests framework, the SOA seems to take for granted practical issues surrounding the resources required for this approach that can often be limited in Canadian healthcare settings. Furthermore, healthcare professionals and parents must ultimately select one option, thereby necessitating the determination of what is 'best' for the child.

One empirical review refers to Steven Leuthner's best interests models that help HCPs determine the involvement of the parents in treatment decisions: the 'expertise' model privileges physician expertise in determining the best interests of the child based on their medical knowledge and neutral involvement, and the 'negotiated' model acknowledges a subjective component to best interests by mediating between the values of the physicians and parents (Cavolo et al., 2021; Leuthner, 2001). Leuthner used a case of a premature infant to demonstrate the conceptual differences surrounding the best interests of infants between these models while commenting on four statements from the American Academy of Pediatrics (AAP) regarding critically ill newborn care. He suggested that the AAP interpreted the role of the HCP as employing their 'best medical judgement' to situations that they framed as 'objective' and 'scientific', while Leuthner sees them as "a personal albeit medically informed value opinion based on the quality of life of a prognosis and outcome" (Leuthner, 2001, p. 196). He suggested this approach aligned with the 'expertise' model, while an approach that incorporated both the 'objective' medical facts, risks, and available data, as well as the 'subjective' moral facts surrounding the value of the 'objective' components, was more aligned with the negotiated model of best interests. Leuthner concluded that while the ‘expertise’ model can be helpful in supporting HCPs in ‘black and white’ cases, this approach may be limiting for cases with greater uncertainty in which case he encouraged the use of the negotiated model to include the broader values of the family (Leuthner, 2001).

These contrasting approaches may parallel Dawson’s (2005) interpretation of the ‘subjective’ and ‘objective’ conception of best interests, although Leuthner encourages the use of both the ‘objective’ and ‘subjective’ together in the negotiated model to determine a child’s best interests. The negotiated model could provide a more comprehensive framework by integrating empirical evidence and the personal values of the family, thus offering a holistic approach to determining a child’s best interests.

One publication evaluated nine relevant frameworks that assisted HCPs in justifying overriding parents’ medical decision-making, including the best interests standard, the harm principle, and the not unreasonable standard (McDougall & Notini, 2014). They stipulated that ‘harm’ is the central moral concept that ethicists employ to judge the appropriate threshold for state intervention, and emphasized that disagreements that fall below the threshold required alternate frameworks for HCPs to mediate sub-optimal decisions from parents (McDougall & Notini, 2014). These frameworks include the ones mentioned above, and Ross’s ‘constrained parental autonomy’, McCullough’s ‘medically reasonable alternatives’, Schoeman’s ‘responsible mode of thinking’, Cooper and Koch’s ‘rational parent standard’, Demarco and colleagues’ ‘balance of costs and benefits’, and Kipnis’ ‘decisional capacity of the minor’ (Cooper & Koch, 1996; DeMarco et al., 2011; Kipnis, 1997; McCullough, 2009; Ross, 1999; Schoeman, 1985). HCPs may utilize any of these frameworks to justify when it is appropriate or not to override a parent’s decision.

In my review of the empirical and non-empirical literature, some of these frameworks arose in other publications in more detail. While this publication only provided an overview of each framework, it allowed for more direct comparison and interpretation when viewing the frameworks together. Based on the information presented in this publication, I created a table to strengthen my interpretations, available in Appendix B: Relevant frameworks for overriding parental decisions (McDougall & Notini, 2014). I interpreted that the central moral concept in these frameworks is not always the ‘best interests of the child’, and, in fact, there were many other concepts that have been proposed to justify overriding a parent's decision. McDougall and Notini reflected on the failure of these frameworks to distinguish between "parental decision-making that is somehow suboptimal from an ethical perspective, and parental decision-making that justifies state involvement to remove parental authority over the decision in question" (2014, p. 452). Additionally, the authors emphasize the importance of defining what 'overriding' represents when discussing its ethical permissibility. I would further argue that these frameworks necessitate a more thorough examination of what they imply about the best interests standard and the extent to which parental decision-making is incorporated (or not).

Interestingly, my interpretations led me to find many more different ethical principles, frameworks, and models explored in the empirical literature than in the non-empirical literature. I found that the non-empirical literature generally relied on beneficence and non-maleficence, or the harm-benefit analysis, with a small minority exploring novel ethical frameworks such as the reasonable interests framework. This suggests that either more philosophizing is required on how we ought to understand children's best interests, or that the frameworks presented in the empirical literature do not hold up to ethical scrutiny and are thus not explored otherwise.

3.3 What factors influence 'best interests'?

This theme is concerned with the many factors that influence and interact with children's best interests, as reported in the non-empirical and empirical reviewed literature. The following table offers a summary of this theme:

Table 5: Relevant factors for 'best interests'

Factor	How 'best interests' is influenced	References
'Empirical' evidence • Prognosis • Futility • Quality of life • The mental health of the child	'Empirical' evidence provides evidence-based risks and benefits for HCPs to weigh best interests. This aligns with the 'objective' account of best interests.	Dawson, 2005; Suryadevara & Domachowske, 2019

- Children's interests at the end of life compared with post-mortem interests		
HCP specialty and professional standards	The expertise and experience of an HCP can cause their determinations of the child's best interests to take for granted that what is best for one patient is also best for others.	(Armstrong et al., 2011; Birchley et al., 2017; Fauchère et al., 2021; Forbat et al., 2015; C. E. Hansen et al., 2016; Isabelo et al., 2019; Janvier et al., 2008; Laventhal et al., 2017; O'Haire & Blackford, 2005; Placencia et al., 2016; Richards et al., 2018; Roen & Hegarty, 2018; Streuli et al., 2021; Tan et al., 2008)
Culture and religion	Cultural and religious factors broaden the relevant considerations of best interests including the child and family's cultural environment.	(Braley-Rattai, 2021; Dawson, 2005; Fauchère et al., 2021; Jivraj et al., 2016; Laventhal et al., 2017; Mack et al., 2024; McDougall & Notini, 2014; Morrison et al., 2015; Suryadevara & Domachowske, 2019; Wiley et al., 2023)
Socioeconomic factors	Financial and marital status of a child's parents influenced an HCP's determination of the child's best	(Forbat et al., 2015; Marcello et al., 2011; Richards et al., 2018)

	interests, namely for resuscitation of extremely premature infants with potential for lifelong disability.	

3.3.1 Non-empirical literature

3.3.1.1 'Evidence-based' factors

In the non-empirical literature, my interpretation led me to understand that there are certain 'evidence-based' factors about vaccines and the diseases they protect against. Suryadevara and Domachowske (2019) proposed that vaccine decisions ought to depend on the prevalence, transmissibility, and severity of the disease(s) they protect against, the effectiveness of the vaccine, and vaccine coverage rates. Similarly, Dawson (2005) used the likelihood and magnitude of risks associated with vaccine decision-making, including the symptoms, contagiousness, and fatality of the disease, and the severity of side effects, availability, and 'effectiveness' of the vaccine, among others to determine the child's best interests.

In my interpretation, although relying on 'evidence-based' factors suggests an 'objective' way of determining best interests, empirical data are never entirely conclusive. There is inherent subjectivity in selecting which evidence to prioritize and how to interpret it. For example, these publications did not include evidence on the psychosocial effects of vaccination in their best interests determinations. The inclusion and absence of evidence seem to represent a subjective choice in deciding what evidence ought to be included in best interests decisions, which may require further consideration. Moreover, assessing the 'effectiveness' of vaccines can pose challenges. For instance, variants of infections such as COVID-19 may have slight impacts on the ability of vaccines to protect against infection or severe illness (World Health Organization, 2021). Therefore, this may raise concerns about selecting and relying on 'empirical' evidence for best interests.

3.3.1.2 Culture and religion

In my review of the non-empirical literature, I found that religious beliefs made up a parent's interpretations of the relevant interests of the child's welfare and best interests. For instance, the risk of rejection from a religious community on the basis of vaccination will likely affect the parents and could affect the child (Dawson, 2005). Personal beliefs and religious exemptions to vaccination have become prevalent justifications for parents to decline vaccination for their children (Kekatos, 2023). These exemptions refer to refusals based on vaccination being against the parent's religious and other beliefs. Suryadevara and Domachowske purported that personal religious beliefs were central to a parent's understanding of what it means to "liv[e] a good life" (2019, p. 117). These authors expressed that some religious beliefs may share a hesitancy towards Western medicine, concerns that vaccination will expose their child to serious harm, and distrust in modern science to counter these beliefs.

In my reflection, this seems to raise important points about the role of religious values in the child's best interests. Interestingly, the parent's religious beliefs seem to be considered without the mention of the child's religious views. Furthermore, this raises questions not only about the challenges of distinguishing the child's religious views from their parents but also about the potential for debate regarding whether children can genuinely hold religious views.

Using an analogy, one can compare the refusal of vaccination based on religion with the refusal of blood transfusion on the same basis. Braley-Rattai (2021) stated that while religious interests are relevant, there are cases where the parents are prepared to accept the morbidity (or death, in the blood transfusion case). In these cases, vaccine refusal as well as blood transfusion refusal on the grounds of religious beliefs ought to hold no moral sway (Braley-Rattai, 2021). This seems to assume that in both cases, morbidity or death is not in the best interests of the child. The family's religious views as a basis for objecting to an intervention in the best interests of the child may be limited for vaccination, as there is ignorance towards the public health dimensions of vaccination and the child's best interests may be viewed as intertwined with public health interests (Braley-Rattai, 2021).

My interpretation of the non-empirical literature discussing culture and religion suggests that medical facts are not the only factors that HCPs ought to consider in relation to their best interests. In my assessment, religious and cultural interests seem to be relevant under the 'biopsychosocial' conception of best interests, as they are likely to affect the child (i.e. if a child or their parents risk rejection from their community based on their vaccination decision). This seems to raise further questions about how these interests are weighed in a child’s best interests, as I have interpreted ‘religious views’ to refer to the parent’s religious views.

3.3.2 Empirical literature

Empirical publications indicated that the prevalent clinical factors influencing an HCP’s determination of best interests were prognosis, rate of survival, severity, life expectancy, age, and quality of life. One publication summarized how neonatologists evaluated best interests differently due to these factors, including fallacious perceptions of the correlation between prognosis and neuro-developmental impairment for a certain treatment (e.g. severe bronchopulmonary dysplasia), perceptions of personhood, and the HCPs’ perceived abilities to “bond” better with older infants that can cause hesitancy in withdrawing life-sustaining measures (Albersheim et al., 2010).

I interpreted this study as highlighting the issue of 'fallacious' perceptions of evidence, suggesting that individuals sometimes misunderstand the concept of best interests. This implies that there is a 'true' determination of best interests, which seems to rest on the assumption that best interests can be objectively defined. However, the question remains whether a harm-benefit analysis alone is sufficient to determine the best interests of children. With this in mind, I have presented the various factors that I interpreted as relevant to best interests that arose from the empirical reviewed literature below.

3.3.2.1 Prognosis

Prognosis may influence best interests determinations and willingness of HCPs to treat pediatric patients, and in fact, may be considered fundamental in dictating the best interests of a pediatric patient for some HCPs (Rasmussen et al., 2016; Street et al., 2000). Prognostication is used to help determine an infant’s best interests by attempting to outline “the most truthful estimation of the possible range of outcomes for a particular child” to assist HCPs in medical decision-making (Rasmussen et al., 2016). For instance, HCPs considered resuscitation to be in the best interests of pediatric patients with a 50% chance of survival, compared to greater variability in resuscitation decisions when patients have a lower chance of survival (Laventhal et al., 2017).

Richards and colleagues found that HCPs rely heavily on prognosis when the chance of survival is ‘good’, initiating treatment with the assumption that the child and family would share the same goals as the care team (Richards et al., 2018). When HCPs expected a ‘bad’ outcome, they engaged more with the families to elicit their values and integrate them into the decision-making process. In this sense, HCPs ‘determined’ the parental role based on their own perception of the child’s and parents’ interests. The authors note that HCPs maintain unequal power and authority in clinical decision-making, as they “are the ones to determine the level of engagement” with parents, based on their perception of the child’s best interests. These authors seem to be expressing a higher valuation of the HCP’s expertise over the parent’s perspective. This seems to align with Leuthner’s (2001) ‘expertise’ model that prioritizes the HCP’s medical expertise in best interests decisions.

Laventhal and colleagues (2017) studied the effects of age and prognosis on best interests determinations, and suggested that the bias against very young children is reinforced by institutional policies and guidelines that rarely advocate for neonates, and recommend HCPs share prognostic information to parents ‘deliberately and carefully’ based on gestational age, and do not presume that resuscitation will occur (Laventhal et al., 2017; Mills et al., 2015). We might assume that an infant’s (gestational) age dictates what medical decisions are in their best interests, employing statistics and the typical development of infants, generally, to inform HCPs’ analyses of harms and benefits. If this is the case, infants may not be viewed as a unique and distinct case, and discussions about their particular best interests may be limited by their gestational age.

Prognosis appeared to be a strong guiding factor for HCPs’ determination of best interests but did not stand alone, and in fact, may have had less weight in these determinations when the prognosis was poor (Mills et al., 2015). When a prognosis was poor, HCPs relied on other factors to inform their determination of best interests. In Laventhal and colleagues’ (2017) study, the young age of a neonate swayed HCPs to determine that resuscitation was not in the patient’s best interests. In another study, even when the prognosis was different, age was a prevailing factor in best interests determinations (Armstrong et al., 2011). Returning to Laventhal and colleagues’ (2017) investigation, participants were asked to rank 8 patients with various ages and prognoses by resuscitation priority in a case where all arrived in the emergency department simultaneously. When comparing an adolescent patient with a poor prognosis with an older patient with the same or better prognosis, HCPs ranked the adolescent patient higher in resuscitation priority (Laventhal et al., 2017). This trend was not applied uniformly to all pediatric patients – neonates were generally regarded as having lower priority for resuscitation than older patients (Hagen et al., 2012), and death was more accepted for this age group.

My interpretations led me to believe that young gestational age seemed directly tied to the idea of 'personhood' since some publications showed how HCPs perceived resuscitation as in the best interests of older children (2-7 years old) since they had 'established relationships' with others (T. W. R. Hansen et al., 2013; Mills et al., 2015). Some authors implied a child's 'status' increases with age (T. W. R. Hansen et al., 2013), which seemed to evoke lesser feelings of tragedy from HCPs compared to children who had formed relationships (Janvier et al., 2008; Mills et al., 2015). Very old and very premature patients were shown to have similar reactions to their deaths, where statements such as "it is better this way", "at least they didn't suffer", and "nature took its course" were generally more acceptable for the very old and young (Janvier et al., 2008). Young age may also have had the opposite effect on non-neonates, where HCPs valued younger patients' lives specifically because they had lived less and deserved to live to experience adulthood (Laventhal et al., 2017). Young people may have been viewed to hold more potential than older people, and therefore, had more at stake when considering whether or not to resuscitate. HCPs may have deemed resuscitation to be in the best interests of older children as they appeared to have more 'personhood' than neonates and are deemed to be more of forming and valuing long-term plans and therefore have a greater value for life preservation (Mills et al., 2015). One study referenced the 'fair innings' argument in defense of this standpoint, where the best interests of the child included considerations of justice in healthcare resource distribution to reduce inequalities in healthcare across the life course (Laventhal et al., 2017).

3.3.2.2 Futility

The concept of medical futility seemed to influence an HCP's determination of the best interests of the child. One publication purported that 'futility' was an ambiguous concept with no clear definition, leading HCPs and parents to differ in their opinion of what futility implies (Bahus & Føerde, 2011). Futility could be very clear to some specialists, where certain conditions were deemed "medically futile" (such as fulminant necrotizing enterocolitis and severe asphyxiating thoracic syndrome) because of their high mortality rate (Placencia et al., 2016). Treatment deemed futile was not in the best interests of the child, as some argue it was cruel and inhumane (Belcher, 2013; Roen & Hegarty, 2018). Concerns over treatment that HCPs deem futile can cause distress, especially when parents wish to initiate or continue aggressive treatment for incurable conditions and HCPs feel their ethical judgement is being threatened (Belcher, 2013). If treatment was deemed medically futile, an HCP was not obligated and could not be forced to initiate or continue it (Sauer et al., 2013; Weiner et al., 2022). When treatment was 'clearly futile', some argued it was ethically acceptable to override parental requests that were not in the best interests of the child (Cavolo et al., 2021), and in some jurisdictions, HCPs were prohibited from providing futile treatment (Sauer et al., 2013; Weiner et al., 2022). HCPs could also limit treatment options or convince parents that their proposed course of action was not in the child's best interests (Roen & Hegarty, 2018).

As I understand these studies, HCPs are generally the stakeholders that empirical publications indicate are responsible for determining the futility of treatment. This dynamic can operate in both directions; treatments that children or parents deem futile may be viewed by HCPs as being in the child's best interests. This discrepancy underscores the complex interplay between medical expertise and familial values in decision-making processes. It raises important questions about whose perspective should ultimately prevail and how to balance professional judgments with the wishes of the child and their family.

3.3.2.3 Quality of life

Quality of life may also factor into best interests judgements, where HCPs' decisions to treat or withhold treatment seemed to depend on their *perception* of the potential quality of life of the pediatric patient. HCPs' predictions about a pediatric patient's quality of life were, in my reflections, complex, as there were differing definitions of what one deemed as a meaningful life with personal fulfillment (Mack et al., 2024; Rasmussen et al., 2016). Some publications expressed that degrees of suffering were closely tied to an evaluation of the child's quality of life, where a life that would be impeded by significant suffering was not in a child's best interests, even if suffering was a trade-off of prolonging life (T. W. R. Hansen et al., 2013; Sauer et al., 2013). Conversely, other studies considered broader relational factors to quality of life and the child's best interests. One publication reviewed the literature on tracheostomy decision-making, and found that criteria for understanding a child's quality of life included understandings of anticipated physical, cognitive, and emotional functioning, degree of physical pain and psychological distress, degree of (in)dependence, threats to perceptions of dignity, familial context, and relational potential (Mack et al., 2024). Alternatively, although HCPs ranked the child's comfort as highly important, another publication showed how secondary priorities may have included prolonging a patient's life (and potentially suffering) to bring tremendous benefit to the child and family for a brief period (Morrison et al., 2015). Therefore, Birchley (2017) proposed that HCPs must consider how to equitably balance a child's suffering with the family's input when determining the best option.

In my view, some of these publications emphasize the relational aspects of evaluating a child's potential quality of life, which seems to differ from the way other factors such as prognosis and age a presented. This may stem from greater uncertainty in predicting the outcomes of treatment, and varying interpretations of what is a 'good' life from HCPs. These studies acknowledged the broader factors and consequences of treatment decisions, such as emotional functioning, familial contexts, relational potential, and benefits to the child and family. From my perspective, these studies employed the harm-benefit analysis to determine best interests, but it should be evident that the consequences they have relied on go beyond what previous findings have presented as 'objective' consequences.

The amount of pain and suffering a child endured or will endure, especially when they are dying, struck me as an important factor for HCPs when considering children's medical decision-making, particularly in the areas of palliation and organ donation. The best interests of a dying child may be challenging to determine, as priorities may be challenging to weigh. Additionally, palliative care medications can hasten dying, which can be challenging for HCPs and parents to justify in the best interests of the child. As one publication demonstrated, HCPs were bound by the Hippocratic oath to 'do no harm', and since 'harm' was ill-defined, there was controversy around whether to reduce the pain and suffering of the dying child, even if this meant hastening death (Sieg et al., 2019). Furthermore, while nutrition was considered a basic human need, this study showed how prolonging life could lead to prolonged pain and suffering for the child (Sieg et al., 2019). Upon reflection, providing nutrition to a dying child seems to raise questions about whether prolonging life is always in the best interests of a child, which may require further consideration about the goals of ‘best interests’ and what it means to optimize the welfare of the child.

There may also be uncertainty about what the child’s quality of life will look like, including the possibility of disability or severe impairment. Quality of life may be closely tied to a fear of disability, where some HCPs were less inclined to determine that resuscitation was in the best interests of a neonate whose life was certain to be affected by significant limitations and suffering due to disability (Laventhal et al., 2017). Only one publication stated that disability had no perceived influence on best interests determinations (Janvier et al., 2008). When weighing the benefits and harms of a proposed intervention, HCPs reported recognizing long-term ‘pain and suffering’ from disability was a harm (Janvier et al., 2008). One’s quality of life was thought to be “in the eye of the beholder” (T. W. R. Hansen et al., 2013), and given that neonatologists have been shown to overestimate the risks of disability (Mills et al., 2015), authors suggested that caution was necessary when considering best interests in terms of quality of life, as deep-rooted social, cultural, anthropological, and evolutionary factors could have led to a “systematic devaluing of extremely premature infants” (Deligianni et al., 2023; Mills et al., 2015).

One publication stipulated that deliberate shortening of a neonate’s life through intervention is deemed unlawful killing, where the possibility of a life with disabilities could not justify withholding life-sustaining treatment (Sauer et al., 2013). Some HCPs reported discomfort when making best interests judgements about quality of life, as poor neurological outcomes may not have directly correlated with poor quality of life (Heide et al., 1998; Rasmussen et al., 2016). Although the possibility of disability should not preclude medical intervention to save or sustain life, parents’ wishes may counter this guidance, which caused HCPs to become troubled (Heide et al., 1998). Other HCPs reported beliefs that intervening to save a child with an existing disability was a success, and ‘creating’ a child with a disability was a failure (Armstrong et al., 2011; Laventhal et al., 2017; Mills et al., 2015). In one publication, HCPs were shown to believe the burden a disabled child would represent to a family is a relevant factor when considering the best interests standard, supporting an ‘enlarged’ conception of the best interests standard (Samaan et al., 2008). They suggested that although the assessment of burdens and benefits of treatment is required to be focused on the patient alone, the ‘enlarged’ conception acknowledged that the interests of ill newborns are hard to distinguish from those of their parents (Hagen et al., 2012; Samaan et al., 2008). In my view, this suggests that HCPs ought to interrogate the hidden implications and values in pediatric medicine to consider other factors that may be important, or irrelevant, to the child, especially given HCPs' overestimation and devaluation of disabled lives.

My interpretation suggests these factors generally rest on empirical evidence of the odds of survival of extremely young children to determine their best interests. This approach seems to be 'informed' and applied similarly across all patients, following the 'objective' conception of best interests. As previously explored, there is inherent subjectivity in using empirical evidence, which seems to be highlighted in HCPs' determinations of quality of life. There is ethical merit to this approach, but it may be worth considering other approaches to determine what is 'best'. Additionally, I perceived there to be assumptions and implications around the presentation of these factors, namely around where decision-making power rests. Here, I interpreted the HCPs as holding the power to decide whether certain treatment (e.g., resuscitation) was in the best interests of the child.

3.3.2.4 The mental health of the child

The mental health of the child may have had an influence on medical decision-making for pediatric patients (Clark et al., 2020; Isabelo et al., 2019; Tan et al., 2008). HCPs indicated that mental health was an important consideration in determining the best interests of the child (Isabelo et al., 2019). One way that HCPs thought about the mental health of the patient was how a prospective treatment decision may affect the mental health of the child. For instance, hormone therapy for transgender youth was believed to be in the best interests of an adolescent who may have been harmed mentally if they had to wait to start therapy (Clark et al., 2020). In this case, HCPs considered the best interests of the child while accounting for potential harm to the child's mental health that may have emerged.

In my view, where mental health is discussed, it seems that these empirical publications are signaling the long-term interests of the child. In this particular example, they seem to be assuming that hormone therapy for transgender youth is 'best' initiated sooner than later, as mental health challenges could arise in the future if the parents do not approve of treatment and the child has to wait until they are capable of making their own decisions. Interestingly, this approach seems to align with what other authors considered 'quality of life' considerations.

On a separate note, the existing mental health of the child may provide another facet for consideration of the child's best interests. A child who currently suffered from a mental illness was shown to influence the attitude of the HCP, in that acting in the best interests of the child was especially important for HCPs to protect patients whose mental illness interfered with their autonomy and decision-making capacities (Tan et al., 2008). One publication stated: "We would expect that individuals who espouse protection of patients from harm would also tend to espouse treatment in a patient's best interests and that both attitudes would be negatively correlated with attitudes that the nature of anorexia nervosa does not lead to loss of autonomy and choice" (Tan et al., 2008, p. 10).

Curiously, this publication seems to be concerned with a child's 'autonomy', but I have interpreted this term as 'agency'. When one is concerned with protecting a child patient from harm and acting in their best interests, the child's 'respect for autonomy' is exercised through the best interests standard as they are incapable of making decisions about their own treatment. This may reflect the notion that acting in the patient who has a mental illness'[8] best interests emphasizes protecting the child from attitudes that may strip them of decision-making *participation* because of their mental illness. However, this raises questions about how HPCs should balance the child's 'protection' and 'participation' in medical decision-making. Separately, the lack of discussion of mental health and mental illness in this review may stem from the exclusion of capacity and competence in relation to best interests, as this is outside the scope of this review.

3.3.2.5 Children's interests at the end of life compared with post-mortem interests

Additionally, the best interests of the child may become muddied when there is a possibility of the child becoming an organ donor after cardiac death. Medications and pre-morbid procedures to preserve and protect organs were shown to cause harm to the child and hasten death, which was deemed not in the best interests of the dying child (Sarnaik et al., 2013; Sieg et al., 2019). Considering the interests of a dying child versus a dead child was very different, as some argued it was easier for HCPs to rationalize the pre-morbid procedures on a dead child:

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[8] To clarify, I do not wish to equate transgender youth seeking hormone therapy with mental illness. This example was merely used to demonstrate how the future interests of a child were considered in treatment decision-making.

> [Y]ou're doing things that are not in this patient's best interests and you were able to rationalize it by saying this patient's already dead. It's okay because he's gone, he's gone. And uh, I mean, I think you can say that in your head like once an hour sometimes. And you will not have that to fall back on. This patient is not dead. (Curley et al., 2007, p. 214)

In my interpretation, these considerations are relevant to childhood vaccination decisions. In both organ donation and vaccination, the treatment decision will impact others, including family members and strangers. This indicates that the interests of others may be relevant in determining a child's best interests.

These factors seemed important for HCPs, especially when answering 'yes or no' questions about a specific treatment (e.g., is resuscitation in the best interests of the infant?) (Streuli et al., 2021). However, publications also stated that best interests are not closely tied to survival rates or disability (Deligianni et al., 2023; Mills et al., 2015). In the following sections, I explore how HCPs have been shown to take a more 'subjective', interpretive approach to determine a child's best interests that extend beyond the child's medical prognosis, age, and other 'objective' factors.

3.3.2.6 HCP specialty and professional standards

HCP specialty and professional standards were found to influence and, at times, conflict with their determination of the child's best interests (Forbat et al., 2015; Janvier et al., 2008; O'Haire & Blackford, 2005; Placencia et al., 2016; Roen & Hegarty, 2018). One HCP expressed that their interests could become entangled with their dogmatic, paternalistic instincts:

> [I]t can be difficult for us to disentangle what's in the child's best interests and what is us wanting to get our own way. Often there are many more than one way of managing a situation, and we have our preferred way. (Forbat et al., 2015, p. 771)

Clinicians were shown to allow their specialized knowledge relating to their discipline or specialty to affect their determination of what was in the best interests of the child, based on the many patient outcomes they had witnessed and their professional norms, among others (O'Haire & Blackford, 2005; Tan et al., 2008). For instance, one publication suggested that the profession of Child and Adolescent Psychiatry gave greater weight to 'best interests' than respecting patient choice (Tan et al., 2008). Past personal experiences of HCPs were shown to colour the advice provided to parents on making decisions in their child's best interests. For instance, one surgeon described their treatment suggestions based on a lack of post-surgical regret in their patients:

> I was very very conservative early on and [...] I said I don't you really need anything done because it's minor [...] and then they came back when they were five or six and they weren't happy and I did surgery on them and then they went away happy. (Roen & Hegarty, 2018, p. 974)

This study demonstrated how HCPs' views can be changed by clinical experience over time. The finding that suggested one profession gave greater weight to 'best interests' than patient preference is, in my opinion, reflecting that patient preference is not a part of 'best interests'. This stood out to me as favouring the 'objective' harm-benefit analysis approach to best interests and contrasting the approach that gives deference to the wishes of the patient and their parents.

Potential implications of using HCPs' expertise and experience to determine a child's best interests include treating children uniformly based on the patients that have come before them. This may cause HCPs to undertreat a patient, have an over-negative opinion on disability, and exclude the views of the child's parents, among others (Janvier et al., 2008; Laventhal et al., 2017). This may be harmful, as viewing all children based on essentially the HCP's opinion of the child's best interests based on years of knowledge and experience can overlook the individual nuances of each child's case.

In one study, HCPs' conceptions of the best interests of the child differed from the conception that ethicists adopted, who took into account other factors such as family interests (Placencia et al., 2016). Placencia and colleagues (2016) surveyed neonatologists and ethicists and found that they varied in their opinions on whether the best interests of the child excluded all other effects or interests not directly affecting the patient. HCPs tended to disagree that family interests placed limits on their obligations to the child, whereas ethicists tended to acknowledge that the interests of the family were inherently and inextricably linked to the child's interests (Placencia et al., 2016). Additionally, bioethics students were more likely to prioritize the principle of respect for autonomy for parental requests to withhold life-sustaining treatment than HCPs (Janvier et al., 2008). This could indicate the dissonance of the leading values in different professions, or perhaps, the underlying values of those who enter their fields (Janvier et al., 2008).

The concept of medical paternalism arose frequently in the empirical literature when HCPs were asked how they navigate best interests decision-making with the child and families. One publication reported that HCPs rarely acted in a purely paternalistic way (Deligianni et al., 2023). They suggested HCPs adopted a ‘soft medical paternalism’ approach, which included overriding parental decisions when they contrasted with the child’s best interests (Deligianni et al., 2023). Other publications report that paternalism remained a prevalent approach among some HCPs who felt their role was to protect the patient rather than to balance the best interests of the child and the family (Fauchère et al., 2021; Tan et al., 2008). This was seen as especially problematic when HCPs made undue assertions that a child’s medical condition interfered with their decision-making authority (Tan et al., 2008).

As I understand it, the prevalence of medical paternalism, even in its softer forms, highlights the tension between medical harm-benefit analyses and respecting parental autonomy. The influence of personal experiences on HCPs’ decisions suggests that their perceptions of the child’s best interests are as variable and context dependent as those of the parents.

Past personal experiences of HCPs have been shown to implicitly inform their determinations of the best interests of the child, rather than using the literature on, for example, post-surgical regret (Roen & Hegarty, 2018). In this study, one HCP reported patients were happy with their surgery and did not have reports of patients returning unhappy with the procedure, from which they inferred that post-surgical regret never occurred (Roen & Hegarty, 2018). HCPs recognized that when their interactions represented a conflict between paternalism and parental autonomy (Birchley et al., 2017), this could cause constraints to placing the child at the center of decision-making (Streuli et al., 2021).

This relates to the unequal power and authority held by HCPs that was noted by Richards and colleagues (2018), where HCPs had the authority to determine the level of engagement of the parents in shared decision-making. The HCP’s personal perceptions of the child’s and parent’s best interests may therefore be more often weighed above those of the parents.

Best interests judgements seemed to be closely related to what the HCP might want for their own child or family member (Armstrong et al., 2011; T. W. R. Hansen et al., 2013;

Janvier et al., 2008). Some physicians reported this as a feeling, as in, the ways they would want their own child to be treated was indicative of their perception of what was in the best interests of the patient (T. W. R. Hansen et al., 2013). Some other studies conveyed this as an approach to consider the best interests of patients in general (Janvier et al., 2008). One physician reflected, “So, my approach will be like: if this is my daughter, how would I be doing it?" (Isabelo et al., 2019, p. 38). This might reflect a physician’s sense of duty to place themselves in the shoes of the child’s parent and treat them like their own child (Isabelo et al., 2019).

In my reflection, these findings reveal the HCP’s specific viewpoints on the child’s best interests. These seem to underscore the inherent subjectivity in assessments of best interests, despite HCPs claiming ‘objectivity’ in their evaluations. From my perspective, the findings expressed above are deeply influenced by their personal and professional experience, which suggests that what is perceived as an ‘objective’ account of the child’s best interests is, in reality, shaped by subjective viewpoints on the empirical and relational consequences of treatment decisions. One example that demonstrates this is the differences between HCPs’ and ethicists’ perspectives on the inclusion of family interests in decision-making; while ethicists often consider the broader familial context, HCPs tend to focus more narrowly on the ‘medical’ aspects, perhaps neglecting the intertwined nature of family and child welfare.

This subjectivity also points to a broader factor: the unequal power dynamics between HCPs and parents in the decision-making process. The authority of HCPs to determine the extent of parental involvement can skew the process toward their implicit biases, potentially sidelining the parents’ views and values. This imbalance is further complicated by the fact that HCPs’ judgments about what is best for the child are often influenced by how they would want their own children to be treated, a deeply personal and subjective criterion.

3.3.2.7 Culture and religion

HCPs may weigh parental and family interests alongside the child’s best interests. One study purported that conceptions of extended family interests included cultural and religious interests (Jivraj et al., 2016). Geographical location, therefore, may influence how parental and family interests are considered. For example, Laventhal and colleagues (2017) reported that HCPs from Australia, Canada, and the Netherlands were more likely to favour parental views over their own best interests determinations, and HPCs from Argentina and Ireland favoured medical paternalism (2017). They hypothesized that understandings of important values may have varied by geographic location due to differences in cultural views of medical interventions such as vaccination or reproduction, access to medical interventions, and religion. Cultural backgrounds may have also shaped how HCPs balanced decision-making with parents. For example, Swiss HCPs preferred a shared decision-making model to determine the best interests of neonatal patients and gave deference to the parent's wishes more than other surveyed HCPs (Fauchère et al., 2021).

Religion may play a significant role in conceptualizing and determining the best interests of the child for COVID-19 vaccination and other medical procedures. Religion may influence a parent's or HCP's understanding of what constitutes the best interests of the child, for example, what 'suffering' means (Mack et al., 2024). McDougall and Notini (2014) purported that parental refusals on a religious basis should take into consideration the child's own religious beliefs, and if there is confidence that the child would make the same decision later on in life, HCPs should give greater weight to parental autonomy. This aligns with my reflections on the non-empirical literature, where the consideration of the parent's religious interests in best interests raises questions about the ability to ascertain a child's own religious beliefs and how to reconcile them.

In Morrison and colleagues' study, HCPs reported prioritizing a family's religious beliefs lower than the child's comfort and the child's and 'family's best interests' (2015). Interestingly, religious beliefs were distinguished from the family's interests in this study, as other publications conceptualized them as parts of the same concept. Wiley and colleagues (2023) indicated that religious-based exemptions were common reasons for parents to refuse vaccination for their children. These authors described how a parent's challenge to vaccine mandates on the basis of religious freedom did not justify exposing their child to disease unless high vaccination rates were maintained (Wiley et al., 2023).

In my interpretation, this relates to the non-empirical literature that explored how a parent's religious and cultural beliefs were viewed as relevant to a child's vaccine decisions. Both literatures present conflicting opinions on how these interests are and ought to be weighed in best interests. This may relate to whether best interests are understood by harm-benefit analyses or whatever the HCP, parent, or patient wishes. In the former, religious interests may be a potential harm (e.g. exclusion from one's religious community) of a vaccination decision for HCPs and parents to consider. In the latter, a parent may refuse vaccination for their child solely because of their own religious affiliations.

3.3.2.8 Socioeconomic factors

Other relevant familial factors outside of culture and religion include the financial interests of the family (Forbat et al., 2015). In one study, an HCP reported feeling that best interests discussions were moving away from the best interests of the child when parents cited concerns over financial loss as a result of the death of a child (Forbat et al., 2015). In this case, there seemed to be an undertone of spite for the parents, whereas another study expressed HCPs encouraging families to think about their long-term interests, including financial stressors, when considering the medical decisions that are in the best interests of the child (Richards et al., 2018). This broader conception of best interests seems to take into account the child's environment and relational quality of life, where financial strain and subsequent deterioration of the family unit are weighed heavily in medical decision-making.

Family characteristics may also play a part in HCPs' weighing of parental views and determination of the best interests of the child. HCPs reported giving different weight to parents' views depending on their age, marital status, and occupation (Marcello et al., 2011). Marcello and colleagues found HCPs gave more deference to older married parent's wishes than a young, single mother's wishes. They found that medical intervention (in this case resuscitation) was considered less frequently in the best interests of the child of an adolescent mother than older married parents. These authors speculated that while the fact that long-term outcomes of extremely immature infants born to single mothers without higher education were poorer than children born to rich, educated, and married parents was 'well-known', some argued that allowing family characteristics to influence a child's medical care was discriminatory. Marcello and colleagues suggested that using these facts to further discriminate against those who are disadvantaged by socioeconomic status was unsettling and morally problematic (2011).

To conclude this theme, I found that the non-empirical and empirical literature identified some similar factors relevant to a child's best interests, including 'empirical' factors based on medical evidence, culture, and religion. The empirical literature seemed to identify a wider array of factors beyond those that I found in the non-empirical literature, including the mental health of the child, and financial and socioeconomic factors. In my interpretation, the ‘empirical’ factors were used when best interests seemed to be understood ‘objectively’, where the HCP was ‘in charge’ of determining best interests. When broader, more ‘subjective’ factors such as religion were considered, I interpreted the HCPs as giving more decision-making input to the parents. Alternatively, this could have been a representation of the HCP considering the interests of the parents and family more in their determination of the child’s best interests and have nothing to do with decision-making power. Regardless, it is interesting that empirical evidence surrounding, for example, the negative effects that children and parents experience when making medical decisions that contradict their religious communities, did not arise in this section. As I perceive it, this may indicate that HCPs generally do not use this kind of empirical evidence in their harm-benefit analysis, which raises questions about the intention behind this.

3.4 Whose perspectives matter?

This theme describes the patterns I identified in the empirical and non-empirical reviewed publications that were concerned with the perspectives, opinions, and voices of the various decision-making stakeholders, including HCPs, parents, the child, and the state.

This theme is not as much concerned with the power or authority of each stakeholder as the final decision-maker and is more concerned with how HCPs consider and navigate other individuals’ participation in the best interests of the child while mediating their own views and wishes. As mentioned before (see: what ethical dimensions are at work within ‘best interest’?), the idea that parental and family interests have their place in determining the best interests of the child is nuanced, and there is a lack of agreement in the literature among various HCPs in different settings. This theme may be summarized in the following table:

Table 6: Relevant perspectives for 'best interests'

Perspective	How ‘best interests’ is influenced	References
Parents	The relevant values and consequences of the parents may influence an HCP’s determination of best interests. Poor parental	(Abdin et al., 2022; Albersheim et al., 2010; Bahus & Føerde, 2011; Belcher, 2013; Birchley et

	behaviour as a reaction to the HCP's views may influence an HCP to acquiesce to the parents' wishes.	al., 2017; Cavolo et al., 2021; Deligianni et al., 2023; Hagen et al., 2012; Kvamme & Voldner, 2022; Laventhal et al., 2017; Mack et al., 2024; Mills et al., 2015; Morrison et al., 2015; O'Haire & Blackford, 2005; Richards et al., 2018; Roen & Hegarty, 2018; Valdez-Martinez et al., 2014; Weiner et al., 2022)
The child	The child's growing 'autonomy' and inclusion in discussions around their treatment can elucidate the values and perspectives that are important to the child and thus can be incorporated into the determination of their best interests.	(Abdin et al., 2022; Quaye et al., 2021; Street et al., 2000; Valdez-Martinez et al., 2014; Weiner et al., 2022)
The state	State intervention is required if it is perceived that parents are not acting in the best interests of the child. Whether the treatment protects against 'clear and present danger' and 'imminent' threats to health may determine the extent to which state intervention is compelled.	(Bahus & Føerde, 2011; Bayefsky, 2018; Bester, 2017; Birchley et al., 2017; Braley-Rattai, 2021; Dawson, 2005; Forbat et al., 2015; Hester et al., 2018; Isabelo et al., 2019; Kvamme & Voldner, 2022; Pierik, 2020; Wiley et al., 2023)

3.4.1 Non-empirical literature

3.4.1.1 Parents

Understanding the concept of ‘parenting’ may be important to interrogate the parent’s perspective. Parents are assumed to provide love, nurturing, and consistency to their child(ren), and therefore may find the idea of parenting attractive because they feel a sense of entitlement to engage in parental decision-making to ensure their child’s welfare. Braley-Rattai (2021) stipulated that if one’s parenting comes into question by an HCP who feels the best interests of the child are or will not be met by the parent’s decision, the very idea of what it means to be a parent is threatened. Diekema and colleagues (2005) suggested that since parents have authority over medical decisions for their child, there may be instances where the HCP must tolerate a decision they disagree with, unless that choice places the child at ‘substantial risk of serious harm’.

Forster (2019) highlighted that equity, professionalism, and treating patients in their best interests ought to be prioritized over moral disapproval of a parent’s choice. Tensions between the ethical principles of non-discrimination and respect for autonomy (including respect for ‘parental’ autonomy) require some navigation here. While Forster purported that “[d]octors have a duty to provide care to patients without discrimination and to respect the autonomy of patients in their healthcare decisions (including decisions made by parents for their children)” (2019, p. 555), this may not encapsulate *all* of the duties of the HCP, including protecting a child from a medical decision made by a parent that they believe to have more risks than benefits.

These accounts of ‘best interests’ seem to align with the ‘objective’ account that best interests are determined by what the individual would choose if they were capable (Dawson, 2005). Dawson describes that when applied to pediatric medical decision-making, the patient is incapable of making their own decision and has never been capable. Therefore, a different way of decision-making must be employed: the parents’ judgement, the HCPs’ judgement, a combination of both, or an ‘objective’ judgement where risks and harms are somehow dispassionately weighed.

3.4.1.2 The state[9]

In my interpretation of the non-empirical literature, I found that 'the state', or government, put forward a distinct perspective of best interests. State intervention was shown to play a role in protecting the child and ensuring their best interests were met if it was believed that the child's parents were not doing so. If an HCP determined that a particular medical intervention was in the child's best interests, and other options or non-treatment were likely to result in harm to the child, Dawson (2005) proposed that the state was obligated to interfere with the decision if the parents are not seen to be protecting their child from these harms. In Dawson's (2005) view, parents did not have an absolute right to make decisions for their children, and those who believed so based on the nature of 'being parents' or their perceived 'ownership' over their child were not ethically or legally compelling, as children should not be exposed to harms based on their parents' beliefs (Dawson, 2005). This 'objective' account of best interests decision-making involving obtaining court orders to treat children may be too 'idealist', where state intervention may not do exactly what we hope for it to do – protect the child. One author suggested that the best interests standard posed challenges as a threshold for state involvement due to its subjective and paternalistic nature (Bayefsky, 2018). In practice, viewing the best interests of the child objectively may be challenging, as the child does not exist in a vacuum so a more ethical conceptualization of best interests may include broader considerations.

Pierik proposed that, in cases of imminent threat to health, necessary medical treatment may be more often considered as 'objectively' in the child's best interests. They concluded that it may be more straightforward for HCPs to decide the child's best interests and for this to be enforced by the state, despite disputes from the parents (Pierik, 2020). When considering prophylactic interventions such as vaccinations, Pierik stated that a clear threat of danger may not be present so one must consider other relevant factors that promote the best interests of the child. This author suggests one should therefore attune oneself more to parental views in the absence of an imminent threat (Pierik, 2020). While I interpreted Pierik to agree that the 'objective' account raises important concerns about the possibility of being 'objective' in best interests determinations, their paper raises questions about the perspectives

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[9] This section is not concerned about legal analysis of the best interests of the child standard in relation to compulsory vaccination, but there are many other papers that discuss this (Cave, 2017; Harmon, 2022; Ó Néill, 2020)

of the state and the relative importance of ‘imminency’. Interestingly, this perspective seems to suggest that state intervention is made complicated for vaccination, as ‘clear and present danger’ does not exist. This raises further questions around how to consider the parental views in these situations – ought we adopt the parent’s view of ‘imminence’? And should imminence influence the state’s perspective?

Involving courts in pediatric vaccination refusal may be ethically contentious – although there are clear ethical and legal justifications for why vaccination is in the child’s best interests, the non-empirical literature seemed to present challenges to justifying state intervention for a prophylactic medical intervention as the threat of contracting a VPD may not present an “imminent” and “life-threatening” risk, the same way that, for instance, blood transfusion for a Jehovah’s Witness child presents risks (Bayefsky, 2018). While an HCP may disagree with parents about whether vaccination is in the best interests of their child, some argued it was inappropriate to refer the child to Child, Youth, and Family Services or a judge to obtain a treatment order (Hester et al., 2018). This publication referred to Diekema’s ‘harm principle’, where state intervention is justified for parental refusals only when the child is placed at significant risk of imminent and serious harm. Another author suggests one ought to consider the imminent and life-saving standards for mandated vaccines. They presented arguments surrounding the unlikeliness that children will die ‘imminently’ from HPV or Hepatitis B, and concluded that vaccinations are not ‘life-saving’ (Bayefsky, 2018). On the basis of these arguments, alternative approaches to legally compelling parents to vaccinate their child could be considered, resting on the concept that children have a “right to a normal life” and infection from a VPD threatens that right (Bayefsky, 2018, p. 504) Hester and colleagues (2018) suggested that HCPs seldom obtained court orders to overturn parental refusals of vaccination.

These findings present an interesting but potentially concerning perspective of state intervention. I interpreted that the reliance on ‘imminence’ may be presented as too narrow. In Bayefsky’s comparison of blood transfusions and vaccinations, the ‘imminence’ of severe illness and death is almost certainly known. For diseases such as measles, tetanus, and COVID-19, this threat still exists but the ‘imminence’ of severe illness and death are difficult to determine. For instance, other preventative measures such as the use of seatbelts are generally in the best interests of the child, but the child may never actually require the seatbelt due to imminent harm in their lifetime. Since ‘imminence’ cannot be determined for VPDs, this raises the question of whether it ought to play a part in the best interests of the child. Additionally, I found it interesting that Hester and colleagues made an empirical claim about the frequency with which HCPs obtain court orders in their non-empirical publication. This may be noteworthy, as it raises questions about the reliability of such claims. These authors did not specify whether their claims relied on anecdotal evidence, personal beliefs, or empirical investigations. This distinction may be particularly significant when discussing complex issues such as the child’s best interests, where decisions can have profound ethical and practical implications.

The state’s perspectives on parental vaccine refusal were shown to depend on the marital status of the child’s parents. State intervention for the best interests of the child and vaccination differed from other medical interventions – vaccination court cases generally arose because the parents pursued litigation against each other, whereas other medical interventions generally arose from an HCP seeking litigation against the parents (Braley-Rattai, 2021). When a child’s parents were divorced, the custodial parent had the autonomy to raise the child as they see fit “without interference […] by the state or the noncustodial parent” (Braley-Rattai, 2021, p. 74). As of 2021, there have been no Canadian court cases of childhood vaccination against the wishes of both parents reported (Braley-Rattai, 2021; Hester et al., 2018), and based on a cursory search, none were found since, suggesting that HCPs may not feel that state intervention is appropriate to ‘protect’ the child when both parents are in agreement with non-vaccination. This raises questions on how the state can best serve the child in such a case, as vaccination is presumed to be in their best interests.

State intervention in children’s vaccination was also referred to in the non-empirical literature when they discussed government mandates for vaccination. Some governments may withhold valuable social goods and services, such as education, to those parents (and their children) who are vaccine-refusing based on ‘non-medical’ choices (Pierik, 2020). Governments have a responsibility to protect the interests of public health. Therefore, parents may be legally compelled to vaccinate their children through mandatory vaccine programs. Vaccination on the basis of the best interests of the child differs from vaccination on the basis of public health interests. The ‘best interests’ view focuses on the individual child’s health and considers direct benefits (and harms) to the child. The ‘public health’ view focuses on the health of the population at large. Decisions made in the best interests of the child may vary depending on individual factors and circumstances, whereas decisions made for public health may advocate for widespread vaccination to achieve collective benefits. The former centers around the ethical responsibility to optimize the wellbeing of a child, while the latter considers the ethical responsibility to protect the population and achieve the greatest good for the greatest number of people.

In addition, some may oppose this view and believe that it is in the best interests of a child to not be vaccinated when others have contributed to mitigating the outbreak through vaccination. Bester (2017) explored this argument and stated that relying on the collective population's protection through herd immunity is unethical (see: What ethical dimensions are at work within 'best interests'?).

In my interpretation, the state's perspective entailed the regulations put forth by governing bodies regarding best interests, as reported in the literature. Many of these regulations implied something about best interests, such as the 'imminency' and 'severity' of the harms one ought to protect a child from. These implications take for granted that the risks of becoming infected by a VPD are ever-present. Therefore, the state's perspective places restrictions on children's healthcare decisions that could arguably contradict their best interests, as they could continue to be exposed to the risks of becoming infected by VPD. Additionally, the absence of Canadian court cases where both parents opposed vaccination raises concerns about whether HCPs and the state are adequately protecting the child's best interests. If these regulations are not being applied, perhaps there is cause to revise them or substitute them with new regulations.

3.4.2 Empirical literature

3.4.2.1 Parents

Almost every empirical publication included in this review discussed the role of the parents in best interests determinations and treatment decision-making for pediatric patients, suggesting the close relationship between the best interests of the child and the perspectives of the parents.

From a subjective account of the best interests standard, one may believe the perceptions and values of the parent and the HCP influence their understanding of the best interests standard, rather than ‘objective’ harm-benefit analyses (Cavolo et al., 2021). One publication suggested that the best interest test could not be objective, as the interpretation of facts depended on who is interpreting them (i.e., an HCP will interpret facts differently than a parent, and vice versa) (Bahus & Føerde, 2011). Others described how clinicians used both ‘objective’ medical information and specific family and child interests, in the present and future, to conceptualize the best interests of the child (Streuli et al., 2021). There is clearly a divide between conceptions about the objectivity and subjectivity of best interests determinations, which may form the basis for HCPs’ confusion and subsequent distress in these cases.

One HCP reported that their guidance on the best interests of the child was most successful when they were sensitive to parents’ states of mind: “something about the parents and the way they were responding, told me that it just wasn't the right time, that we needed yet another episode of intensive care” (Birchley et al., 2017, p. 933). Other cases of poor parental behaviour seemed to limit the HCP’s ability to exercise their views:

> …she just up and left, yelled at me and then wanted to leave so it was very hard to negotiate with her, so I said 'That's fine, that's how you feel but, you know, you can't leave because we need to sort out what's going on with the feeding' and she was like, 'This is my child, you can't tell me how to feed him'”. (O’Haire & Blackford, 2005, p. 253)

This paper proposed that, ideally, HCPs would assess each family individually, adjusting their approaches to meet the needs of the family. In practice, HCPs were often time- and resource-limited and lacked the support to implement this kind of approach (O’Haire & Blackford, 2005).

In my interpretation, some HCPs may have felt that respect for ‘parental autonomy’ conflicted with their determination of the child’s best interests, whereas others believed that family interests could not and should not be separated from what was in the child’s interests. For instance, one publication stated that parents’ and siblings’ preferences should not be accounted for in determinations of children’s best interests (Bahus & Føerde, 2011), and others went further to state the family was too emotionally involved to make an ‘objective’ decision that is in the best interests of the child, due to feelings of insecurity and loss of control (Street et al., 2000; Weiner et al., 2022). This led me to understand that these HCPs seemed to be conceptualizing ‘best interests’ ‘objectively’, although I interpreted this more as ‘dispassionately’. From this conceptualization, HCPs did not seem to believe a parent’s (or their own, I presume) emotions played an important role in determining the child’s best interests. This raises questions about how to truly separate an ‘emotion’ from a ‘perspective’, ‘value’, or ‘view’, as feelings such as insecurity or mistrust seem to inherently seep into one’s perspectives. I presume that this is also possible the other way around, where an HCP’s emotions (such as feeling a loss of control over the situation) can influence their opinions of whether to involve the parents or not.

In neonatology, HCPs had difficulties determining the best interests of patients born in the ‘grey zone’ (23-25 and 6/7th weeks old), as the obligation to resuscitate infants within this range increased with gestational age (Mills et al., 2015). However, in alignment with the parent’s wishes, withholding intensive care was generally considered acceptable (Mills et al., 2015).

HCPs reported wanting to support and respect parental autonomy and being hesitant to interfere with parents’ choices, even if they might not have been in the best interests of the child (Weiner et al., 2022). Some HCPs were torn on whether familial burdens ought to place limits on their obligations to the child, but they rejected an approach to best interests determinations that focused exclusively on the interests of the infant (Placencia et al., 2016).

In the empirical literature, I found that parents may have provided a protective aspect, where HCPs wished to involve the parents so that they could provide post-treatment support and care to ensure treatment was adhered to (Isabelo et al., 2019). Additionally, HCPs described counselling parents to consider their own interests and stressors that may have resulted from the child’s treatment decision, such as financial strain, divorce, and divided attention for other children (Richards et al., 2018). My interpretations led me to believe that this approach contrasts the ‘objective’ approach, where HCPs have given the parents space to consider the factors that will affect them as well as the child. In one approach, this may be seen to ‘decenter’ the child from the decision as the family’s interests are being considered, however, a broader definition of the standard may propose that these interests are extremely relevant to the child as they affect their biopsychosocial environment.

In my findings, some cases were identified that complicated the balancing of the HCP and parents’ perspectives. For instance, some publications demonstrated that occasionally, parental decisions could subject the child to ‘unnecessary pain and suffering’, forsaking the principles of beneficence and non-maleficence (Bahus & Føerde, 2011; Deligianni et al., 2023; Heide et al., 1998). In other publications, the expression of strong parental wishes concerning life-prolonging treatment conflicted with an HCP’s determination of the best interests of the child when parents were of the mindset that HCPs were to aggressively treat disease (Albersheim et al., 2010; Bahus & Føerde, 2011; Belcher, 2013; Roen & Hegarty, 2018; Valdez-Martinez et al., 2014). This was further challenged when parents saw the death of their child as a failure, and they wished to exhaust all possible treatment options (Abdin et al., 2022; Richards et al., 2018).

In these cases, I perceived that the parents and HCPs had differing goals for ‘treatment’. When the parents were described as expressing strong wishes for life-prolonging treatment, subjecting the child to potential pain and suffering, this signaled to me that the parents may have been valuing longevity of life over quality of life. I understood the HCPs to be more concerned with quality of life. These conflicts may have arisen due to fundamental differences in the understandings of the goal of medicine, and perhaps communication and discussion about these conflicting understandings could allow HCPs and parents to come to an agreement about the child’s best interests. When HCPs felt pressured to follow the parent’s orders, even though this contradicted their determination and may have been perceived as unrealistic or futile, moral distress arose because their ethical principles were threatened, as well as the parent-doctor relationship (Belcher, 2013; Valdez-Martinez et al., 2014).

In empirical studies, uncertainty and moral distress was found to influence an HCP’s determination of a child’s best interests. Uncertainty distress was evident in HCPs’ navigations of best interests when the child’s quality of life was difficult to determine, and the notion of the ‘right thing to do’ was ill-defined (Deligianni et al., 2023). HCPs felt that following the parents’ wishes may have caused pain to the child or was considered futile, causing stress and feelings of providing treatment ‘for show’ (Deligianni et al., 2023; Morrison et al., 2015). Parents were shown to place pressure on HCPs when prognosis and quality of life were uncertain, as the family may feel that greater hope exists for their survival (Mack et al., 2024). Uncertainty distress resulted when HCPs were unsure about whether they had done right by the child or how to balance the parents' values and preferences with the child's best interests (Deligianni et al., 2023).

Moral distress is closely related to uncertainty distress, and some publications use the terms interchangeably (Deligianni et al., 2023). HCPs expressed feelings of trouble and moral distress when they were unable to act in the best interests of the child, often due to parental disagreement of those interests (Heide et al., 1998; O'Haire & Blackford, 2005). A situation may become 'morally' distressing when HCPs deem the treatment decision as morally wrong. For example, when a child was not cooperating with treatment, HCPs employed coercion, which might always cause distress from HCPs but became *morally* distressing when coercion felt morally wrong (Weiner et al., 2022). When tensions arose within the decision-making triad, HCPs felt their 'moral agency', or their capacity to enact their moral responsibility to make moral decisions was limited (O'Haire & Blackford, 2005).

Moral distress was also experienced by HCPs when parents were hostile when their wishes were overridden in the HCP's determination of best interests of the child (O'Haire & Blackford, 2005). For instance, one HCP reported moral distress when a mother "yelled at [her] and then wanted to leave so it was very hard to negotiate with her [(the mother)]" after they expressed the best interests of the child were to remain in the hospital to sort out feeding issues (O'Haire & Blackford, 2005, p. 253). In this case, moral distress stemmed from the moral dilemma of simultaneously acting in the best interests of the child and disregarding the mother's wishes. Moral distress also arose when HCPs considered morally concerning therapies such as tracheostomy or long-term ventilation as a 'destination therapy' (Mack et al., 2024). Finally, moral distress arose when HCPs witnessed injustices to their patients based on non-medical criteria that undocumented migrants experience, as the best interests of the child did not appear to be a primary consideration (Kvamme & Voldner, 2022).

Additionally, the significant amount of uncertainty and moral distress in empirical studies indicates the dire necessity of improving understandings of how HCPs ought to navigate a child's best interests. In my interpretations, HCPs often have a clear sense of what they consider 'moral' treatment and may become distressed when pressured to pursue an alternative treatment. If this approach is taken for granted, it seems that morally problematic treatments may occur because HCPs are pressured into providing sub-optimal care. This may imply that parents ought to have less influence over decisions regarding their child's best interests. Conversely, HCPS might be guided by a personal sense of morality that may not align with broader ethical standards and could simply be reflecting their discomfort providing treatment that conflicts with their own subjective values. In this case, the focus should be on helping HCPs understand the family's values and priorities to alleviate their distress and ensure a more harmonious decision-making process.

Many publications proposed suggestions to ameliorate this incongruity, including holding meetings to discuss the decision-making responsibilities and expectations for all stakeholders, clarifying the legal and ethical balance of parental autonomy and the best interests of the child, and exploring the nuanced and complex values of parents and HCPs that are emphasized in their recommendations (Hagen et al., 2012; Laventhal et al., 2017; Mack et al., 2024; Weiner et al., 2022).

Mack and colleagues (2024) brought attention to the importance of clarifying the expectations of all stakeholders, including the parents, team members, and the child. They stated that setting realistic expectations for the roles of the decision-makers (i.e., the parents and team members) was a dynamic and longitudinal process. Centering the child's participation in the decision-making process required anticipation and attention. Weiner and colleagues (2022) suggested involving these stakeholders in discussions to reflect on each person's decision-making expectations. These authors proposed that communication could lead to enhanced understandings of expectations and ideas for care from all stakeholders. This aligns well with my earlier reflections on clarifying the goals of treatment from the HCP and parent's perspectives.

Hagen and colleagues (2012) found that HCPs may have misinterpreted the guidelines and law surrounding best interests, leading to best interests 'not being respected' in all cases. For instance, they curiously found that HCPs would abstain from care if a parent requested so, despite the HCP's belief that treatment was in the child's best interests. Hagen and colleagues (2012) hypothesized that HCPs' decisions were affected by their implicit attitudes or pre-existing 'false' knowledge that may have led the HCPs to make assumptions about the severity of the child's prognosis. They found that their results contradicted the national guidelines under which the HCPs practice, which asks HCPs to 'override' parental decisions if they have conflicting perceptions of the child's best interests. They called for legal and ethical clarification of the balance of best interests and parental exercise of autonomy, given these findings. Interestingly, the language used by Hagen and colleagues does not clarify what 'overriding' a parental decision entails, perhaps suggesting that this also requires clarification.

Finally, Laventhal and colleagues (2017) found that, in cases of extremely preterm infants, HCPs exhibited a nearly equal divide of supporting their own assertions of best interests and deferring to the family's choice. They called for further exploration of either *how* the values of parents are considered by HCPs, or which values of parents are considered by HCPs (the sentence read: "Future work in this domain could further explore the complexed and nuanced values of expectant parents are considered by physicians, as these are increasingly emphasized in guidance for antenatal consultation" (2017, p. 12)). Regardless, both appear to be important calls to further explore and clarify how best interests should be understood by HCPs, perhaps within the social, political, and cultural contexts of the HCPs.

Based on my interpretations, there are varying approaches to considering HCPs and parents' wishes in best interests determinations, and to what extent they are or ought to be considered. HCPs have clearly expressed difficulties ensuring the child's best interests are upheld while mediating relationships with parents (Weiner et al., 2022). This has led to an inconsistent application in clinical practice, possibly due to the challenging and unclear nature of determining the best interests of children, which may make it difficult for HCPs to determine whether or not the parents' wishes should be rejected, or when parental involvement is misinterpreted by HCPs and parents.

3.4.2.2 The child

The child's perspective was found to impact HCPs' determinations of the best interests of the child. In one study, HCPs faced challenges when considering the child's growing 'autonomy', as this seemed to add another stakeholder to the decision-making process, which was difficult to navigate when the child and parents had competing views (Weiner et al., 2022). Additionally, the concurrence between children and their parents was shown to convince HCPs that such a decision, even though it may have conflicted with their determination, was in the child's best interests (Valdez-Martinez et al., 2014).

In my interpretation, the former study may be signaling the developing capacity of the child, rather than autonomy, as capacity is a precursor for respecting one's autonomy in medical ethics. In this case, my interpretation is that HCPs recognized that a child's capacity for understanding and appreciating the treatment risks and benefits could develop, and without necessarily deeming them capable of making their own decisions, they instead gave them more room to express their perspectives. Both studies seemed to emphasize that the HCP was charged with the power to decide if and how the child's perspectives were considered.

In one publication, HCPs attempted to include children in discussions to help establish what was in their best interests (Abdin et al., 2022). Quaye and colleagues (2021) reflected that this made children feel more valued and less anxious, and helped keep the child and their best interests at the center of decision-making. Abdin and colleagues (2022) found that HCPs mediated information sharing of the child's diagnosis and treatment options, as they (and the child's parents) believed that this would upset the child. Although there was a general agreement that HCPs believed they ought to involve children, especially if they could understand what was happening, these authors purported that HCPs may have desired to 'protect' children from becoming upset by sharing information.

Quaye and colleagues (2021) demonstrated that when HCPs directed treatment questions or discussed test results with the parents instead of the child, this acted as an obstruction to understanding the best interests of the child. These authors found that the current and future interests of the child appeared to be essential to promoting the best interests of the child, therefore, HCPs ought to have engaged the child and parents and weighed the competing interests to reach a 'compromise' that promoted the child's best interests (Quaye et al., 2021). Street and colleagues stated that the United Nations Convention on the Rights of the Child (UNCRC) and other important documents supported that the views of children ought to be given "due weight in accordance with their age and maturity" (2000, p. 350). From my perspective, this statement may raise questions about how 'due weight' is determined, and by who. Additionally, if the child is incapable, how do we or should we navigate their views if they differ from those of their parents or the HCP?

In my interpretation, if one adopts the 'objective' view that clinical harms and benefits analyses determine best interests, the child's perspective may seem less relevant as the emphasis is on ensuring the medical outcomes minimize harm and maximize benefits. Understanding the child's perspective may still be important, as it may help HCPs tailor their communication and approach to make treatment more acceptable and less distressing for the child, indirectly influencing the overall benefit of the treatment. Additionally, HCPs can attune themselves to the child's growing understanding of their illness and potential treatments to determine how to weigh their views in determining their best interests.

3.4.2.3 The state

The empirical reviewed publications also explored the perspective of the state regarding children's best interests. HCPs were found to avoid involving courts when they could not agree with the family (Birchley et al., 2017). Birchley and colleagues described how the majority of participants had not had an experience involving courts in resolving best interests disputes, stemming from their beliefs that court decisions could be inconsistent and the process was "arduous, divisive, and lengthy" (2017, p. 932). Along with these concerns, HCPs seemed to hold beliefs that legal processes placed pressure on them to agree with 'unreasonable' demands from families. HCPs expressed concerns about the irretrievable breakdown of the HCP-parent-child relationship and the adversarial nature of involving the courts, as this could erode trust in the healthcare system (Forbat et al., 2015). State involvement was also avoided due to institutional views that this would be seen as a failure on the HCP's part (Birchley et al., 2017). In other publications, HCPs express frustration with the legal system disregarding their statements to child protection lawyers about the best interests of the child, suggesting that the child's interests are not a primary consideration by these intervening stakeholders (Kvamme & Voldner, 2022). Another empirical paper described how the absence of legal precedent to argue that non-vaccination constitutes medical neglect may supply justification for parents to refuse vaccination in the best interests of their child (Wiley et al., 2023).

This differs from the non-empirical literature, as HCPs avoided state intervention for reasons other than ethical justification. This may suggest that HCPs do not consider the same reasons, frameworks, or thresholds for state interventions as suggested by the non-empirical literature. Perhaps it is more favourable for HCPs to concede to the parents' wishes rather than involve the legal system, even though the majority of court cases regarding vaccination have compelled children to be vaccinated, in agreement with HCPs (Braley-Rattai, 2021).

Another reason for the inconsistent application of these ethical principles in real-life cases may result from an absence of guidance for HCPs to apply these principles (Valdez-Martinez et al., 2014).

In my interpretation, these findings do not indicate that state intervention is always unethical. In a consequentialist view, these findings may tip the scales to prove that the harms of state intervention on the HCP outweigh the benefits. This does not explain the potential benefits on the child, nor is a consequentialist approach the only way to determine the ethical permissibility of best interests. From a deontological view, the HCP's duties outlined in the Hippocratic oath may be required to be upheld in order to determine ethical permissibility. In addition, although there are potential difficulties or even harms to the HCP, parents, or children when state intervention is sought, this should not dictate whether we pursue these actions if they are in the best interests of the child. The complexity involved in state intervention does not absolve HCPs of the responsibility to act ethically and protect the child's welfare.

The UNCRC arose as an important state perspective for HCPs to consider in a child's best interests (Bahus & Føerde, 2011; Birchley et al., 2017; Isabelo et al., 2019; Quaye et al., 2021; Street et al., 2000). Some physicians professed to always follow the UNCRC and gave treatment in the best interests of children (Isabelo et al., 2019), as well as ensured they were informed and imparted information on their care (Quaye et al., 2021; Street et al., 2000). Additionally, Street and colleagues (2000) highlighted that the UNCRC considered that the age and maturity of children should inform the weight their views are given. Despite this, studies found differences in perceptions of what constituted the best interests of patients, as stated by the UNCRC (Bahus & Føerde, 2011; Birchley et al., 2017; Isabelo et al., 2019). One publication interpreted the UNCRC to indicate other significant interests at play that HCPs must consider, including parental interests (Birchley et al., 2017). Another publication stated that the guidelines were directed at parents, but may have also been interpreted as grounds for HCPs to seek legal opinions if they believed the parental decision was not in the best interests of the child (Bahus & Føerde, 2011).

In summary, the theme 'Whose perspective is 'best'?' explores the perspectives of the individuals that were important to best interests in the empirical and non-empirical reviewed literature. The non-empirical literature described the parent's perspectives and the state's perspective, while the empirical literature described the parent’s, state’s, and child’s perspectives. Interestingly, the child’s perspectives were largely absent from the non-empirical publications. In my reflections, these publications may presume that since the child is incapable of medical decision-making, their perspectives were not worth exploring or theorizing about. The empirical literature shows that children do have perspectives on their treatment, and there are benefits to including those perspectives, so perhaps more normative investigation is required to deepen understandings of how those perspectives ought to be elicited and considered in the child’s best interests.

3.5 Who decides what is ‘best’?

This theme examines the distribution of decision-making power and authority among the various stakeholders involved in a child’s best interests. It focuses on who ultimately holds the final decision-making authority, as described in both empirical and non-empirical publications. The stakeholders I identified were HCPs, parents, both HCPs and parents, and children, each of whom had differing levels of influence over decisions that impact the child’s best interests. This theme may be summarized in the following table:

Table 7: Relevant decision-makers for 'best interests

Decision-maker	How ‘best interests’ is influenced	References
Parents	‘Parental autonomy’ was expressed by HCPs as difficult to navigate when they disagreed with the parent’s decision.	(Braley-Rattai, 2021; Diekema, 2005; Hester & Salter, 2022; Nihlén Fahlquist, 2023; Suryadevara & Domachowske, 2019)
The child	Children who are incapable are never the sole decision-maker, but can contribute by sharing their beliefs, preferences, and values. HCPs can ensure these are given due	(Quaye et al., 2021; Streuli et al., 2021; Weiner et al., 2022)

	consideration in the child’s best interests.	
‘Shared’ – parents and HCPs	Parents and HCPs were found to hold different ‘expertises’ which they brought to decision-making.	(Abdin et al., 2022; Belcher, 2013; Birchley et al., 2017; Clark et al., 2020; Forbat et al., 2015; Laventhal et al., 2017; Mack et al., 2024; McDougall & Notini, 2014; O’Haire & Blackford, 2005; Popejoy et al., 2022; Quaye et al., 2021; Roen & Hegarty, 2018; Valdez-Martinez et al., 2014; Wiley et al., 2023)

3.5.1 Non-empirical literature

3.5.1.1 Parents

Respect for autonomy is considered a prevalent ethical principle in healthcare decision-making and was described in the literature as the right to self-governance (Nihlén Fahlquist, 2023). It seems that when children are deemed legally incapable of making their own medical decisions, their right to respect for autonomy is translated into parental autonomy, referring to the parent’s right or responsibility to make decisions on behalf of their child, “to do what they think is in accordance with the child’s best interests” (Nihlén Fahlquist, 2023, p. 129). Nihlén Fahlquist reflected on the unusualness of the use of ‘autonomy’ since, in this case, the medical decision was not concerned with the individual’s own care (Nihlén Fahlquist, 2023). Additionally, they purported that parental autonomy be “normatively problematic” (Nihlén Fahlquist, 2023, p. 129). They did not expand on this point.

Furthermore, parental autonomy was raised frequently in the context of vaccination, as well as other medical decision-making contexts (Braley-Rattai, 2021; Hester & Salter, 2022; Nihlén Fahlquist, 2023; Suryadevara & Domachowske, 2019). One publication suggested that the best interests standard was aimed primarily at parents to guide moral decisions since they are responsible for making those decisions (Hester & Salter, 2022). This can cause tensions between parents and HCPs when their ideas of the best interests of the child conflict. HCPs are also bound by their duty to uphold the best interests of the child, and they often must work together to reach this goal (Diekema & Bioethics, 2005).

3.5.1.2 Shared decision-making

In the non-empirical literature, Hester and Salter purported that parents ought to locate their best interests judgement with attunement to the network they interact with, informed by the family’s experiences, beliefs, and understandings (2022). When parents were viewed as participants in decision-making, they brought their conception of what is ‘best’ to the clinical encounter, whether that matched or contrasted an HCP’s opinion. HCPs were encouraged to engage in discussions with parents to understand their concerns about vaccination, guided by their interpretation of the child's best interests. From a shared decision-making lens, the goal of these encounters ought to be for the HCP and parents to arrive at a decision that centers around the child’s best interests (Hester & Salter, 2022).

Additionally, when best interests were viewed as a shared process between HCPs and parents, difficulties could arise around mediating the specific expertise both parties relied on. Parents may be empowered by the authority to make the decision as well as the knowledge of their child’s and family’s experiences and values, while clinicians have expertise in medical beneficence (Hester & Salter, 2022). While there remains a power difference, one publication suggested that each party has value in contributing to the deliberation of the best interests of the child (Hester & Salter, 2022). Where vaccination is considered, parents must express their reasons for non-vaccination. Whether they consist of skepticism of safety or belief in alternative therapies lacking scientific grounding, these are still reasons with importance in the family’s worldview. The HCP may engage in persuasion to explain the medical outcomes of developing the VPD should the child develop it and provide scientific evidence on the safety and utility of the vaccine. This is proposed to assist in finding common values and interests for the child, their parents, and the HCP (Hester & Salter, 2022).

3.5.2 Empirical literature

3.5.2.1 Parents

Generally speaking, parents were responsible for making decisions in the best interests of their children when they were deemed decisionally incapable, based on the ethical principle of respect for autonomy (Street et al., 2000; Valdez-Martinez et al., 2014). In one publication, some parents expressed uncertainty regarding their role and responsibilities in decision-making, and where the limits of their responsibilities lay (Weiner et al., 2022). Another publication demonstrated that parents wished to maintain control over the decisions about their child’s health (Richards et al., 2018). While parents had the right to consent to treatment on behalf of their child, HCPs were not compelled to provide treatment if it was not in the best interests of the child and was not consistent with the child’s needs and well-being (Bahus & Føerde, 2011; Mills et al., 2015; Wiley et al., 2023). HCPs acknowledged that while they may have adjusted their practice to meet the needs of families, it was ultimately their duty to ensure the care provided was safe (O’Haire & Blackford, 2005). This pattern was interesting to me, as the HCPs seemed to be reflecting that their perception of the best interests of the child was always ‘right’, and where the parents did not or could not agree, they would not have to provide treatment.

Some other publications more subtly reported a lack of concordance between HCPs’ explanations of respecting and limiting parental decision-making authority, suggesting they were strongly influenced by their own best interests evaluations, especially in cases where there was a clear treatment benefit (Albersheim et al., 2010; Curley et al., 2007). Another publication stipulated that when an HCP deemed treatment (resuscitation) in the child’s best interests, parental refusal of such treatment should have been overridden by the HCP (Laventhal et al., 2017). Yet, this study demonstrated that most physicians would pursue treatment that the parents expressed they wished for, even if the HCP determined that such treatment would contradict their understanding of the child’s best interests. Many other publications reflected this tension, where HCPs did not uphold treatment decisions in their assessment of the best interests of the child and instead deferred to what the parents wanted (Fauchère et al., 2021; Hagen et al., 2012; Janvier et al., 2008; Marcello et al., 2011). I found this to be a common practice when prognosis and treatment benefits were uncertain, particularly in neonatology, when the HCP is unclear on the ‘best’ treatment option and there lacks a definitive reason to overrule parents (Cavolo et al., 2021; Deligianni et al., 2023). In contrast, one study found an HCP to have held the most decision-making influence to be inappropriate (Roen & Hegarty, 2018). For example, one HCP stated: “Who decides hypospadias surgery is necessary? Me [laughter]” (Roen & Hegarty, 2018, p. 975). This study interpreted that the HCP’s laughter was their acknowledgement of the unsuitability of physicians taking on decision-making on behalf of the parents.

Interestingly, I interpreted these authors to be presenting events where they ‘granted’ parents the power to decide for their child, despite their belief that the parent’s decision would contradict the child’s best interests. Firstly, I understood this to mean that HCPs describe that they believe they have ultimate decision-making authority, where they can decide how much authority the parents (and presumably other decision-makers) have over the child’s best interests. Secondly, their understandings of best interests are not described as modified by who makes the final decision. While they described that the child’s best interests remained static, HCPs appeared to consider the broader situation of the parent’s interests when passing up the power to make the decision. In my interpretation, what these publications are presenting is a different determination of the child’s best interests that includes the broader environment and interests such as the parents. By ‘allowing’ the parents to make the final decision, HCPs are, in a way, making their own decisions about the child’s best interests. If they truly believed the parent’s decision went against the best interests of the child, would the HCP not be entitled to override that decision and enact state intervention? As reflected before, there may be practical reasons why HCPs wish to avoid contradicting parents’ decisions, however, they must keep in mind that their duties are to ensure the child’s wellbeing. Finally, when the HCPs were ‘unclear’ on best interests, I interpreted this to be caused by a lack of empirical evidence about potential outcomes for the treatment. Given all of these reflections, in my view, some HCPs seem to wish to reflect their determinations of the child’s best interests as ‘objective’ and reliant on empirical evidence about potential harms and benefits, and when these are unclear, they forfeit final decision-making power and allow the parents to make the final decision. From my perspective, this is signaling that HCPs do maintain final decision-making authority and agree with the parent’s determination of the child’s best interests.

Alternatively, one study found that HCPs identified parental decision-making authority, the best interests of the child, parents as primary caregivers who must live with the decision and long-term outcomes, and standards of practice as underlying principles that guided HCPs' views about parental rights (Albersheim et al., 2010). Many HCPs were found to value the involvement of the parents and families to help establish what was in the best interest of the child (Abdin et al., 2022; Cavolo et al., 2021; Mills et al., 2015; Morrison et al., 2015; Rasmussen et al., 2016; Samaan et al., 2008), and some even believed parents were in the *best* position to make treatment decisions for their child and family (Belcher, 2013). Some studies found that the child existed within the family unit, and it was not in their best interests to move forward with an HCP's belief of what was right for the child if was wrong for the family and would negatively affect the family environment (Abdin et al., 2022; Samaan et al., 2008). These publications raised potential conflicts with other views of best interests, including those that said the family interests were not or should not be considered.

3.5.2.2 The child

In my assessment, the view that parental autonomy dictated the best interests of the child may have positioned the child's perspective as secondary to the parents' wishes and decisions. Streuli and colleagues (2021) suggested that parents could have facilitated elicitation of their child's views by recognizing that their child was not the sole decision-maker but with growing capacity, there may be a handover of responsibility and decision-making capacity. As previously mentioned, further consideration of the ability to separate the child's wishes from the parents may be required to better understand this perspective.

Adopting the view that HCPs are the most qualified to determine the best interests of the child due to their specialized knowledge and expertise may similarly de-prioritize the child's views. A child's ability to express their voice was largely dependent on the actions of HCPs and their parents (Quaye et al., 2021). When HCPs sought out the child's views, this often entailed listening to the child's beliefs, preferences, and values, and ensuring they were given due consideration in care planning (Quaye et al., 2021). In some cases, HCPs found difficulties striking a balance between involving the child in decision-making participation and protecting them from too much information (Quaye et al., 2021; Streuli et al., 2021; Weiner et al., 2022). In my interpretation, this reflects a similar pattern to parental decision-making power, where HCPs determine the extent to which others, such as children, have decision-making power.

3.5.2.3 Shared decision-making

HCPs reported negotiating relationships with parents in various ways, congruent with the lack of clarity on how they were included in decision-making. The literature showed how HCPs and parents experienceed conflict when navigating decisions in the best interests of the child. Abdin and colleagues (2022) described two court cases of conflict between HCPs and parents that ultimately helped decision-making by placing authority in other hands. These cases (Charlie Gard and Tafida Raqeeb) were described as important landmarks in understanding how and when to implement decision-making strategies when the relationships between parents and HCPs have broken down (Abdin et al., 2022).

HCPs viewed the family unit and their relationships with them as equally or more important than the perception of the child’s survival (Clark et al., 2020; Laventhal et al., 2011). To preserve this relationship, HCPs reported using strategies such as avoiding discussions on aspects they believe would concern parents. For example, HCPs shared how they “have never heard a doctor tell a parent it was futile to continue treatment. [They] have heard talk among the nurses when parents aren’t around that what was being done was futile, but no one is willing to approach the doctors to question them about the futility of a situation” (Belcher, 2013, p. 53). HCPs also reported reframing their description of the child’s care plan in terms that they believed to be more acceptable to parents, such as “possibilities for the future”, when they did not share the HCP’s views (Birchley et al., 2017; Popejoy et al., 2022). HCPs also presented all treatment options early so that parents could delay treatment before it became ‘dangerous’ to refuse (Popejoy et al., 2022). Establishing and maintaining trust between decision-making stakeholders was found to be important, as harm could be caused to the child if parents felt their autonomy was disrespected, which may lead to the loss of trust and potential disengagement from the healthcare system (Wiley et al., 2023). Some HCPs weighed the potential health and risk of disease of the child lower than the preservation of trust to ensure the child continued to engage with the healthcare system (Wiley et al., 2023).

HCPs enacted compromise, equipoise, negotiation, and persuasion to maintain the relationship between themselves and the child’s parents. One publication reported HCPs acquiescing to the family’s preferences to a certain extent:

> I was prepared to compromise and whilst care was good enough [...] I didn't feel I had enough grounds to push my case against Mum's strong, strong conviction […] So, you compromise until you can't compromise anymore because you've got to a position where clearly the child is being put at risk. (Popejoy et al., 2022, p. 522)

In empirical publications, a compromise involved weighing the competing interests of the child and their parents to reach a decision that promoted the best interests of the child (Quaye et al., 2021). A compromise was also expressed when parents or HCPs accepted a lower standard, for example, when the interests of the child were compromised for the sake of a greater goal or the parents' interests, or when HCPs felt their professional integrity was at risk of becoming compromised by pursuing a decision they felt was not in the best interests of the child (Clark et al., 2020; McDougall & Notini, 2014). HCPs also expressed negotiating with families to reach a consensus on the child's best interests. HCPs reported negotiating parental participation, which involved collaborating between the child, parents, and HCPs to enact moral agency (O'Haire & Blackford, 2005). 'Gentle negotiation' was found to be important for HCPs to encourage parents to weigh medical and familial assessments of the best treatment when they sought confirmatory information and advice from outside sources such as other families rather than professional advice (Abdin et al., 2022).

One publication proposed a 'best interests compromise model', involving strategic framing of the suggested treatment while involving the parents and the patient in decision-making (Popejoy et al., 2022). Another proposed that seeking the child's views and preferences could help HCPs find a compromise during care planning in the child's best interests (Quaye et al., 2021).

The empirical literature suggested that a professional obligation existed for HCPs to use persuasion to encourage patients and parents to accept their advice (Popejoy et al., 2022). When HCPs felt strongly that their determination to the best interests of the child was more appropriate than the parents', they employed persuasion to uphold their duty to help families arrive at the best decision for the child (Popejoy et al., 2022). Persuasion was reported to be used by HCPs to maintain their moral identities by helping the parents come to terms with their determination (Popejoy et al., 2022). HCPs attempted to persuade the parents in a softer way to frame the treatment options differently. For instance, one publication that discussed hypospadias surgery, a non-essential penile surgery for cosmetic reasons, demonstrated how some HCPs used non-medical framing to focus on the child's well-being and the parent-child relationship by expressing that the child's body, despite anatomical differences, is still loveable and the child should have the ability to make their own decisions 'when they are old enough' (Roen & Hegarty, 2018).

In my reflection, these dimensions raise questions about the true 'shared' nature of these decisions. In many of these studies, I interpreted the authors' findings to suggest that HCPs aimed to align the parents' perspectives with their own, rather than genuinely sharing the decision. HCPs may feel this is truly how decisions are and ought to be shared, but I presume that parents and children might not agree. If HCPs, parents, and children aim to share decisions, further understandings of each stakeholder's perspectives are required.

I found that trust in the relationship was an important aspect of HCPs' negotiations with parents concerning the child's best interests. Issues surrounding trust were found to be a core concern for HCPs' abilities to execute their status as moral agents in determining the best interests of the child (Valdez-Martinez et al., 2014). In one publication, HCPs felt that parents sought a trusting relationship with them when considering treatment options (Abdin et al., 2022). Another publication suggested that there was a variation in trust between HCPs and parents, depending on the parent's health beliefs or their abilities to trust others that predated the child's illness (Valdez-Martinez et al., 2014). This posed difficulties for the HCPs in this study, as their behaviour and communication style promoted trust for some parents and was perceived as threatening or intrusive for others (Valdez-Martinez et al., 2014). When trust between HCPs and parents was eroded, there was a risk of alienating the parents (Forbat et al., 2015). As one parent reflected,

> From that time on [clinicians saying that nutrition could not be withheld] I was quite suspicious really of the medical establishment and/or the hospice in pretty much in every way […] I was on the alert and lookout for the kind of possibilities that things might be done that I didn't feel were in my son's best interest. (Forbat et al., 2015, p. 771)

When there was a severe disintegration of the relationship, HCPs expressed concerns that the best interests of the child ceased to be the main focus and both parties felt they lost control of the situation (Forbat et al., 2015).

The empirical literature suggested that HCPs desired mechanisms and strategies to navigate conflicts with parents over the child's best interests. HCPs have called for practices for timely responses and resolutions to disputes with parents that reduce moral distress for themselves, the care team, and families to realign trust and the trajectory of care for the child (Mack et al., 2024; Valdez-Martinez et al., 2014).

In summary, the non-empirical and empirical literature identified various decision-makers with fluctuating power. Both works of literature indicated (implicitly or explicitly) that HCPs held the authority to determine the participation and power of the parents and children. This may be a condition of the research question and search strategy, as I sought to understand HCPs' interpretations of the child's best interests. It is possible that including literature from the perspectives of parents or children might have presented a different narrative.

3.6 Conclusion

These findings indicate that best interests are not uniformly conceptualized or applied among the empirical and non-empirical literature I reviewed. They also indicate that many ethical dimensions, factors, perspectives, and decision-makers shape and constrain children's best interests. These findings demonstrate the agreements and disagreements between the non-empirical and empirical literature, highlighting areas for further engagement to strengthen how best interests are understood and applied. This next chapter presents a deeper interpretation and discussion in light of these findings.

Chapter 4

4 Discussion

The ambiguity of the best interests of the child standard has permeated many healthcare decision-making contexts. This thesis begins to respond to the question “How are best interests for children’s health decisions understood by HCPs in empirical studies and how ought best interests be understood by HCPs in normative articles?” I aimed to compare and contrast both empirical and non-empirical literature to develop insights on agreements, discordances, and key areas where further clarity would be of value.

This chapter presents a refined discussion of the results presented in Chapter 3. Tensions, surprises, and silences in the reviewed literature are interpreted and reflected on. Considering this discussion, implications for practice and theory are offered. Future directions for research, a discussion of the limitations of this study, and the provision of answers to the research question will be discussed in Chapter 5.

4.1 Summary of the findings

My critical analysis of the reviewed empirical and non-empirical publications revealed five prevalent insights regarding best interests and healthcare decision-making for children. My findings indicate the varying conceptualizations of best interests that pose difficulties to its theoretical and practical application. They illustrate the agreements and conflicts within and across each body of literature that present challenges to determining children’s best interests. These findings highlight areas for additional interrogation to improve healthcare decisions in the child’s best interests.

4.2 Uncertainty of empirical evidence and the ‘myth’ of ‘medical objectivism’

My findings demonstrate that ethical tensions between the best interests of the child and parental autonomy may force HCPs to make value judgments on the decisional weight of the parent’s wishes, especially when they challenge aspects of those of the HCPs. There seems to be a high value accorded in both the non-empirical and empirical literatures to the notion of an ‘objective’ account of the best interests that ignores the parental and familial wishes and places greater decisional weight on the HCP’s analysis of benefits and harms, on the basis of their medical expertise and experience. Striving for medical objectivity may allow HCPs to feel confident they are making the ‘best’ decision based on their knowledge and might avoid ongoing debates and potential conflict or tension in the parent-clinician-patient triad relationship. One might say the opposite: that excluding parental wishes from discussions about what is in the child’s best interests further exacerbates conflict or tension between the triad. Problematizing medical objectivity, my findings indicate that perspectives that view best interests as a ‘subjective’ determination involving the child’s greater life environment place more ethical weight on the wishes of the parents. In the face of medical uncertainty, such as COVID-19, the parents’ perspectives in best interests decision-making may become prioritized and HCPs may be more likely to defer to how the parent wishes to raise their child. Alternatively, HCPs may feel less equipped to assuage parents’ fears about the proposed treatment when there is a deficit of medical evidence demonstrating one approach optimizes the child’s welfare more than another, and therefore make more room for the parents’ perspectives and values in discussions. This review aims not to deem one approach ‘right’ or ‘wrong’ as it pertains to childhood vaccination decision-making, but to unpack the potential implications of each approach so one can reasonably understand and either agree or object to the balancing of values.

Additionally, controversy around the ‘objective’ conception’s implications may arise from skepticism around distinguishing metaphysical facts independently from what one ‘believes’ about them. The objective account raises ontological questions regarding the existence of an ‘objective’ determination of welfare and best interests. Is it possible to identify ‘best interests’ independently from what one believes to be in one’s interests?

Other theoretical issues may arise from a consequentialist approach, where there is a lack of clarity around how to weigh incommensurable interests. This means that the determination of ‘best interests’ relies on the maximization of welfare even when one is mistaken or ignorant about which decision truly maximizes one’s welfare. In other words, the so-called ‘objective’ account of the best interests standard is open to criticism as one may say they are maximizing welfare but are flawed in their weighing of interests or taking advantage of their position of power, as in, using their individual conception of best interest. Dawson reveals some of the flaws evident in viewing 'best interests' purely objectively, and although "there is an answer as to what will maximise welfare even if we are not clear what it might be", it is not clear how this argument translates from theory to practice (Dawson, 2005, p. 80).

Dawson's (2005) 'objective' perspective of the best interests standard asks one to focus on the benefits and risks of childhood vaccination and non-vaccination. He described that what is in the child's best interests will be the action that brings about the least harm and greatest overall good, determined by weighing "objectively both the likelihood of the risks occurring and the magnitude of those risks" (Dawson, 2005, p. 83). He demonstrated this using select empirical factors about an infection and its vaccination, for instance, the risk of illness, disease fatality, and potential risks of the vaccination.

In theory, it might be compelling to rely on empirical factors quantifying the likelihood of risks and the magnitude of these risks to weigh the benefits and harms of vaccination, non-vaccination, or infection to determine best interests. Non-vaccination and infection are distinct, as it is not guaranteed that an unvaccinated child will contract COVID-19 (although it is likely given the prevalence and contagiousness). Basing best interests decisions on medical 'facts' provides a platform for HCPs to make best interests judgements dispassionately (Dawson, 2005).

Potential flaws with the 'objective' approach include the scarcity of empirical evidence about new diseases and vaccines, like the situation during the COVID-19 pandemic, the fact that empirical evidence is never 'conclusive', and problems with being truly 'objective' in health and medicine. Firstly, there can be uncertainty of evidence in the wake of a global pandemic, where empirical evidence is not always readily available to inform best interests decisions. Dawson outlines the necessity of avoiding 'misjudgment': a decision based on a lack of relevant information or factors that might bias a judgment. He states, "A decision that weighs the evidence of the relevant relative risks of harm, without any of the potential elements that might lead to a misjudgment, will be a vital component of any judgment as to what is in the infant's best interests" (2005, p. 85). From his perspective, there seems to exist a 'correct' interpretation of what is in a child's best interests, *sans* bias or other factors leading to misjudgment.

A ’misjudgment’ might stem from issues around relying on incorrect ‘facts’ (e.g., misinformation surrounding COVID-19 vaccination risks or adverse effects). Instances where empirical evidence was distorted and used nefariously, such as Wakefield’s now-discredited studies on measles vaccines and autism, raise further questions of whether empirical evidence ought to be the only basis of best interests decision-making (Wakefield et al., 1998; Wakefield & Montgomery, 2000). These instances also highlight the problem of being misinformed as a decision-maker. HCPs and parents may hold different values as more or less important when making best interests decisions, but simply relying on incorrect facts can lead to unethical and harmful decisions.

With greater certainty through empirical evidence, there exists a dispassionate way to determine the option that optimizes welfare for the child without misjudgment. However, the question remains: is this the ‘best’ way to determine what is in the best interests of the child?

Empirical evidence is rarely, if ever, conclusive, and simply tames uncertainty (Ioannidis, 2005). Empirical evidence captures researchers’ experiences and experiments, which can be inherently influenced by the researcher’s contextual factors (Longino, 1990). This raises questions surrounding the ability to make ‘objective’ determinations based on empirical evidence. ‘Objectivism’ may be defined as: “the belief that certain things (especially moral truths) exist apart from human knowledge of perception of them; the tendency to lay stress on what is external to or independent of the mind” (Wilson, 2000, p. 206). The very notion of approaching medicine ‘objectively’, as a ‘detached observer’, may represent an ‘ideal’ within the medical community that views health and disease as generalizable phenomena, independent of social, political, economic, and other contexts (Wilson, 2000).

However, clinical decision-making may be viewed as inherently situated against the backdrop of the HCP’s, patient’s, and family’s personal beliefs, values, and perspectives (Kleinman, 1980). The context in which empirical data is interpreted and applied can vary significantly, influenced by factors such as cultural norms, political climates, and economic conditions, among others (Epstein, 1998). Moreover, the complexity of health and illness may necessitate considering subjective experiences, which empirical data alone may be incapable of capturing (Wilson, 2000). Thus, while empirical evidence can help reduce uncertainties, its interpretation and application are unavoidably subjective, challenging the notion of pure objectivity in medicine.

So, how can we apply the ‘objective’ approach when the child does not exist in a vacuum, and pandemics limit the readily available information to make such a determination? Perhaps this provides a compelling case to look to other more subjective health interests that could deepen our understanding of the best interest of the child, especially in a global pandemic where vaccination is paramount to protecting a child from potential severe illness and death (Farrar et al., 2022).

4.3 The weight of ‘parental autonomy' in a child’s best interests

Can one still judge the best interests of the child while considering broader health interests that are not necessarily medically objective? From the ‘objective’ view, this may be unethical as there are no other relevant interests beyond those that can be determined independently from the individual’s wishes, while others might encourage consideration of the broader interests that may be morally significant to the child, such as their parents’[10]. My findings suggest there are more subjective factors that are relevant in determining the best interests of a child in relation to vaccination that consider their culture, religion, familial values, etc. Parents generally know the child better than the HCP and thus may be best positioned to understand what the child would choose if they were capable, so perhaps they ought to have greater authority to determine these interests and weigh them.

I found the use of the term ‘parental autonomy’ when referring to the parents’ decision-making authority interesting, as ‘autonomy’ refers to self-governance, or in healthcare, the right to make decisions for oneself. In some empirical investigations, the term was used to refer to the wishes and preferences of the parents in the decision-making process (Laventhal et al., 2017; Weiner et al., 2022). In the non-empirical literature, Chervenak and colleagues philosophize that parental autonomy operates “under the constraint of” the best interest standard (Chervenak et al., 2016, p. 306). Additionally, Nihlén Fahlquist and colleagues philosophize that parental autonomy may have different meanings and is “normatively problematic” (without expanding) (Nihlén Fahlquist, 2023, p. 129). Both empirical and non-empirical literature point out that respecting parental autonomy can come into conflict with an HCP’s determination of what is in the best interests of the child. However, there seems to be a lack of clarity on what this principle means, and thus, how to

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[10] I am presuming that parents are part of an infant’s interests.

weigh it when considering the best interests of the child. For instance, does parental autonomy indicate the expression of the child's right to respect for autonomy, operationalized through substitute decision-making (in the best interests of the child)? Or is it referring to a principle that includes a parent's right to make decisions on behalf of their child, per their own preferences? The former might explain how parental autonomy operates under best interests, where a parent has the right to make decisions in the best interests of the child, while the latter seems to emphasize the parents' preferences as central to the decision. Further clarity on how parental autonomy is and ought to be considered in children's best interests determinations is required.

In my findings, the parents' wishes were deemed relevant up to a certain point, which was often when the parents' wishes clashed with those of the HCP and their determination of the best interests of the child. This abstract 'threshold' was reached when parental autonomy contradicted the evidence-based determination of the best interests of the child, in which case HCPs were seen to exercise their abilities to override a parent's decision, in the best interests of the child. When this threshold was reached, my findings suggest there are stark differences in the non-empirical and empirical literature about considering parental hesitancy or refusal. The non-empirical literature views state intervention as the next option, while the empirical literature discusses relationship-building and continued conversations with the parents.

Moral theorists have proposed various ethical justifications for state intervention, including the best interests standard, the harm threshold, and the reasonableness standard, among others (Bester, 2017; Hester et al., 2018; Hester & Salter, 2022). This justification of overriding the parents' wishes represents a weightier valuation of the HCPs' determinations of what is in the child's best interests, concordant with the belief that vaccination is best for most healthy children. Views of modern medicine value empirical evidence, which shows that vaccination is the best way for children to be safe from COVID-19 infection while experiencing childhood to the fullest (Canada, 2021). My findings indicated that contrasting or opposing views that do not support childhood vaccination imply to these believers that such parents are not upholding their duty to protect their children from harm (Diekema, 2005) and are in fact placing the child in harm's way (Nihlén Fahlquist, 2023). Of course, some view vaccination as a medical intervention whose harms outweigh the benefits, but my findings showed that this is a morally problematic view when the harms of COVID-19 infection for the child and relying on ‘herd immunity’ (which is not always so easily established for certain diseases such as COVID-19 (Morens et al., 2022)) are compared (Bester, 2017). Arguments that state intervention ought to be enacted when a parent’s view of the child’s best interests does not align with the HCPs may be overly reliant on empirical evidence and medical conceptualizations of the best interests of the child. Given the problematization of the ‘objective’ approach and empirical evidence described above, this suggests state intervention should not be the sole conclusion to all HCP-parent disagreements. My findings suggest that there are broader factors that can and should influence the child’s best interests, which ought to be examined further to determine a more appropriate threshold for state intervention.

In contrast, my findings from empirical studies signaled that HCPs favoured continual dialogue with the parents rather than state intervention. Some studies viewed a parent’s idea of their child’s best interests as directly related to their values and experiences, just as it does for HCPs (Armstrong et al., 2011; Isabelo et al., 2019; Janvier et al., 2008; Laventhal et al., 2017; Richards et al., 2018; Roen & Hegarty, 2018). This may involve cultural and religious values or beliefs, as well as other interests including financial and socio-demographic factors. Within the empirical literature, my findings highlighted the importance HCPs placed on the parents’ perspectives in vaccine decision-making for their children, and the willingness of HCPs to acquiesce to parental determinations of the best interests of their child. A non-empirical publication demonstrated this trend for prophylactic treatments such as vaccination, where the absence of imminent risk of clear and present danger may justify attending to parental views on their child’s best interests (Pierik, 2020). This may be true for some childhood vaccines, but during the COVID-19 pandemic, I would argue that there was (is) a risk of imminent harm globally. Some views of the determination of a child’s best interests perceive the accuracy or ‘truthfulness’ of a parent’s beliefs as non-obligatory – just that their determination is reliant on their beliefs (Dawson, 2005). This conception supports parental views based on religious or cultural beliefs but does not say anything about the amount of weight we ought to give these beliefs. Further exploration of what ‘counts’ as religion may provide interesting and helpful insights to deepen understandings of how they (ought to) influence a child’s best interests.

Potential reasons for the dissonance between the empirical and non-empirical perspectives on how to approach situations where parents are perceived as not acting in the best interests of the child may stem from power and authority differences. While those who theorize about the standard, including ethics theorists and bioethics teams in healthcare settings, may have *ethical* authority to provide normative guidance, HCPs may feel they have *epistemic* authority due to their experience and expertise with children. Epistemic authority here refers to the credibility HCPs hold simply by being an HCP – the 'doctor knows best' view (Popowicz, 2021). Those who theorize about best interests may focus on creating fair and consistent approaches for children, which may lean farther on the side of caution to follow the legal statutes designed to 'protect' children from potentially harmful decisions. One may find it difficult to refute an ethical theorist's stance as they are perceived to have superior ethical insights. However, for HCPs, decisions are more complex and personal, involving consideration of the psychological impact on themselves, the child, and the family. Involving the state may not be as 'straightforward' as normative guidance makes it out to be, especially if the HCP has developed a relationship with the child and family. While HCPs are vested in these cases, theorists do not have much stake in these matters. This dichotomy highlights the need for further exploration into how these perspectives can and ought to be integrated to form a more balanced approach to determining children's best interests.

Parental views are important in discussions regarding childhood COVID-19 vaccination and help HCPs gain insight into the values of the family but perhaps ought not to be dispositive of one's approach to parental vaccine hesitancy. They can be important in guiding HCPs' recommendations and discussions with the family to foster trusting relationships within the triad. While some of my findings suggest that we ought not and *cannot* rely on a subjective determination of the best interests of the child for vaccine decision-making, my findings suggest that this may pigeonhole best interests and further exacerbate parental mistrust in vaccinations. Approaching the best interests of the child by *considering* a child's greater interests, parents included, may assuage parental fears that vaccination is not in the interests of their child. By considering greater interests, the intention is not to place higher merit on these interests, but rather to place some ethical weight (rather than none) on parental values as they are presumed to hold importance in a child's life. This ought not to be performative to assure parents that their views are being 'heard', nor should this only be practiced when parents agree with the HCPs' determination of the best interests of the child.

4.4 The child's perspective in best interests?

Lacking from my findings was a rich[11] discussion on the role of the child in determining their best interests. Opportunities to include this discussion may have been limited by the search terms and inclusion criteria, as I was searching for the views of HCPs rather than children. It is worth noting that while HCPs' views frequently addressed the parents' perspectives, their accounts did not explicitly report their consideration of the views of the child in empirical research. The significant number of publications pertaining to the best interests of premature infants may reflect the challenges encountered by neonatologists in eliciting and considering the views of infants. This raises the question; how can HCPs elicit the views of infants and give them due weight in their best interests determinations? One publication stipulated that the best interests of an infant involved consideration of the quality and value of their life, restoring their health, and preventing them from experiencing physical or psychological harm; however, the infant's 'voice' was not enough to determine the optimal treatment and further consideration of the emotional and psychological consequences to the family (Sieg et al., 2019).

Many scholars and clinicians have argued for increased recognition of children's agency and their ability to share their views, or 'voices', on health matters that concern them (Esser, 2016). Franco Carnevale developed Childhood Ethics theory which purported that all children are 'agents', regardless of age or legal capacity (Carnevale et al., 2021). Carnevale stated that rather than viewing children as incapable or incompetent, they ought to be viewed as agents who have stakes involved and who wish to participate in their healthcare decisions. Therefore, viewing children as agents is integral to understanding their best interests (Carnevale, 2021). According to Childhood Ethics, when HCPs and theorists do not anchor their practice or philosophizing in agency, this risks relying on a binary of self-determination versus incapacity (Carnevale et al., 2021). This poses a barrier to 'listening to' the child's

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[11] By 'rich' I mean that there was mention of some HCPs eliciting and attending to the child's voice in the reviewed publications, but a richer discussion would involve consideration of how their voice ought to be weighed in best interests determinations, how normative theories discuss how we ought to engage with the child's voice, etc.

voice, as the legal determination of capable or incapable dictates whether the child's values and beliefs ought to be 'listened to'. While one may believe that we cannot elicit the views of infants as they cannot speak vocally, some scholars and clinicians believe that "listening to children's voices" takes on many different forms, and we can infer something about the child's best interests even through silences, non-expressions, and difficult-to-understand expressions (Carnevale, 2020; Facca et al., 2020; Spyrou, 2016). This conception of children's 'voices' is a metaphor for their views. Children's 'moral experiences' are the experiences that encompass "a person's sense that values (they) deem important are being realized or thwarted in everyday life" (Carnevale, 2021; Hunt & Carnevale, 2011, p. 659). Recognizing children's voices as morally meaningful expressions of agency can and should impose ethical weight in discerning what is 'best' for them. This implies that HCPs ought to listen to their child patients' voices, even when they are not decisionally capable, in order to be attuned to their moral experiences regarding vaccination and make an informed judgement of their best interests.

Childhood Ethics theory may have important implications for the 'objective' view of best interests that proposes that 'subjective' determinations of best interests cannot be made for incapable children. Dawson states: "[W]e have no insight into the relevant party's beliefs as they do not have any that are sophisticated enough to count" (Dawson, 2005, p. 80). Dawson does not clarify what constitutes a belief that is 'sophisticated enough, but the underlying logic seems to invalidate a child's input in their best interests as soon as they are deemed incapable. This contrasts with Carnevale's (2021) position that children are agents who can and do express their agency even without decisional capacity. The 'objective' perspective seems to limit the inclusion of children's voices in best interests by requiring a certain level of sophistication in their beliefs, which would exclude many children from the decision-making process (especially young children who are the target population for many childhood vaccines). In contrast, there is ample evidence that even young children have views (Hogan & Greene, 2005) and moral experiences, regardless of their capacity. This perspective suggests that their voices ought to be elicited, and healthcare decisions in the best interests of the child should integrate children's voices more comprehensively, recognizing their agential expressions and the ethical significance of their moral experiences. This shift could lead to more nuanced and ethically optimal assessments of the child's best interests, particularly in complex and contentious areas such as childhood vaccination.

4.5 Ethical implications of vaccination: beyond individual benefits

To highlight another complexity of the best interests of the child for vaccination, this prophylactic intervention holds dual benefits for the individual child and the community which adds interesting but complicated aspects to determining a child's best interests. The strongest argument for vaccination is not for the individual child but for the health of the public. The public health aspect of vaccination is a key consideration that distinguishes all literature on best interests and healthcare generally with best interests and vaccination. Vaccination may have weaker arguments for the best interests of the individual child. However, they may nonetheless be justifiable given that such interventions benefit others as well. Vaccinations provide a critical public health benefit by protecting others, including those who cannot be vaccinated[12].

Weighing the benefits and burdens of vaccination in the best interests of a child can therefore be complicated. In the context of vaccination, the benefits to the individual child may appear weaker compared to the benefits for the community. For instance, benefits may include the individual child's protection from the disease, which can have severe health consequences including hospitalization, long-term complications, or death. Indirect benefits include contributing to the collective benefit or protecting others who cannot receive the vaccine. This aspect may be considered a benefit to the child if it includes their broader interests such as protecting vulnerable members of their community but raises questions about how to determine the benefits relevant to a 'best interests' argument. A layer of complexity is added when best interests are considered in health interventions that have a dual purpose for the individual and the broader community. Weighing burdens is also complex. Burdens of vaccination vary across types of vaccination but generally include potential pain from the needle, bruising, fever, and allergic reactions. Burdens may also include the likelihood and severity of contracting the disease against which the vaccine protects. Clearly, there are aspects to determining whether vaccination is in the best interests of an individual child that are not found in other medical treatments, such as the benefits to

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[12] While this may raise questions about the moral justifications for coercive vaccine policies and possibilities of other less coercive measures, this is beyond the scope of this thesis.

public health, which further complicates how best interests are conceptualized and understood.

4.6 Implications for policy and practice

Given my findings from both empirical and non-empirical engagement with the scholarship on the best interests standard, there is room to engage with some of the philosophical claims absent from practice (or at least empirical studies related to practice). The non-empirical publications reviewed in this study emphasized the ethical duty that HCPs have to uphold the best interests of the child, and when parents make contradicting decisions, HCPs are justified in deferring to the state to legally compel parents to, for instance, vaccinate their children. This seems to clarify to HCPs that they may be ethically justified in overriding a parent's decision that they do not believe upholds the best interests of the child but raises questions around exactly what 'best interests' refer to and who gets to decide. In my findings, some HCPs reported being 'medically objective' in their best interests determinations, but as articulated previously, medical objectivity is inherently subjective. HCPs may be basing their determinations on medical evidence, but the weight of this evidence is set against the temporal, cultural, social, economic, and political context of the choices.

Additionally, the notion that HCPs may activate state intervention for parental decisions that contradict their opinion of the child's best interests seems to place more power on HCPs than parents in the decision-making process. Ultimately, it might seem that while the 'objective' approach helps prevent parents from making decisions in accordance with their own wishes, it gives HCPs the power to do exactly that. My findings from empirical publications revealed that HCPs may have attitudes, influenced by their experience and expertise, that bias them when determining what is in the best interests of a child. Therefore, this raises questions about the ethical implications of this approach that places decision-making power in the hands of HCPs, as some were shown to hold biases against, for example, resuscitation of extremely premature infants.

Given my findings and reflections, I suggest greater consideration of the policies and practices of HCPs that guide best interests decision-making is required. Policies and practices should reflect the broader understanding of the best interests of an individual child, including specific contexts and ethical considerations that make each patient a unique case. While the best interests of the child ought to be met in medical decision-making, policies must strive to clarify what that means and how it can be operationalized in practice.

4.7 Implications for theory

A key finding from this investigation was the lack of agreement in empirical publications on how the role of the parents was navigated. Conversely, non-empirical publications seemed to have clear and consistent answers – if parents cannot agree with HCPs on the best interests of the child, HCPs ought to override their decisions. I did not find this surprising, as theorists are unlikely to consider practical implications surrounding communication and relationship-building between HCPs and parents. Given the frequency with which these issues were raised in the empirical literature, this raises important questions for theorists to grapple with. While providing answers that will satisfy both HCPs and parents in all cases is unlikely, theorists ought to consider what approaches are satisfactory to ameliorate tensions between these stakeholders. This may also be important for theorists to take up, as the time and resources to do so in practice are limited.

Furthermore, given the many subjective aspects identified in the literature in relation to determining a child's best interests, theorists may investigate whether the standard is achieving its intended goals. If not, there is good cause to either discard best interests or clarify and codify it. Additionally, exploring alternative approaches and considering their potential to achieve the goals of best interests may be helpful.

4.8 Conclusions

In conclusion, this chapter presented a refined discussion of the findings in light of my interpretations. Problems with the 'objective' approach, the weight of parental autonomy, the child's perspective, and the greater benefits of vaccination were discussed in this chapter. This chapter concluded with a consideration of the implications for policy, practice, and theory that arose from this investigation. The next chapter will present future directions for research, a discussion of the limitations of this research, and the provision of answers to the research question.

Chapter 5

5 Conclusion

This concluding chapter offers potential future research directions in light of the findings and discussion in Chapter 3 and Chapter 4. This chapter concludes with a discussion of the limitations of this research and the provision of answers to the research question.

5.1 Future research directions

At the outset of this investigation, it was clear that the best interests of the child lacked conceptual clarity. Given my positionality and prior knowledge, I was aware that even those who study pediatric ethics found the conception and use of the standard complicated. While I set out to further clarify how best interests are defined and applied, I was nonetheless surprised by how contested the standard was within the healthcare field. There is a consensus that the best interests standard is important; however, how the standard takes into account the views of the HCPs, the views of the parents, the views of the child, the medical, familial, and contextual factors, the division of decision-making authority, and the relevant ethical dimensions arose as an important takeaway of this investigation, expanded on below.

Firstly, my findings indicated the widespread variance in determining best interests based on weighing the harms and benefits to the child ‘objectively’ vs. ‘subjectively’. The former was found to rely on medical factors such as prognosis or likelihood of contracting a disease, whereas the latter considered parental and familial factors such as religion or finances. As most current research takes an ‘either-or’ approach despite all of these factors arising as important considerations of a child’s best interests, future research could seek to clarify how to reconcile these varying opinions.

Secondly, many ethical dimensions arose in my findings as relevant considerations to the best interests standard such as beneficence, non-maleficence, herd immunity, harm, and various models to determine the ethical permissibility of overriding a parent’s decision. These dimensions seem to be important to considering what is in a child’s best interests and interpreting them collectively presents a complex challenge. Difficulties lie in reconciling these considerations that seem like they should align, as expressed in the non-empirical literature (i.e., the decision that promotes beneficence, non-maleficence, justice, and respect for autonomy the most is in the best interests of the child), but in practice were shown to create ethical tensions and cause HCPs to experience moral distress, making it challenging to adopt a definitive position. In empirical publications, HCPs were responsible for applying ethical principles, norms, and models while navigating multiple contextual factors and constraints. HCPs were found to be personally invested in these cases, presumably because they were guided by their own interests. This suggests that, since HCPs have more ‘skin in the game’, further theorizing is required to consider HCPs’ own consequences and the best interests of the child in these applied settings.

Thirdly, my findings indicated that HCPs, parents, the child, the family, and the state had differing and sometimes conflicting perspectives and decision-making roles. Additionally, I found that the division of decision-making power was not expressed the same for each stakeholder in all publications. For instance, the reviewed literature frequently described tensions between HCPs and parents but was divided on who made the final decision. Generally, empirical publications discussed that HCPs would acquiesce to the parents’ best interests determination more than non-empirical publications, and non-empirical publications discussed ethical justifications for HCPs to override parental decisions more than empirical publications. In my interpretation of both literatures, the former places the final say in the hands of the parents, and the latter allows the HCP to make the final decision, or rather, transfers this power to the state. This divide raises further questions on how to address the teetering division of power between these two important stakeholders, as well as if there are any other stakeholders for which decision-making power concerns did not arise, but might still merit consideration (i.e., the child and the family). Future research into the navigation of these stakeholders’ divisions of decision-making power could be pursued for further clarity on who decides what is in a child’s best interest.

Interestingly, my findings did not reveal any reviewed studies that discussed parents as the sole decision-makers of the child’s best interests, without considering the acceptance of their opinions by HCPs (Heide et al., 1998). While this perspective did not arise in the literature, it may not be indicative that this never happens in practice. Making decisions in the best interests of the child may be mainly explored in scholarly literature when HCPs feel that parents are making poor choices for their child, and vice versa. For instance, we may not be interested in researching the best interests of the child when parents seek out vaccination for their child or agree to routine and COVID-19 vaccination for their child, as this is an accepted public health measure (by HCPs and theorists). In my view, the best interests standard is only actively considered when parents are hesitant or refusing a recommended treatment to mediate discussions and, if necessary, invoke state intervention. This is problematic, as treatments that have become accepted as ‘gold standards’ may not be suitable for each individual child. Furthermore, instances where HCPs and parents agree, presumably when their interpretations of the child’s best interests align, provide an interesting setting for further investigation into the relevant conceptions, ethical dimensions, factors, perspectives, and decision-makers that lead to agreement.

Finally, many factors arose as relevant to the best interests of the child, such as prognosis, age, HCP specialty, culture, religion, etc. My findings indicated that these factors were important, but could also be controversial (i.e., setting an age limit for resuscitation (Janvier et al., 2008)). My interpretations suggested that these factors often underpin one’s determination of best interests and can be decisive for some HCPs (e.g., what they would choose for their own child). Additionally, the factors chosen to underpin the determination are subjective to one’s individual context and circumstance. This highlights how what is ‘best’ is in the eye of the beholder. Balancing these factors depends on the individual – whether it be the HCP, the parent, the child, etc. – emphasizing the need for more research to make these determinations justly, while also catering to the unique circumstances of each child.

These complexities intimate a greater normative question: how ought HCPs consider the role of the parents and the best interests of the child for pediatric COVID-19 vaccination (and other healthcare interventions)? The tension between the best interests standard and parental autonomy is especially prominent in prophylactic treatment measures such as vaccine decision-making that has dual benefits to the child and the public. Given this tension, there seems to be strong reasoning to elucidate and untangle the aforementioned complexities through further consideration of what is required from HCPs, parents, and children.

The lack of empirical studies regarding vaccination and the best interests of the child represents a significant silence in the existing scholarship – an area where research is conspicuously absent. This gap suggests there are underlying reasons for the dearth of publications on this topic. Based on my experiences with recruitment of HCPs for an interview-based study, one possible explanation is the reluctance of HCPs to discuss vaccination, given its increasingly polarizing nature. This can pose barriers to gathering data and perspectives to understand this phenomenon more deeply. This silence may be an important finding in and of itself, as it speaks to the necessity of this discourse surrounding childhood vaccination. Additionally, understanding these barriers is crucial for future research on other healthcare topics that involve discussions around deeply held beliefs, ethical considerations, and varying opinions among stakeholders. For instance, trans and gender non-conforming children are a particularly vulnerable group for which conflict among parents and HCPs can cause disputes over best interests (Houston, 2020). Recognizing and addressing these tensions through further research can help inform policy and practice regarding children's best interests.

Curiously, many empirical studies included in this review utilized surveys and questionnaires without subsequent participant interviews. This methodology raises concerns for investigating a complex ethical standard such as the best interests of the child. Surveys and questionnaires, often constrained by limited answer options, check boxes, or short answers, may not provide participants with sufficient room to deeply explore and articulate the nuanced ways in which they consider and apply the standard. Such instruments may fail to capture the rich, contextual insights and the depth of reasoning that participants use in their clinical decision-making. As a result, relying solely on these methods may risk oversimplifying participants' perspectives and may lead to an incomplete or distorted understanding of how the best interests standard is interpreted and implemented in practice.

5.2 Limitations

This review has some limitations that must be considered. First, the scope of this thesis was not broad enough to present a novel ethical argument about the best interests standard and pediatric COVID-19 vaccination; however, this may be an aim for future research. While my findings included ethical reasoning and justifications for certain approaches, an explanation of how these findings fit together to produce particular arguments for how we ought to consider the role of the parents in the best interests of the child was beyond the scope of this investigation. The ethical complexity and tensions that arise in pediatric vaccine decision-making were explored in a critical, interpretive fashion to produce hypotheses and speculation, rather than definitive explanations. A richer understanding of potential explanations will be important to this field and should be investigated in the future. Second, this review was limited by the existing empirical literature on vaccination and best interests. While broader healthcare contexts provided some insights into how the best interests standard is conceptualized and applied in general, further research may be required to make direct connections to pediatric COVID-19 vaccination. Third, most of the included literature was conducted in high-income countries, predominantly the United States, Canada, and Australia. Ethical values, and thus reasoning, conceptualization, and application of ethical standards vary in low-income settings where politics and culture factor in differently. Poor access to healthcare and low education rates may also affect how the best interests standard is considered and applied. Additionally, this review may have been limited due to the ambiguity of the concepts under investigation. The lack of clarity of how 'best interests' are conceptualized (as a guiding principle? A legal threshold? Inclusionary or exclusionary of the child's social and familial interests?) reflects the body of literature in this field, which, for the most part, avoids deeply conceptualizing the very standard they sought to investigate. To effectively consider greater normative questions, we ought to clarify exactly what we mean by the best interests standard.

5.3 Conclusion

In summary, this study aimed to deepen understandings of the best interests standard through a critical interpretive review of the empirical and non-empirical literature on best interests and children's healthcare decisions. This study demonstrated that engaging with both types of literature regarding the understandings of best interests and children's healthcare decisions provides considerable insights into the ways in which best interests is interpreted and used by theorists and HCPs.

This study's research question was "How are best interests for children's health decisions understood by HCPs in empirical studies and how ought best interests be understood by HCPs in non-empirical articles?" As my investigation was concerned with how best interests is understood, while a common definition cannot be synthesized, I will point out widespread areas of agreement and disagreement.

Since most studies advocated that decisions should be made in the best interests of the child, and a small minority were dissatisfied with the norm and wished to eliminate it, my assessment suggests that further exploration and use of the standard is worthwhile. I expected more authors to set aside the best interests standard due to its vagueness and other criticisms. The prevailing support for the use of the best interests standard seems to indicate its value in guiding ethical medical decisions for children.

Furthermore, a majority of the studies discussed the role of the child's parents alongside best interests. From my perspective, this universal agreement regarding parental involvement signaled that parents are important to a child's best interests; however, the reviewed publications were split on how parental views were and should be considered and navigated by HCPs. In my interpretation, the reviewed literature put forward four scenarios of parental involvement: parents made the final decision (often when given deference by the HCP), HCPs made the final decision, a mélange of the two where decisions aimed to be 'shared' and room for nuanced discussion was present, or the decision was made by the state.

In situations when parents made the final decision, HCPs were shown to accede to parental determinations of the best interests of the child, even when this went against their determination. Poor parental behaviour or staunch disagreement between the HCP and the parents were often at the root of these cases. My findings suggested that HCPs forfeited their say in the child's best interests to avoid their own distress when dealing with 'difficult' parents who opposed their views. This is not to say that all parents who make decisions on their perception of the best interests of the child are in conflict with the HCP, but I presume those instances are more explored in the scholarship regarding children's best interests than those where, for example, an HCP and parent agree that the child should be vaccinated in their best interests. On a separate note, in other cases where parents had the 'final say', HCPs were uncertain about future long-term implications of the decision (e.g., resuscitation of an extremely premature infant) and thus deferred to the parents' wishes. Based on these findings, I perceived that HCPs were not necessarily forfeiting their decision-making power, and rather considering the parents' wishes for the future of their family in their own determination of the child's best interests.

When HCPs made the final decision, I interpreted that they based their decisions on empirical evidence, as well as their experience and expertise. My findings suggest that medical paternalism was employed to convince parents of their determination of the child’s best interests or exclude parents from the decision-making process entirely.

When HCPs and parents shared the final decision, I interpreted that both parties aimed to agree on one understanding of the best interests of the child. Some non-empirical publications forwarded decision-making frameworks to emphasize that HCPs and parents ought to be considered as ‘epistemic equals’ with similar weight given to each person’s views. In my interpretation, HCPs did not seem to uptake this framework in practice and instead approached shared decision-making by attempting to compromise or negotiate treatment decisions with parents. The latter case seems to depict another version of when HCPs have final decision-making power: HCPs engaged in discussions to attempt to reach a mutual understanding with the parents; if the parents did not concede or if an impasse was reached, they were found to defer to the parent’s wishes, enact medical paternalism, or enact state intervention.

Much of the non-empirical literature and some empirical studies discussed state intervention to override a parent’s decision that contradicted the HCP’s determination of the child’s best interests. In my interpretation, this fourth decision-making scenario in which the state decided raised interesting questions. For instance, how to approach the complexity and rarity of the practical application of HCPs enacting state intervention for cases on the margins, such as parental refusal of childhood vaccination. These cases have important implications for children’s best interests, and ought to be taken up by theorists in more practical ways.

So, how do or should HCPs involve parents in children’s medical decisions? Based on my findings, it is a guise of the four approaches explored above. When HCPs and parents are torn on their interpretations of the child’s best interests, it was found that HCPs overrode parents’ decisions, deferred to parents’ decisions, ‘shared’ decisions, or employed state intervention. Questions remain about the ‘best’ way to involve parents. Some empirical publications seemed to answer this question by balancing both the parents’ and HCPs’ relative expertise without privileging either party’s views. However, there is still room to theoretically advance these ideas for applied settings.

The ‘objective’ approach raises further opportunities for consideration. If ‘best interests’ relies on factors that are supposedly ‘objective’, perhaps the parents ought to be excluded. Perhaps even HCPs ought to be excluded, and it ought to be determined by some ‘neutral’ party such as an ethics committee, or even artificial intelligence. Still, one will run into problems as the evidence and consequences considered will always be subject to judgment on the decision-maker’s part. It is possible to present factors and consequences objectively, such as the child’s prognosis and the family’s risks for rearing a child with a severe disability, but this does not explain how these factors ought to be weighed ‘objectively’. The distinction between the ‘objective’ and ‘subjective’ approaches seems less helpful in understanding best interests and may require one to accept a consequentialist ethic which ignores other important ethical considerations such as the duties of HCPs and parents to the child.

In conclusion, this thesis demonstrated the myriad practical and theoretical perspectives important to understanding children’s best interests. The ‘best’ way to do so is to acknowledge these as implicit and explicit factors at play in children’s healthcare decision-making and avoid taking for granted some approaches that have become reified. Given these contributions, the hope is to advance ethical healthcare decision-making for children, bringing theorists and HCPs one step closer to achieving this goal.

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Appendix A: Reviewed articles

#	Reference	Country	Objective	Study design	Participants	Context	Codes
1	Abdin et al. 2022	United Kingdom	To explore factors that influence professionals in deciding whether to withdraw treatment from a child and how decision making is managed.	Semi-structured interviews	15 Health professionals	Treatment withdrawal for children with life-limiting illnesses	Parental role of determining BIS/working with parents; State intervention; Relationship building/trust; Child's voice/assent; Other: Competence, severity, parental denial, negotiation, Charlie Gard, Tafida Raqeeb, culture
2	Albersheim et al. 2010	Canada	To assess the attitudes of Canadian neonatologists towards the authority of parents to make life-and-death decisions for their babies.	Semi-structured interviews; Standardized scenarios/ Vignettes; Survey	164 Neonatologists	Life-and-death decisions for sick neonates	Definition of BIS; Parental role of determining BIS/working with parents; Other: Uncertainty, harm principle, survival, personhood
3	Armstrong et al. 2011	Ireland	To determine whether healthcare providers apply the best interest principle equally to different resuscitation decisions.	Survey	148 Consultants, trainees in neonatology, paediatrics, obstetrics and 4th medical students.	Resuscitation of critically ill patients	Definition of BIS; Other: Age, your own child, medical student vs physician, prognosis, QoL, disability
4	Bahus and Førde 2011	Norway	To understand whether the attitudes of Norwegian doctors regarding surrogate decision power in end-of-life care conform to legal rules.	Survey	640 Doctors: internal medicine, paediatrics, surgery, neurology, and neurosurgery	End-of-life care for critically ill children	Parental role of determining BIS/working with parents; UNCRC; Bioethical principles; Other: Criticism of BIS, futility, BIS not upheld, time
5	Belcher 2013	United States	To understand the perceptions and lived experiences related to futile care and moral distress of nurses who provide care to extremely immature newborns.	Semi-structured interviews	10 NICU Nurses	End-of-life care for critically ill children	Parental role of determining BIS/working with parents; UNCRC; Bioethical principles; Other: Criticism of BIS, futility, BIS not upheld, time

6	Birchley et al. 2017	United Kingdom	To explore how the best interests standard operates in practice, particularly with decisions related to planned non-treatment.	Semi-structured interviews	39 parents, doctors, nurses and members of clinical ethics committees	Non-treatment decisions	Definition of BIS; Parental role of determining BIS/working with parents; State intervention; UNCRC; Other: Passing time, paternalism, parental autonomy, prognosis
7	Cavolo et al. 2021	International Other: USA, Canada, Australia, UK, Switzerland, Poland, Italy	To present (1) the ethical concepts related to the debate on resuscitation of extremely premature infants (EPIs) as they are described in the ethical literature; and (2) the ethical arguments based on these concepts.	Systematic review	N/A; ethical literature	Resuscitation of extremely premature infants	Definition of BIS; Parental role of determining BIS/working with parents; Bioethical principles; Other: BIS framework, suffering, uncertainty, values, negotiation, expertise, prognosis
8	Clark et al. 2020	Canada	To explore ethical and clinical decision-making processes of health-care providers, as well as the health care experiences of trans youth with family discordance.	Semi-structured interviews	15 health-care providers and trans youth	Hormone therapy for transgender youth	Parental role of determining BIS/working with parents; Relationship building/trust; Bioethical principles; Other: Time, lack of clarity on the law/standard, harm principle, not unreasonable standard, BIS framework
9	Curley et al. 2007	United States	To describe whether pediatric clinical staff members believe that a donation after cardiac death (DCD) program could be consistent with the mission and core values of a children's hospital.	Focus groups	88 intensivists, anesthesiologists, surgeons, nurses, respiratory therapists, and hospital clergy	Donation after cardiac death	Parental role of determining BIS/working with parents; Other: BIS of dying children vs. dead children, altruism
10	Deligianni et al. 2023	Greece	To study moral distress in neonatologists in the context of caring for extremely premature infants (EPIs)	Semi-structured interviews	20 neonatologists	Moral distress	Definition of BIS; Parental role of determining BIS/working with parents; Moral distress; Bioethical principles; Other: Uncertainty, QoL, paternalism, shared decision-making, survival rate, uncertainty

11	Forbat et al. 2015	United Kingdom	To explore clinician and family experiences of conflict in paediatric services, in order to map the trajectory of conflict escalation.	Standardized scenarios/vignettes with interviews	46 health professionals and parents	Conflict between clinicians and families	State intervention; Relationship building/trust; Other: Uncertainty, financial interests of family, specialty, withholding treatment
12	Hagen et al. 2012	Norway	To study attitudes regarding life-saving interventions	Survey	266 members of the Norwegian Pediatric Association	Life-saving interventions	Parental role of determining BIS/working with parents; Other: Age, better to do something than do nothing and let patient die, BIS in conflict with parental autonomy, BIS not upheld, QoL, prognosis, disability
13	Hansen et al. 2013	Norway	To study the attitudes of Norwegian physicians to resuscitation of hypothetical patients all at risk of neurological sequelae.	Survey	1069 physicians	Resuscitation	Bioethical principles; Other: Age, what we want for our own children, personhood, QoL, disability
14	Janvier et al. 2008	Canada	Legal and ethical standards require resuscitation when it is considered to be in the patient's best interest. We hypothesized that newborn infants might be dealt with according to different standards, compared with older patients.	Survey	524 physicians, university students in different disciplines, including law, anthropology, bioethics, and medicine	Resuscitation in newborns	Parental role of determining BIS/working with parents; Harms vs. benefits; Other: Age, vaccination, survival rate, values, ethics, what you would do for your child
15	Jivraj et al. 2016	United Kingdom	To seek local perinatal professionals' views of elective ventilation and referral for organ donation	Survey	49 Perinatal healthcare professionals	Elective ventilation and referral for organ donation	Parental role of determining BIS/working with parents; Other: Harm principle, family interest, organ donation

16	Kvamme and Voldner 2022	Norway	To describe how public health nurses (PHNs) experienced challenges and dilemmas in ensuring the best interests of the undocumented migrant child	Semi-structured interviews; Focus groups	7 public health nurses	General healthcare decisions	State intervention; Moral distress; Other: BIS in conflict with regulations, immigrants, social
17	Laventhal et al. 2017	Argentina, Australia, Canada, Ireland, The Netherlands, Norway and the United States	To study many countries willingness to forego intensive care (and accept comfort care) at the surrogate's request.	Survey	2237 physicians	Resuscitation	Parental role of determining BIS/working with parents; Bioethical principles; Other: Age, prognosis, country, disability, personhood, recommendations
18	Mack et al. 2024	Canada	To collate the available evidence on decision-making for tracheostomy/LTV in children	Scoping review	N/A	Tracheostomy/long-term ventilation (LTV)	Parental role of determining BIS/working with parents; Relationship building/trust; Moral distress; Harms vs. benefits; Other: Time, QoL, suffering, life expectancy, age, religion, culture, family wishes, proportionality (balancing benefits vs. harms)
19	Marcello et al. 2011	Canada and United States	To determine whether parental characteristics affect estimates of best interests and intervention decisions for preterm infants.	Survey	820 nurses, physicians, and students.	Resuscitation	Parental role of determining BIS/working with parents; State intervention; Harms vs. benefits; Other: Family characteristics, family interests, age, uncertainty, BIS vs. parental autonomy, BIS not upheld
20	McDougall et al. 2014	International	To review the ethical literature on conflicts between health professionals and parents about medical decision-making for children.	Systematic review	N/A	Medical decisions overridden by HCPs	Parental role of determining BIS/working with parents; State intervention; Harms vs. benefits; Other: Overriding parental decisions, harm principle, BIS frameworks, BIS alternatives

21	Mills et al. 2015	Australia	To investigate how Australian neonatologists made decisions when incompetent patients of different ages needed resuscitation	Survey	109 consultant neonatologists working in Australian neonatal tertiary centres	Resuscitation	Parental role of determining BIS/working with parents; Other: Age, prognosis, QoL, hospital policy, disability, personhood
22	Morrison et al. 2015	United States	To understand the relative importance of nine pediatric end-of-life decision-making priorities	Survey	364 nurses, attending physicians, and fellow physicians	End-of-life decisions	Parental role of determining BIS/working with parents; Moral distress; Harms vs. benefits; Other: Family interests, religion, resources, suffering, time
23	O'Haire and Blackford 2004	Australia	To investigate the issues for nurses in facilitating parental participation in the care of the hospitalized child	Semi-structured interviews; focus groups	9 nurses	Hospital treatment decisions	Parental role of determining BIS/working with parents; Moral distress; Other: Professional duties, conflict, knowledge, moral agency, family wishes, parent behaviour
24	Othman 2019	Malaysia	To explore doctors' treatment decisions made without parental consent when managing adolescents presenting with sexual and reproductive health issues.	Semi-structured interviews	25 doctors	Sexual and reproductive health issues	Parental role of determining BIS/working with parents; UNCRC; Other: BIS as a social consideration, welfare, what HCPs want for their own children
25	Placencia et al. 2016	United States	To determine how neonatologists and bioethicists conceptualize and apply the Best Interests Standard (BIS)	Survey	666 neonatologists and 242 ethicists	Life-sustaining therapy (LST)	Parental role of determining BIS/working with parents; Other: Specialization differences, Neonatologists vs. ethicists, knowledge, family interests, futility, involving other HCPs, policy

26	Popejoy et al. 2022	United Kingdom	To explore the communication strategies used in shared decision-making for children with life-limiting conditions.	Semi-structured interviews; Observation	23 children, parents, extended family and professionals	Tube-feeding	Parental role of determining BIS/working with parents; Relationship building/trust; Other: Time, persuasion, knowledge, professional
27	Quaye et al. 2021	Sweden	To describe ways in which children's best interests were observed to be expressed in paediatric settings during their hospital visit	Observation	32 children aged 2-17 years, with different diagnoses and hospital admissions and their parents	Hospital treatment	UNCRC; Child's voice/assent; Other: Child-focused information, restraint, fear, suggestions for practice, communication
28	Rasmussen et al. 2016	Canada	To explore physician perspectives about neurological prognosis in neonatal hypoxic ischemic encephalopathy	Semi-structured interviews	12 neonatologists and pediatric neurologists	Prognostication	Parental role of determining BIS/working with parents; Other: Prognostication, QoL, disability, parental values
29	Richards et al. 2018	United States	To understand how neonatal and pediatric critical care physicians balance and integrate the interests of the child and family in decisions about life-sustaining treatment	Semi-structured interviews	22 physicians from neonatal, pediatric, and cardiothoracic intensive care	Life-sustaining treatment	Parental role of determining BIS/working with parents; Relationship building/trust; Other: Family interests, QoL, life expectancy, time, limiting options, uncertainty, suffering,
30	Roen and Hegarty 2018	Scotland, England, and Sweden	To examine how health professionals frame hypospadias and hypospadias surgery in medical and non-medical ways	Interviews	32 Health professionals specializing in diverse sex development	Hypospadias surgery	Parental role of determining BIS/working with parents; Other: Knowledge, medical paternalism, happiness, personhood

31	Samaan et al. 2008	Ireland	To explore the clinical staff attitudes towards ethical decision making in neonatal intensive care units (NICUs) in Ireland and Europe	Survey	64 doctors and 228 nurses	Ethical decision-making for extremely preterm infants	Definition of BIS; Parental role of determining BIS/working with parents; Other: Limiting interventions, withholding, parental interests, disability
32	Sarnaik et al. 2013	United States	To explore the views of pediatric intensive care physicians on the ethics of pediatric donation after cardiac death	Survey	264 physicians	Pediatric donation after cardiac death	Parental role of determining BIS/working with parents; Other: Altruism, knowledge, ethics
33	Sauer et al. 2013	Belgium, France, Germany, Italy, Portugal, Sweden and the Netherlands	To compare attitudes towards end-of-life (EOL) decisions in newborn infants between seven European countries.	Focus groups	14 pediatricians and lawyers	End-of-life care	Parental role of determining BIS/working with parents; State intervention; Other: Disability, futility, suffering, withholding treatment
34	Sieg et al. 2019	International	To examine what neonatal palliative care entails, how parents perceive healthcare providers' actions, what they potentially need at the end of their infant's life.	Systematic review	N/A	Neonatal palliative care	Parental role of determining BIS/working with parents; Harms vs. benefits; Other: Hastening death, suffering, withholding treatment
35	Street et al. 2000	United Kingdom	To investigate the factors considered by staff, and the practicalities involved in the decision making process regarding the withdrawal or withholding of potential life-sustaining treatment	Survey	41 consultant staff, hospital and ward managers	Life-sustaining treatment	Parental role of determining BIS/working with parents; State intervention; UNCRC; Child's voice/assent; Other: Gillick case, prognosis, family wishes, suffering, QoL
36	Streuli et al. 2021	Switzerland and the United States	To revisit current theoretical debate on the interrelationship of the best interests standard and substitute decision-making.	Semi-structured interviews; Focus groups	47 children, parents and health care professionals	Paediatric decision-making	Definition of BIS; Other: Substitute decision making (SDM) as an alternative, limiting treatment options, BIS alternative, BIS framework, capacity, paternalism

37	Tan et al. 2008	United Kingdom	To determine the range of attitudes amongst psychiatrists towards competence to make treatment decisions and treatment refusal by patients with anorexia nervosa.	Survey	686 psychiatrists	Treatment refusal for anorexia nervosa	Other: Autonomy, capacity, mental illness, professionalism, protection, paternalism
38	Valdez-Martinez et al. 2014	International	To determine what constitutes best medico-legal practice for children under 19 years regarding cancer treatment.	Systematic review	N/A	Treatment decisions for children with cancer when cure is no longer possible	Parental role of determining BIS/working with parents; State intervention; Relationship building/trust; Bioethical principles; Other: moral deliberation
39	van der Heide et al. 1998	The Netherlands	To discuss the most recent decisions in newborn infants to hasten death or not prolong life.	Face-to-face interviews	31 neonatologists/ intensivists and 35 general pediatricians	End-of-life decisions	Parental role of determining BIS/working with parents; Moral distress; Bioethical principles; Other: parental autonomy vs. BI of child
40	Weiner et al. 2022	Sweden	To describe performed moral case deliberations and present a nationwide study of difficult situations and moral questions raised by healthcare professionals during moral case deliberations in Swedish childhood cancer care.	Qualitative systematic text condensation	16 Nurses, physicians, and social workers	Cancer care	Parental role of determining BIS/working with parents; Moral distress; Child's voice/assent; Bioethical principles; Other: Guidance for HCPs, BIS not upheld, uncertainty
41	Wiley et al. 2023	Australia	To explore and characterise the normative arguments made about parental refusal of routine vaccination, with the aim of providing researchers, practitioners, and policymakers with a synthesis of current normative literature.	Systematic review	N/A	Vaccine refusal	Parental role of determining BIS/working with parents; State intervention; Relationship building/trust; Harms vs. benefits; Other: Parental autonomy, herd immunity, religion, mandates, patient dismissal

42	Baxter 2012	United States	To analyze a case of an infant whose mother refused vaccination.	Ethical analysis	N/A	Childhood vaccination	Other: Dual benefits of vaccination, weighing benefits and harms, terminating therapeutic relationship, relationship-building
43	Bayefsky 2018	United States	To respond to earlier critiques of mandatory vaccination and offer a set of arguments in support of an HPV vaccine mandate.	Ethical analysis	N/A	HPV vaccination	State intervention, imminent and life-saving, public health
44	Bester 2017	United States	To examine an argument which may negatively influence measles vaccination uptake. According to the argument, an individual child in a highly vaccinated society may be better off by being non-vaccinated; the child does not risk vaccine adverse effects and is protected against measles through herd immunity.	Ethical analysis	N/A	Measles vaccination	Serious risk, disability, harms vs. benefits, religion and culture, herd immunity
45	Braley-Rattai 2021	Canada	To propose that parents lack a moral or legal right to an absolute refusal of vaccinations on behalf of their children	Legal analysis	N/A	COVID-19 vaccination	Herd immunity, the Charter, free-rider, autonomy, UNCRC, state intervention, parental role, religion
46	Chervenak et al. 2016	United States	To address the ethics of early childhood vaccination, including counseling parents, the physician’s public role, and implications for policy makers.	Ethical analysis	N/A	Childhood vaccination	Professional responsibility, state intervention, herd immunity, terminating therapeutic relationship, recommendations for HCPs

47	Dawson 2005	United States	To explore one particular argument that focuses on the idea that such vaccinations are justifiable because they are held to be in the best interests of a particular child.	Ethical analysis	N/A	Childhood vaccination	What is best interests, best interests criteria, parental role, paternalism
48	Diekema 2005	United States	To assist pediatricians in understanding the reasons parents may have for refusing to immunize their children and provide practical guidance to assist the pediatrician faced with a parent who is reluctant to allow immunization of his or her child.	Report	N/A	Childhood vaccination	Community interest and public health, parental role, herd immunity, terminating therapeutic relationship, recommendations for HCPs
49	Forster 2019	Australia and United States	To examine the ethical underpinnings of conscientious objection and whether the right to conscientious objection can be applied to the refusal to treat unvaccinated children.	Ethical analysis	N/A	Refusal to treat unvaccinated children	Parental role, terminating therapeutic relationship
50	Hester et al 2018	United States	To argue that the role of the harm principle is not to replace the BIS, but to supplement it, charged with one specific task: determining when parental refusal of a medical recommendation should be challenged through state action.	Ethical analysis	N/A	Childhood vaccination	Herd immunity, state intervention, parental role, religion
51	Hester and Salter 2022	United States	To provide a cohesive ethical framework—the “ reasonable interests framework” (or RIF)—that captures and integrates multiple standards of pediatric decision-making.	Case study	N/A	Pediatric decision-making	Parental autonomy, parental role

52	Hodges et al. 2002	United States	To argue that children should not be subjected to prophylactic interventions "in their best interests" or for public health reasons when there exist effective and conservative alternative interventions, such as behavioural modification, that individuals could employ as competent adolescents or adults to avoid adverse health outcomes.	Ethical analysis	N/A	Prophylactic mastectomy, immunisations, cosmetic ear surgery, and circumcision	Best interests criteria, public health, vulnerability
53	Lara Carrion and Bramstedt 2023	Greece and United States	To present four pediatric donation and transplant dilemmas for ethical exploration and offer guidance to clinical teams, noting that mandates are controversial, and there is no global harmonization regarding requirements.	Ethical analysis	N/A	Pediatric COVID-19 vaccination	Child voice, parental autonomy, transplant
54	Malm and Navin 2020	United Kingdom and United States	To provide an ethical analysis of some societies' decisions to neither recommend nor fund varicella vaccination for healthy children	Ethical analysis	N/A	Varicella vaccination	Parental role, terminating therapeutic relationship, pox parties, herd immunity
55	Nihlén Fahlquist 2023	Canada, United States, Europe	To argue that capable children should be encouraged to take moral responsibility not only concerning risks and benefits to themselves, but also for others.	Ethical analysis	N/A	COVID-19 vaccination	Public health, child voice, moral responsibility, capacity, parental autonomy, state intervention,
56	Pierik 2020	International	To argue that vaccination policies should be justified in terms of a proper weighing of the rights of children to be protected against vaccine-preventable diseases and the rights of parents to raise their children in ways that they see fit	Ethical analysis	N/A	Measles vaccination	Parental autonomy, parental role, state intervention

57	Rus & Groselj 2021	Slovenia	To apply a framework for ethical analysis of vaccination in childhood based on the four principles of biomedical ethics (respect for autonomy, nonmaleficence, beneficence and justice) to provide a comprehensive and applicable model on how to address the ethical aspects of vaccination at both individual and societal levels.	Ethical analysis	N/A	Childhood vaccination	Beneficence, dual benefit, parental role, public health, recommendations for HCPs
58	Suryadevara and Domachowske 2019	United States	To use a case study to apply the best interest standard and the harm principle, two approaches to surrogate decision-making for children, to vaccination.	Case study	N/A	Childhood vaccination	Paternalism, clinical factors, religion, terminating therapeutic relationship

Appendix B: Relevant frameworks for overriding parental decisions (McDougall & Notini, 2014)

Framework	Moral Concept	Summary Quote
Harm principle	Harm	“a health professional is ethically justified in seeking state intervention when the parents’ decision ‘significantly increase[s] the likelihood of serious harm as compared to other options’” (pg 450)
Constrained parental autonomy	A child’s basic needs	“families have group goals, distinct from the self-regarding goals and interests of each member, and that parents may ‘compromise the interests of the child [for the sake of a group goal or another family member’s interests], provided that they do not sacrifice the child’s basic needs’” (pg 450)
Best interests	Best interests	“According to Kopelman, parents’ failure to choose the treatment option that is in the child’s best interests is not the appropriate threshold for state intervention. Rather, the parents’ choice of a harmful or unreasonable option plays this role. Best interests are then used, in a separate second step, to guide the state’s decision about the appropriate treatment to require.” (pg 450)
Choice within the range of medically reasonable alternatives	Medical reasonableness	“‘the paediatrician and parents are co-fiduciaries of the child who is a patient’ and thus that the paediatrician has the obligation to present all of the ‘medically reasonable alternatives’ to parents. He defines medically reasonable alternatives as all the ‘technically possible and physically available clinical management plans that have a reliable evidence base of expected net clinical benefit’” (pg 451)
Responsible mode of thinking	Responsible mode of thinking	“parents’ medical decisions should be overridden ‘only if it can be shown that no responsible mode of thinking warrants such treatment of a child’. The implication is that a mode of thinking is sufficiently responsible ‘unless the parental decision would seem from most perspectives as shockingly reckless or negligent’” (pg 451)
Reasons that other reasonable people could refuse	Not unreasonableness	“They argue that there are different types of reasons, and identify a ‘domain of judgments that are idiosyncratic or shared only by some particular social or cultural group’. They call these ‘reasons that other reasonable people could refuse’. They argue that parental refusals of treatment based on such reasons ought to be overridden in cases when treatment is likely to bring significant benefit to the child. Their position is that ‘[o]nly

		decisions based on universal reasons are acceptable for surrogate refusal of highly beneficial treatment'" (pg 451)
Rational parent	Rational decision-making	"a rational parent standard would require that a parent demonstrate the ability to prioritize options for her child within the context of her own value system. The absence of a definable value system, and the absence of demonstrated and consistent decision-making ability, would bring the parent's capacity to make decisions for her child into question." (pg 451)
Balance of costs and benefits	Economic interests	"'the best interest of the patient be...overridden if marginal costs...are greater than marginal treatment benefits when the costs to third parties are considered'" (pg 451)
Decisional capacity of the minor	Decisional capacity	"when a child agrees with the parental refusal and there is 'grounded confidence that the child will still own the decision later on in life', this should be given 'great weight in medical decision-making'" (pg 451)

Curriculum Vitae

Micaela Forte

EDUCATION

Master of Science in Health and Rehabilitation Sciences **September 2022-August 2024**
Western University

- Supervised by Dr. Maxwell Smith and Dr. Jacob Shelley.

Honours Bachelor of Health Sciences **September 2018-June 2022**
Western University

- Dean's Honor List all four years, graduated with Distinction.
- Relevant Courses: Social Determinants of Health, Ethics and Policy Issues in Pandemic Response, Professional Ethics in Healthcare, Advanced Health Policy.

RESEARCH EXPERIENCE

Research Assistant **July 2021-Present**
Western University and the HELP Lab

- Under the principal investigator Dr. Jacob Shelley, coordinate weekly team meetings to assess progress, address roadblocks, and troubleshoot solutions to meet deadlines.
- Developed the inclusion and exclusion criteria for a systematic review pertaining to the best interests principle in pediatric decision-making relating to medical treatment.
- Screened 1300+ studies using Covidence according to the screening criteria and ensured review focused on pediatric treatment decisions in Canada.

Research Assistant **February 2022**
Western University

- Study titled "Listening to children in health care matters: Examining the intersection of family-centred care, best interests, and children's agency".
- Funded by a Western Strategic Support for CIHR Success Grant.
- Transcribed interviews while ensuring Western University HSREB protocols were followed during transcription to reduce risk and breach of privacy for participants.

Research Practicum Student **September 2021-May 2022**
Ornge and Western University

- Performed literature reviews and wrote concise reports on relevant studies pertaining to continuing medical education in the paramedicine field to strengthen a needs assessment study.
- Analyzed the submission guidelines for the Journal of Continuing Education in the Health Professions to ensure submission would meet all requirements of the journal.
- Created a model for the needs assessment paper, including titles, sections, subsections, and relevant submission guidelines.
- Researched Delphi Study and Modified Delphi Study methodology, including validity and reliability, and presented findings to the greater research team.
- Prepared a Delphi study outline to be submitted to the UWO Research Ethics Board.

Market Access Summer Intern **Summer 2019 & 2020**
Patient Access Solutions, Inc.

- Conducted landscape reviews for input into strategic reimbursement and pricing plans.
- Developed PowerPoint presentations on clients' drugs and presented to clients to inform their applications, one of which being a presentation on the impact of drug shortages on the healthcare system.

TEACHING EXPERIENCE

Graduate Teaching Assistant **September 2022-June 2024**

Western University

- Provided teaching assistance, evaluation, and academic support for undergraduate courses in healthcare law, public policy, and bioethics.
- Guest lectured on health misinformation for a class of 250+ students.

Teaching Assistant Training Program **September 2022**

Western University Centre for Teaching and Learning

- Participated in seminar-style workshops to improve teaching and grading for TAs.
- Ran two microteaching sessions where I received positive feedback on lessons and teaching style.

COMMUNICATION & INTERPERSONAL SKILLS

Communications Officer **July 2021-Present**

Western University HELP Lab

- Organized HELP Rounds in partnership with LHSC which explored pressing ethical issues in health care and public health.
- Created and uploaded weekly posts on social media pages to promote speaker events and recently published work by HELP Lab members.
- Conducted research to inform public policies that address health inequalities.
- Led the organization of the Summinar Series by coordinating panelist attendance and mediating discussions regarding COVID-19's impact on various industries.
- Raised awareness of the Lab by creating social media pages on Instagram, Facebook, Twitter, and LinkedIn.

Head Guard **August 2019 – June 2022**

Western Student Recreation Centre (WSRC)

- Facilitate exceptional personal relations skills by informing patrons on COVID protocols in a friendly manner, ensure members have access to equipment, and liaise with varsity coaches.
- Uphold the values of the WSRC and emulate these during shifts to inspire younger guards to do the same.
- Respond proficiently to first aid situations and ensure lifesaving certifications are relevant through taking courses to further first aid skills and abilities to teach first aid to others, and taking recertification courses to maintain knowledge and skills.
- Implemented and oversaw WSRC marketing through social media.

LEADERSHIP SKILLS

Director of Impact **June 2021 – June 2022**

RollUP Solutions

- Promoted organization by noting and retaining records of all incoming and outgoing donations.

- Conducted interviews with recipients of various backgrounds, such as those in Northern Ontario, to learn about prior experienced barriers without a wheelchair and the impact that the RollUP wheelchair made on their quality of life.
- Researched, prepared, and published monthly blog posts to inform the community on RollUP's impact.
- Generated monetary donations to RollUP by preparing and submitting grant proposals.

Director of Community Relations **September 2020 – June 2022**
BoostHER

- Coordinated with team members to design and launch initiatives within the undergraduate community of Canada to allow women to feel empowered within the classroom and workplace.
- Screened and interviewed candidates for various BoostHER positions and for the mentorship program, pairing students with prominent Canadian women executives.
- Chaired the creation of the organization's inaugural webpage.

VOLUNTEER AND CHARITY EXPERIENCE

Clinical Ethics Observer **April 2023**
London Health Sciences Centre

- Observed and participated in ethical consultations with patients, families, and healthcare providers in a large academic hospital setting under the guidance of experienced clinical ethicists.
- Participated in educational sessions and workshops on topics such as informed consent, end-of-life decision-making, and conflict resolution in healthcare.

Children's Hospital Golf Classic Work Team Member **September 2022 – Present**
London Health Sciences Centre

- Garner sponsorship and donations for the annual golf tournament whose proceeds go towards Children's Hospital in London Ontario.
- Meet monthly with a diverse team of highly motivated volunteers to meet donation goals.
- Raised over $420,000 for the Children's Hospital at LHSC.

Judge **February 2023**
Ontario Ethics Bowl

- Judged high school students' public speaking and debating skills surrounding topics of moral philosophy and ethics.

Orientation Leader – Charity **August 2020 – May 2021**
Western University

- Raised awareness and support for local London charities by organizing Orientation Week activities with the charities and encouraging incoming first years to participate.
- Directed event planning and solicited food donations for the entire freshman class.
- Spearheaded a safe in-person Orientation Week during the pandemic.

Choreography Executive **September 2019 – May 2021**
Western SPUR Charity Fashion Show

- Directed over 100 models and oversaw music and fashion design.
- Problem-solved ways to continue choreography throughout the pandemic to ensure a final product was produced and funds were raised for the chosen charities.

- Raised $9,195 for the Canadian Centre for Gender and Sexual Diversity (2020) and True North Aid (2021).

PUBLICATIONS

Z. Ritchie, **M. Forte**, M. J. Smith, & J. Shelley. (2024). How ‘Ought’ the Best Interests of Children be Considered in Medical Decision-making? Canadian Journal of Bioethics, 7(2–3), 222–224. https://doi.org/10.7202/bioethics

M. Forte, Z. Ritchie, R. Zlotnik Shaul, G. Teachman, C. Houston, M. J. Smith, J. Shelley. “Clarifying the best interests standard in children’s medical decision making: Toward a consistent and reliable guide for practice”. Status: in progress.

CONFERENCES & WORKSHOPS

“Navigating Parental Autonomy and the Best Interests of the Child for COVID-19 Vaccination: A Critical Interpretive Review.” Poster presented by **M. Forte**. Canadian Bioethics Society/International Conference on Clinical Ethics and Consultations 2024. Montreal, QC. May 29-31, 2024.

“How ought the best interests of children be considered in medical decision-making? A collaborative workshop toward a consistent and reliable guide.” Presented by Z. Ritchie, **M. Forte**, L. Soparlo, J. Shelley, M. J. Smith. Canadian Bioethics Society 2023 Workshop and Community Forum. Virtual. May 15-18, 2023.

“Finding the best practice in best interests? Reflections of a scoping review on the best interest standard in pediatric medical decision making” Presented by **M. Forte**, Z. Ritchie, J. Shelley, M. J. Smith. 2023 Child Health Symposium. London, ON. May 30-31, 2023.

“Navigating ethical tensions with vaccine-hesitant parents in the Pediatric ICU.” Presented by **M. Forte**. Health and Rehabilitation Sciences Conference 2023. London, ON. February 1, 2023.

“Clarifying the Best Interests Standard in Children’s Medical Decision Making: Toward a Consistent and Reliable Guide for Practice” Presented by **M. Forte** and L. Soparlo. Western University Undergraduate Student Research Internship Conference. London, ON. August 2022.

SCHOLARSHIPS AND AWARDS

Ontario Graduate Scholarship	**2023-2024**
Rotman Institute of Philosophy Graduate Fellowship	**2023**
Dean’s Honour List	**2019-2022**
Undergraduate Student Research Internship	**2022**
Scholarship of Excellence – Western University	**2018**
Education Award – YMCA Camp Wanakita	**2018**

CERTIFICATIONS

TCPS 2: CORE 2022	**2023**
Teaching Assistant Training Program	**2022 – Present**