Children and Family's Experiences While Living with Congenital Heart Disease in Northwestern Ontario

by

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Author's Declaration

I hereby declare that I am the sole author of this dissertation. This is a true copy of the dissertation, including required final revisions, as accepted by my examiners. I understand that my dissertation may be electronically available to the public.

Abstract

Background:

Within Canada, heart defects are the most serious congenital condition and a leading cause of infant mortality. This research highlights what is often overlooked: the day-to-day realities of children and families living with congenital heart disease (CHD) in Northern contexts.

Purpose:

The purpose of this dissertation was to explore the experiences and day-to-day realities of children diagnosed with CHD and their families living in rural, remote, and northern areas of Northwestern Ontario.

Methods:

This research was underpinned by Bronfenbrenner's Bioecological Theory and van Manen's hermeneutic-phenomenological approach. A total of 14 families participated, comprising 27 individuals, including 13 mothers, 4 fathers, and 10 children diagnosed with CHD. Data were collected through semi-structured interviews with children and their parents, alongside the use of field notes. Children underwent a two-phase consent process; first, parental consent was obtained, followed by the child's assent.

Analysis:

Child and parent interview data were analyzed using van Manen's hermeneutic-phenomenological approach.

Findings:

Parental findings centred around the core theme of liminality with four additional themes: 1) Torn from the Ordinary: Living Apart for Care, 2) Care in Pieces Across the Northern

Landscape, 3) Fragile Bodies: Lasting Imprints of Ruptures in Time, 4) Embodied Hypervigilance: Protective Parenting. Four core themes emerged from the child findings, including 1) Children living in normalcy, 2) Feeling different in physical activities, but not defined by it, 3) Emerging health agency: From passive to active agents in care, and 4) Remembering with others: Development gaps and relational memory

Conclusions:

Clear differences emerged in how CHD is lived within families. Considering the coexistence of both liminality and normalcy within the same family unit highlights the complexity of lived experiences, particularly living with CHD in a northern context where geography and access have significant influence over health care trajectories. The findings suggest that the experiences of families in the north caring for children with CHD are shaped by much more than the illness and must be understood within the broader interconnected systems in which they live. There is a critical need for further qualitative research, in particular with children living with CHD in northern contexts and their families.

Dedication

This thesis is dedicated to my mom, Dr. Sally Dampier, who has been my inspiration and greatest supporter.

I also dedicate this thesis to my beautiful daughter, Emma. You have brought so much light into this world. Becoming your mom has been my greatest chapter yet.

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Chapter One: Introduction

1.1 Introduction

According to Canada's Health Act, established in 1985, the main objective of health care in Canada is "to protect, promote and restore the physical and mental well-being of residents of Canada and to facilitate reasonable access to health services without financial or other barriers" (Government of Canada, 2023a, p.3). This is facilitated through five fundamental principles: "public administration, comprehensiveness, universality, portability, and accessibility" (Government of Canada, 2023a, p. 5).

Unfortunately, despite the wording of Canada's Health Act, the vast and diverse landscape of rural, remote, and northern regions within Canada poses significant access challenges (Health Quality Ontario, 2018). For example, while rates of chronic diseases and illnesses and thus mortality are higher in Northwestern Ontario (NWO) than in Ontario generally, healthcare and social services are often limited (Health Quality Ontario, 2018; Northwest Local Health Integration Network (NWLHIN), 2018). This is compounded by some communities having fly-in-only access, with limited transportation options (Health Quality Ontario, 2018), as well as funding, education, employment opportunities, and socioeconomic challenges (Huot et al., 2019; Miller et al., 2018).

Additionally, complex funding, societal and political factors within Canada contribute to the disparities and exacerbate healthcare challenges for children and families, especially those living in rural, remote and northern regions (Canadian Institute for Health Information (CIHI), 2006; Campbell et al., 2019; Gillespie, 2023; Raphael, 2016; Young et al., 2019b). The principles of Canada's Health Care Act imply that children and families residing in these regions should have equitable access to health care services comparable to those of their counterparts

elsewhere in Canada. However, rural, remote, and northern regions are often underserved and lack specialized paediatric healthcare services. Within the local context of NWO, healthcare professionals have identified paediatric cardiac services in need of increased services, research, and action (T. Bruni, Personal Communication, September 9th, 2022). This doctoral study utilized a hermeneutic phenomenological approach to explore the experiences of children diagnosed with congenital heart disease (CHD) and their families living in rural, remote, and northern areas of NWO. This dissertation outlines the background information, literature review, research questions and objectives, methodology and conceptual framework that framed this research, followed by a review of the research findings and discussion.

This research highlights what is often overlooked: the day-to-day realities of children and families living with CHD in Northwestern Ontario. Bringing forward the voices of children and their families from Northwestern Ontario, the research findings offer a deeper understanding of what living with CHD looks like in this unique context. It points to gaps in care and describes how these gaps are experienced and navigated in everyday life, drawing attention to the ways in which current systems do not always fit with the realities of the north. This research provides practical direction for shaping policy, funding, and care delivery. It makes clear where changes are needed, particularly around delivery, organization, coordination, and support, to ensure care is more manageable for families living in northern communities.

This research provides a deeper understanding of children's perspectives and how they often differ from those of their parents, and the possible reasons behind this. In a field where children's voices are often underrepresented, this work takes on a more inclusive approach situating children's experiences alongside those of their families. Grounded in an interpretive approach that seeks to understand the lived experiences, this approach adds depth to children's

roles, agency and understanding of their care. It provides deep insight into the parents' experiences and the impacts of fragmented systems and ongoing demands, well beyond moments of care, that place them in a constant state of uncertainty.

1.2 Background

The background section provides contextual grounding for the research. It is based on an environmental scan of pediatric cardiac services and resources in Northwestern Ontario for children living with CHD and their families. The environmental scan was competed with assistance from Debra Gold, Lakehead University Librarian and included a comprehensive search of the literature and supporting grey literature. Data bases including PubMed, Nursing and Allied Health Database (ProQuest), Cumulative Index to Nursing and Allied Health Literature (CINAHL), Google Scholar, and other varying sites such as government websites, and the Canada Commons databases were explored to ensure that grey literature was reviewed. The search revealed no resources specific to CHD child and family supports in the NWO area. With limited information and resources available within the local context, I spoke with key stakeholders at the Thunder Bay Regional Health Sciences Centre (TBRHSC) who helped address key issues and barriers that led to the development of this research project. I start this section by defining what rural, remote and northern regions imply; then, I highlight important health outcomes and disparities as a pretext for the discussion of CHD in the context of NWO. I then define and describe CHD within the Canadian and local NWO context. The section concludes with a discussion of the determinants of health, their influences and impacts on children and families generally, and those living with CHD specifically.

1.21 Defining Rural, Remote & Northern Regions

A common definition of rural, remote, and northern regions is absent within Canada and globally (CIHI, 2006; Schiff and Møller, 2021; Subedi et al., 2020). Within Canada, several geographical classification systems are used, but they have been criticized for lacking precise classification of rural, remote, and urban communities (Subedi et al., 2020). Statistics Canada lists three methods for calculating geographical areas to determine urban and rural areas: the Remoteness Index (RI), Statistical Area Classification (SAS), and the concept of Population Centers (POPCTRs) (Subedi et al., 2020). Statistics Canada (2020) describes the RI as an excellent tool for use in the Canadian context because it accounts for geographical elements related to accessibility, unlike the SAS and POPCTRs tools (Subedi et al., 2020).

Canada's Provincial North is often described as the 'Forgotten North' (Coates et al., 2014), as it is "among the most marginalized, externally controlled and impoverished regions in the country" (Coates et al., 2014, p. 6). The lack of aggregated, up-to-date data from the northern provinces is partly due to varying provincial definitions of their northern administration regions (NARs) (Schiff and Møller, 2021a). Challenges with the NARs stem from differences in the northern provinces' geographical landscapes and their proximity to services and resources (Schiff and Møller, 2021a). There are variations between NAR-defined areas, as some may contain cities, larger towns and differing populations (Schiff and Møller, 2021a). Møller and Schiff (2021a) use the Modified Beale Codes, as per du Plessis et al. (2001), to discuss the broad areas of the Provincial and Territorial north.

> The modified Beale codes provide 10 distinct categories for metropolitan and non-metropolitan analysis based on the relative weighting of parameters of population size, density, and context and include consideration of the size of a territorial unit: local,

> community, or regional. Code 10 is the classification for "northern hinterland," which includes all three territories, and provides a breakdown by province of the southernmost latitude considered within this code. This approach to defining the north is valuable since it includes the Provincial North and provides a concise definition for that region (Schiff and Møller, 2021a, p. 5).

Defining rural and urban regions is essential when discussing the geographical disparities and their impacts on health and health outcomes within these regions. For this study, the du Plessis et al. (2001) Modified Beale Code 10 "northern hinterland" was used to define the local area of NWO.

1.22 Population Health: NWO

Northwestern Ontario covers a large geographic area, spanning from the Minnesota border, along the northern shoreline of Lake Superior, heading west to Manitoba and northward to Hudson Bay coast (Destination Ontario, 2026). Ontario Health North West region provides health care services for 58% of Ontario's landmass (Ontario Health, 2026). Despite the region's vast size, the population is relatively small and widely dispersed (Northern Policy Institute, 2019; Ontario Health, 2026). Approximately 46% of the population resides in urban areas, 34% in rural areas, and the remaining residents live in population centers classified as small or medium (Health Quality Ontario, 2017). Children aged 0-19 account for 22.3% of the NWO population (Statistics Canada, 2021). One in five people identifies as Indigenous, which is higher than the Ontario average overall (Health Quality Ontario, 2017). However, Indigenous scholars and community-based research would argue that national census estimates likely underestimate the true Indigenous population in Ontario (Anishnawbe Mushkiki Community Health and Wellness, 2020). This is due to the long-standing impacts of colonial policies and colonization

(Anishnawbe Mushkiki Community Health and Wellness, 2020). A lower percentage of people identify French as their first language than the provincial average; however, some areas of NWO have higher percentages of French-speaking residents than Ontario overall (Health Quality Ontario, 2017).

Increased mortality, hospitalizations, and chronic disease rates are just a few of the health inequities and social injustices that populations in rural, remote, and northern regions face compared to their urban counterparts (Huot et al., 2019; Kulig & Williams, 2012; Subedi et al., 2020). The inequalities are even greater for Indigenous populations in these regions (Kauppi et al., 2021; Subedi et al., 2020; Møller, 2018). Research from NWO is consistent with research in rural, remote and northern regions generally. NWO has higher rates of mental health conditions, addiction (Northern Policy Institute, 2020), suicide, and chronic diseases such as diabetes, compared to the southern part of Ontario (Health Quality Ontario, 2017; NWLHIN, 2015). NWO has a lower life expectancy compared to southern Ontario, with the average life expectancy for individuals residing in NWO being 78.6 years compared to the provincial average of 81.5 years (Health Quality Ontario, 2017; Office of the Auditor General of Ontario, 2023).

In a recent 2024-2025 COMPASS report conducted by the Northwestern Health Unit, students from eight secondary schools across Northwestern Ontario were surveyed, which included youth in grades nine through twelve (Northwestern Health Unit, 2025). Findings highlight concerning patterns in substance use and mental health in this region compared to Ontario's national average. Approximately 21% of students reported using an e-cigarette within the last 30 days, and nearly half indicated that they had tried vaping for a variety of reasons, including curiosity and to relieve anxiety (Northwestern Health Unit, 2025). Rates of binge drinking were higher in Northwestern Ontario (22%) compared to the Ontario average (15%)

(Northwestern Health Unit, 2025). Cannabis use within the past 30 days was reported as nearly double the provincial rate, with approximately 22% of students in Northwestern Ontario reporting use versus the Ontario average of 11% (Northwestern Health Unit, 2025). Self-rated mental health reports were only slightly lower in Northwestern Ontario, with 55% rating their mental health as good, very good or excellent compared to 60% provincially (Northwestern Health Unit, 2025).

The lack of population data for people residing in Northern Ontario, especially among rural and remote Indigenous communities, perpetuates marginalization and inequalities (Anishnawbe Mushkiki Community Health and Wellness, 2020; Wald & Johnson, 2024; VanderBurgh et al., 2020). Understanding the local context, demographics, and geographical landscape of NWO allows for a deeper understanding of the complex barriers to healthcare access and services that impact the many health inequalities and social injustices within the region.

1.23 Paediatric Congenital Heart Disease

Within Canada, heart defects are the most serious congenital condition, with approximately one case identified for every 80-100 births (Canadian Congenital Heart Alliance, 2026; Miao et al., 2023). Besides prematurity, CHD is a leading cause of death within the first year of an infant's life (Keenan-Lindsay et al., 2022; Rockman-Greenberg et al., 2014; Statistics Canada, 2023). CHD refers to structural abnormalities of the heart present at birth that disrupt normal cardiac function, which often results in heart failure or hypoxemia (Keenan-Lindsay et al., 2022). There are more than 35 known defects, the most common being a ventricular septal defect (VSD) (Keenan-Lindsay et al., 2022). Across Canada, the prevalence of VSD is 12 of 1000 births, with around half of infants exhibiting symptoms before they turn one (Narvey et al.,

2017; Keenan-Lindsay et al., 2022). A more severe form of CHD is critical congenital heart disease (CCHD); it often presents with duct-dependent lesions and, for optimal health outcomes, requires interventions early in life (Keenan-Lindsay et al., 2022). Within Canada, it accounts for around 25% of children diagnosed with CHD (Narvey et al., 2017).

CHD is a chronic condition, and despite successful interventions, it requires continuous monitoring throughout a person's life (Fregonas & Kugamoorthy, 2024). With many advances in Paediatric cardiology, children with CHD can live well into adulthood, living past middle age (Dellborg et al., 2022). However, this may come with significant burdens on the child's quality of life (QOL) (Cherestal et al., 2022), Children living with CHD face many complex barriers to overall health and development (Azhar et al., 2016; Farr et al., 2018; Spillmann et al., 2021). Children with CHD are at risk of co-morbidities, which may lead to disability or chronic illness, resulting in long-term health impacts (Knecht et al., 2015; Parker et al., 2024). Complications and symptoms can occur throughout their lifetime, even after corrective surgery (Dallaire et al., 2021). In addition, CHD is associated with neurodevelopmental impairments (Billotte et al., 2021; Cassidy et al., 2017; Millen et al., 2025; O'Connor et al., 2023) and mental health challenges (Lepage et al., 2025b; O'Connor et al., 2023). Children with CHD require continued follow-up and interdisciplinary care to address their complex and evolving health needs (Cherestal et al., 2022). These and associated health outcomes are influenced by social determinants of health (SDOH), such as socioeconomic status (SES), access to services, and geographic location (Abell et al., 2025; Bucholz et al., 2018; Cherestal et al., 2022).

Despite the known complexity of CHD, limited research has examined the impact of remoteness on the risk of mortality among children with CHD (Udine et al., 2021), especially within the Canadian context and no specific studies within the local context of NWO (Olugbuyi

et al., 2022). Existing studies have more commonly explored maternal socioeconomic (SES) inequities, geographical diversity and risk of CHD, although findings are inconsistent (Ngwezi et al., 2018; Yu et al., 2014). Inconsistencies have been linked to the complex nature and varying measures of SES indicators (Braveman et al., 2005; Miao et al., 2021). To address these inconsistencies, the maternal and social deprivation indices were used within a recent population-based retrospective cohort study completed in Ontario. The research findings concluded that maternal rural residents increased CHD odds compared to their urban counterparts (Miao et al., 2021).

In a Canadian study, Olugbuyi and colleagues (2022) examined the impact of SES and remoteness on infant mortality from CHD. The study found that neither remoteness nor socioeconomic status impacted hospital mortality for severe and critical CHD. However, increased remoteness had a heightened mortality risk for moderate CHD (mCHD) (Olugbuyi et al., 2022). These findings could relate to delays in referral, diagnosis, appropriate interventions, and inadequate monitoring (Olugbuyi et al., 2022). They hypothesized that poorer outcomes for infants with mCHD may be due to decreased prenatal diagnosis from the obstetrical ultrasound, as detection is enhanced for severe CHD. Delays in referrals and interventions may have also played a role, whether due to lower perceived risk or limited resources. It is also possible that families living in remote regions have fewer resources and less access to appropriate monitoring, which increases the risk of mortality for a child with mCHD. Similarly, in a recent Canadian population-based study, it was found that geographic remoteness alone did not affect time to first intervention, age at diagnosis, or primary care visits (Conway et al., 2024). However, children living in more remote areas had fewer cardiology follow-up visits and more emergency room visits per year (Conway et al., 2024). Lower SES was also associated with an increased reliance

on ED visits per year (Conway et al., 2024). Although survival outcomes appear similar, both studies highlight gaps in ongoing supportive cardiac care and healthcare access for these children residing in remote regions of Canada.

Udine et al. (2021) provide further evidence, along with Olugbuyi and colleagues (2022), supporting the need to enhance regional care coordination and improve access to specialized Paediatric cardiac care. Findings from the study showed that significant geographical variation impacted infant mortality due to CHD (Udine et al., 2021). The authors listed poverty and distance to a paediatric care center as the most influential SDOH linked to mortality risks for infants living with CHD.

Specific to surgical outcomes and CHD mortality, two studies were reviewed. Both were conducted in the United States and examined geographical distance and its impact on infant and children's mortality risk in relation to surgical interventions at a specialized center while living with CHD. Both studies reported that remoteness did not increase mortality risks (Millen et al., 2023; Pinto et al., 2012). These findings highlight the benefits of regionalized, specialized cardiac care for children with CHD requiring surgical intervention (Millen et al., 2023; Pinto et al., 2012). However, both studies highlighted that although there were no differences in mortality rates, they did not account for adverse events and higher morbidity rates for this vulnerable group (Millen et al., 2023; Pinto et al., 2012). Increased understanding and research around the effects of remoteness on adverse events affecting patient morbidity and follow-up care for children living with CHD is needed (Millen et al., 2023; Pinto et al., 2012). Unlike Olugbuyi et al. (2022) and Udinet al. (2021), these studies did not account for SES, which is a limitation of this study. Another limitation noted by Pinto et al. (2012) was the small sample sizes for participants living more than 300 minutes from a surgical center. This study also does not

indicate the maximum time participants live from a surgical center; within NWO, many families must travel more than 5 hours by passenger vehicle or by plane.

There is a need to improve healthcare delivery in areas remote from paediatric specialty hospitals and in economically challenged communities (Udine et al., 2021). With limited supporting evidence and variations across the few studies identified on children living with CHD and the impacts of remoteness and SES, there is a need for increased research in this area (Millen et al., 2023; Olugbuyi et al., 2022; Pinto et al., 2012). All studies reviewed were also conducted from a quantitative lens, limiting consideration of children's and families' lived experiences and underscoring the need for greater use of qualitative methodologies.

1.24 Canadian Paediatric Cardiology Services

According to the Canadian Paediatric Cardiology Association, only 15 paediatric cardiology service centers exist across Canada and only eight surgical cardiac centralized programs (Canadian Cardiovascular Society, 2023; Conway et al., 2024; Olugbuyi et al., 2022). Private practice accounts for a small minority of cardiologist within Canada (Conway et al., 2024). These 15 centers are situated in highly populated metropolitan areas, for example, in Edmonton and Toronto. Although most cardiac programs have outreach programs for children and families in rural and remote communities, they are limited in the services they can provide (Olugbuyi et al., 2022). The outreach clinics support 10-30% of children and families residing in areas 100 km and sometimes greater than 300 km away from the clinic (Olugbuyi et al., 2022). Children and families residing in rural areas face the burdens of long drives or air travel to the outreach clinics and additional air travel challenges when needing increased support from specialized cardiac centers in urban areas (Olugbuyi et al., 2022). This means that children living with CHD in remote areas face significant challenges with healthcare access, and if clinical

deterioration occurs, the risk of additional adverse health outcomes increases – including mortality (Kaur et al., 2022; Olugbuyi et al., 2022).

In addition to limited paediatric cardiology services within Canada, families living in rural areas face challenges with prenatal screening, which, if missed, require them to travel to specialty areas. The findings from this Canadian study are consistent with literature from the United States, which reports that living in rural areas can lead to decreased prenatal diagnosis of CCHD (Hill et al., 2015; Krishnan et al., 2021). Although there is limited literature in Canada on this topic, a recent study from Alberta examined the impact of SES and the remoteness of residence (RoR) on the timing of CCHD prenatal diagnosis (Kaur et al., 2022). The study found additional risks for families living in rural areas of Alberta, including lower rates of CCHD prenatal diagnosis and elevated risks of being diagnosed late (Kaur et al., 2022). These findings are concerning as missed prenatal diagnosis, especially for CCHD and for families living in rural areas, means children are being born in regional hospitals, which may require long transportation time to tertiary centers where specialty services are needed (Kaur et al., 2022). The increased time to a specialty center where appropriate diagnosis and management of care for a child's CHD can result in decreased survival rates and unhealthier preoperative conditions in some cases (Kaur et al., 2022).

1.25 NWO Paediatric Cardiac Services

An environmental scan was conducted to identify resources and supports for children living with CHD and their families living in Northwestern Ontario. This search revealed limited tools, services and resources available within this context. Given these findings, I consulted with key stakeholders at the Thunder Bay Regional Health Sciences Center (TBRHSC) to develop this research project. This included many conversations with Dr. Bruni (pediatrician and the

medical program Director for the Women & Children's Program), Crystal Edwards (director of women's and children's and mental health programs), and Amy Halvorsen (manager of the children's and women's departments). After initial meetings with key stakeholders, Dr. Bruni arranged a meeting between A. Halverson and myself to address more detailed questions about children living with CHD in the local context of NWO and the care services provided.

During our discussions, they all highlighted a need, from a clinical perspective, for research focusing on health care supports and services for children and families living with cardiac conditions in the NWO region. According to Halvorsen, Edwards, and Dr. Bruni, children and families living in NWO with CHD have limited cardiac health care services. TBRHSC uses pulse oximetry screening (Narvey et al., 2017) to enhance the detection of CCHD among all newborns between 24 and 36 hours after birth (A. Halverson, personal communication, January 11th, 2023). Although this practice is essential for early detection and prevention of critical incidents, it does not always detect problems. If this issue occurs, as cited in the literature above, infants may be born at regional hospitals such as TBRHSC, where support is limited, and, upon birth, the infant and family would need to be flown to a specialized center. In 2022, a new virtual paediatric program was established by the London paediatric cardiologists to support rural and small towns in the hospital's service area from Kenora to Marathon, which spans nearly 800km. This allows patients to be seen virtually by their specialist if needed, without needing to travel to London. This is not led directly by TBRHSC; it is handled directly through London Hospital and its referral process.

Around 225 patients are rostered in the TBRHSC paediatric cardiology outpatient files (A. Halverson, personal communication, January 11th, 2023). These cardiac patients are only those assessed by the paediatric team at TBRHSC, who then refer them to a paediatric cardiology

center. As there is no paediatric cardiologist in Thunder Bay or the surrounding areas, children with cardiac conditions are assessed by pediatricians and referred to the Children's Hospital at London Health Sciences Centre (LHSC), The Hospital for Sick Children (Sick Kids), or Winnipeg Health Sciences Centre if they live closer to the Manitoba border. Most children assessed for cardiac conditions within the region are sent to LHSC, the tertiary care center for Thunder Bay. Sick Kids are usually involved with more complex cardiac cases requiring more intricate surgeries. Children seen in London, or even in other centers referred from TBRHSC, remain on file within the paediatric outpatient clinic (POP) so that all test results completed at TBRHSC can be shared with the specialized primary care providers (A. Halverson, personal communication, January 11th, 2023).

Most children are referred to LHSC, and the cardiologist team will be the primary care team. They order diagnostic tests as needed and can provide health care services via telehealth, from London, or at the cardiology clinics in Thunder Bay (A. Halverson, personal communication, January 11th, 2023). LHSC holds a cardiac clinic twice a year at the TBRHSC POP for children, followed by their team; this usually occurs in the fall and winter months (T. Bruni, personal communication, December 2022). Children from all over the region come to Thunder Bay to attend these clinics. The cardiologists triage the cases and decide who they will see at the visiting clinic. Cardiac services are limited for children living in NWO (T. Bruni, personal communication, December 2022). Therefore, families must take time away from work, which can create financial hardship. Although financial aid exists, such as the Northern Health Travel Grant, compensation for lost earnings and the cost of paying caregivers to look after other children or dependents is not covered (Ontario Ministry of Health and Long-Term Care, 2023). It

also does not include financial aid for more than one parent to accompany their child (Ontario Ministry of Health and Long-Term Care, 2023), which places strain on the family unit.

Multiple healthcare partners are often involved with the child's care, and there are challenges with continuity of care and follow-up. Other issues include hospitals using different electronic medical record systems, which pose challenges around consults and the receipt of ordered tests, regarding funding and billing for the paediatric cardiologist across centers (A. Halverson, personal communication, January 11th, 2023). During the COVID-19 pandemic, issues with the provincial lockdowns caused many challenges for children and their families living in NWO. Children who lived close to the Manitoba border and were followed by the Winnipeg Health Science Center could not access their primary cardiac care providers (A. Halverson, personal communication, January 11th, 2023). This left children and families without their usual support, requiring them to travel long distances to be consulted by centers not previously involved in their care (A. Halverson, personal communication, January 11th, 2023).

Although there are advancements in paediatric care in the region, gaps remain in specialized services for children with cardiac conditions. Children and families are burdened by many aspects of care, which cause shifts across all areas of family health and wellbeing.

1.251 NWO Paediatric Cardiac Services 2026 Update. On April 30th, 2026, A. Halverson provided me with an update on the cardiac services in NWO and some recent changes that were made to the delivery of the cardiac clinic from London to Thunder Bay. According to Halverson, a third cardiac clinic has been added, which is expected to help meet increasing demand (A. Halverson, personal communication, April 30th, 2026). Clinics are now scheduled to be held in spring, summer and fall (A. Halverson, personal communication, April 30th, 2026). Amy shared,

> We still avoid the winter as the travel is so unpredictable that it has a high likelihood of missed visits. Even when we tried for a fall visit in early November in the past, there were weather issues in the North which caused some cancelled flights. A common issue that we see is missed appointments to the cardiac clinic. Even with the clinic going on this week [end of April 2026], we had a number of no shows due to failed travel arrangements from Northern Reserves and NIHB not having the arrangements in place. NIHB has made a number of changes that do not seem to help, in fact making this worse (A. Halverson, personal communication, April 30th, 2026).

This update is important, as it provides clinical context that further supports this study's findings and implications. Although this study did not include Indigenous participants, it further highlights the gaps in fragmented care and supports across diverse northern landscapes. Amy further shared,

> Sometimes, I believe partially due to remoteness and lack of communication channels, some patients end up lost to follow up. The cardiologist or our clinic may be trying multiple times to reach the family to reschedule, but there are times that the original numbers are no longer in service, or families do not have phone access and are unreachable (A. Halverson, personal communication, April 30th, 2026).

These point-of-care observations align with this study's findings, particularly regarding fragmented care and the ongoing challenges families face when accessing their child's cardiac care services.

1.3 Social Determinants of Health

For many communities within Northern Ontario, especially Indigenous communities, increased rates of health inequities are coupled with intersecting social and ecological

determinants of health (Health Quality Ontario, 2018; VanderBurgh et al., 2020). Such determinants shape the social and economic structures of local communities and countries worldwide (Møller, 2018; Raphael, 2016). The literature highlights disparities in health between children and families residing in rural, remote, and northern areas compared to their urban counterparts, often due to intersecting SDOH (Miller et al., 2018; Raphael, 2016; Young et al., 2019a). SDOH are key factors influencing individuals' health and health outcomes; they determine whether a person can holistically meet their needs and utilize resources within their local environment (Davidson, 2019; Raphael, 2016; Schiff & Møller, 2021b). Considering SDOH that affects populations differs from a traditional biomedical model, which does not account for such concerns (Raphael, 2016).

Continued factors that drive and influence health inequities include the maldistribution of resources, power, and money across communities (Bourgeault et al., 2017; World Health Organization, 2008). Møller (2018), departing from Reading and Wien (2009), discusses how the proximal, intermediate, and distal SDOH affect people and how they may intersect, causing profound health inequalities. Although many SDOH play a significant role in child and family health outcomes, the following section will explore areas with the greatest impact on populations across the lifespan, with specific considerations for those living in rural, remote, and northern regions. Lastly, the impacts of SDOH will be considered further, with a specific focus on the unique implications for children and families living with CHD in rural, remote and northern areas.

1.31 Physical Environments and Health Care Access and Services

Physical environments are proximal determinants of health and are essential factors when considering populations' access to healthcare services and health outcomes (Raphael, 2016;

Young et al., 2019a; Reading and Wien, 2009). With an increasing degree of rurality, increasing complexities such as higher rates of lower socioeconomic, lack of infrastructure, lack of access to education and educational attainment is also often seen, which impacts health outcomes and contribute to health inequalities (Davidson, 2019; Møller, 2018, Raphael, 2016). Lack of infrastructure, roads, weather conditions, and internet access widens health disparities by limiting access to health services for populations residing in rural, remote, and northern areas (Huot et al., 2019; Raphael, 2016; Young et al., 2019a). As mentioned above, definitions of rural and remote areas are inconsistent across the literature. A formal definition of rurality in the Huot et al. (2019) article was not provided; instead, the authors discussed health care access within the context of the 'circumpolar north'. This differs from Statistics Canada's calculation methods and modified Beale codes for defining geographical areas. The circumpolar north refers only to regions of countries that are subarctic and arctic above the 60th parallel north, which would not account for the majority of the communities in NWO (Huot et al., 2019). Although rurality measures are diverse in the literature, disparities in health outcomes among populations residing in geographically dispersed areas are consistently reported, highlighting the significant impact of geography, infrastructure, natural and physical environments on population health (Young et al., 2019).

Colonization and continued colonialism, including oppression, racism and discrimination, continue to contribute to healthcare access and service inequities for populations residing in rural and remote regions (Kulig & Williams, 2012; Kassam, 2021; Møller, 2018, Young et al., 2019). Raphael (2016) discusses 'oppression and access to care: embedded contexts' and the intersecting SDOH and lists systemic, point of care and social location factors as key components in barriers to accessing health care. Geographical and social location play a vast role in health care

advantages and privileges related to SDOH throughout the life course (Davidson, 2019; Raphael, 2016). Social locations and neighbourhoods impact childhood experiences, housing, food, and education; it also intersects with other key areas, such as the 'isms' of SDOH, including racism, colonialism and discrimination, which can further influence access to health services (Raphael, 2016). In Ontario, the average time to access an emergency department is 30 minutes; however, for about 25,000 Ontarians living in remote communities, accessing a doctor in an emergency department requires flying by plane or helicopter (VanderBurgh et al., 2020, p. 400). This is significant, given that many communities in Northern Ontario have limited local emergency response services (Mew et al., 2017). Communities also rely heavily on nursing stations with limited resources and on-site physician supports, leaving nurses to manage complex cases until transfer to larger centers can occur, which can take several hours even on good days VanderBurgh et al., 2020). The delay in transfers can be linked with various challenges including weather, mechanical issues, visibility, and staffing issues (VanderBurgh et al., 2020). This contributes directly to delays in treatment, negatively impacting health outcomes (Health Quality Ontario, 2017; VanderBurgh et al., 2020).

From 2016 to 2021, Canada's rural population increased by 26,609 to 6.6 million (Statistics Canada, 2022a). Although growth rates in Canadian rural areas increased, they were 15 times slower than those in urban areas (Statistics Canada, 2022a). Due to variations in rural and urban population growth rates, the rural population decreased from 18.7% to 17.8% between 2016 and 2021, while the urban population increased significantly (Statistics Canada, 2022a). Statistics Canada (2022a) suggests that urban areas are growing faster than rural areas, mainly because immigration settlement patterns are concentrated in urban areas. Understanding population patterns in rural, remote, and northern regions will aid healthcare planning and

delivery. This is particularly important for the paediatric population, who require adequate and timely health care services to support growth and development while meeting chronic and acute health care needs.

According to the 2021 census, there was a 11.5% increase in the Indigenous population residing in large urban centres, highlighting a trend of urbanization for this population (Statistics Canada, 2024). It is now reported that almost 44.3% of all indigenous peoples in Canada reside in urban centres (Statistics Canada, 2022b). This number may be higher on different days as Indigenous peoples from rural, remote or northern areas may temporarily relocate for health care or schooling, yet the census only accounts for permanent residents (Statistics Canada, 2022b). In 2021, the Indigenous population was reported to be 33.6 years old, compared to the non-Indigenous population at 41.8 years, indicating higher birth rates among the Indigenous population (Statistics Canada, 2023). The growth in urban centers is due to various factors. Legally, individuals are reclaiming their Indigenous ties due to Bill-C31 (Government of Canada, 2026). Socially and economically, urban migration is linked to employment, education, access to healthcare, and social and safety supports for these individuals (National Association of Friendship Centres, 2021).

It is important to note that there were variations in population data on Indigenous people residing in urban vs. rural areas in Canada. The Organization for Economic Co-Operation and Development (OECD) defined rural and urban areas using a broad regional typology based on driving distance to urban centers and geographic ecosystems (OECD, 2020; OECD, 2011). Whereas the National Association of Friendship Centers (2021) does not explicitly define rural vs. urban areas. This is important, as the OECD cites that 60% of the Indigenous population resides in rural areas, whereas the National Association of Friendship Centers (2021) cites that

61% reside in urban areas, which is slightly higher than Statistics Canada's (2022) reporting. This is crucial for researchers and policymakers to acknowledge, as the discrepancy in population data is due to differing measurement systems; these statistics are important because they provide critical information for resource planning.

Population trends for both Indigenous and non-Indigenous populations within Canada are important to highlight and understand as they should influence health care planning and access, especially for those living in underserved and isolated communities.

1.32 Education, Employment, Income, and Food and Housing Security

Levels of education, employment, income, food, and housing are proximal determinants of health (Reading & Wien, 2011) that interact with and, therefore, influence family dynamics and household health (Davidson, 2019; Møller, 2018; Raphael, 2016; Santrock, 2020). Families with higher socioeconomic status usually have higher educational attainment. Education affects employment, influencing an individual's income, which, in turn, affects access to adequate housing, food, and overall well-being (Davidson, 2019; Ferdinand et al., 2014), better health outcomes (Aalhus et al., 2018) and child health development (Raphael, 2016). Income impacts disease, disability, and morbidity, with incidence rates increasing as income decreases (Davidson, 2019). In addition, income inequality directly relates to infant mortality rates (IMR) (a key measure of population health) in Canada.

People residing in rural, particularly remote, and northern communities face barriers to accessing culturally appropriate and culturally safe education (Berger, Epp, and Møller, 2006; Government of Canada, 2025; Møller, 2016; Sneddon-Ghosal et al., 2024). In addition, providing education generally (Persaud et al., 2025) as well as education within healthcare settings (Møller, 2016) that are still rooted in colonial systems is complex and poses barriers for

many Indigenous peoples (Government of Canada, 2026a; Møller, 2016). It is crucial that The Truth and Reconciliation Calls to Action (TRC), specifically actions 6 through 12 focusing on integrations of culturally appropriate curriculum, increased funding and success rates, are addressed to remedy the lasting effects of residential schools and work toward improving Indigenous access to education, improve retention and graduation rates and also increase rates of Indigenous people in education, health and other professions (Truth and Reconciliation Commission of Canada, 2012). Educators and healthcare providers must have historical knowledge and appropriate cultural and linguistic training and experience to address Canada's TRCs (Møller, 2016). It is through necessary training that changes within institutions may have a positive impact on children and families. Populations residing in rural, remote, and northern areas experience socioeconomic challenges, including lower levels of educational attainment (Zarifa et al., 2019), and higher unemployment rates, which, in turn, can affect overall health and well-being (Kulig & Williams, 2012). This again highlights the need for culturally safe educational systems to empower and support communities.

Housing and health are closely linked; when an individual experiences homelessness or is precariously housed, it is often linked to poor health outcomes (McFadyen, 2022). Homelessness is increasingly recognized as a concern within Canada (Raphael, 2016; Strobel et al., 2021). Unfortunately, within rural and northern communities, the magnitude and rates of these issues remain hidden (Buck-McFadyen, 2022; Kauppi et al., 2021; Waegemakers Schiff et al., 2016). Houses with poor infrastructure or environments can be linked to health risks, such as mental health, asthma and respiratory infections (Kauppi et al., 2021). Specific implications for children living with housing challenges include lower respiratory tract infections (Kovesi et al., 2022) and long-term impacts on development (Raphael, 2016; Santrock et al., 2020).

Within Canada, Indigenous people are over 11 times more likely to utilize homeless shelters compared to non-Indigenous people, highlighting a severe disparity (Falvo, 2019). Within northern and remote regions, homelessness is even more prevalent among Indigenous populations (Agrawal & Zoe, 2024).

1.33 Social Support, Social Exclusion, and Racism

Social support and resources are intermediate SDOH, which directly influence proximal SDOH, while social exclusion and racism are distal SDOH (Møller, 2018; Reading & Wien, 2009). These SDOH cannot be understood as isolated factors; an individual's access to social supports is heavily shaped by past and current systems of oppression (National Collaborating Centre for Determinants of Health [NCCDH], 2022). Grounded in historically rooted social biases and hierarchies, oppression refers to a group being subordinate or devalued by another (Egale Canada, 2021). This creates institutional barriers to equity, often experienced as disenfranchisement, marginalization, or social exclusion (Egale Canada, 2021).

Strong social support networks provide supportive social structures that support individuals and can offer direct and indirect health benefits (Davidson, 2019). While healthy support systems can foster healthy behaviours by increasing self-efficacy and self-worth (Liu et al., 2021), severe adverse health effects can be seen among those who are socially isolated (Davidson, 2019). Unfortunately, populations marginalized by institutional barriers often experience profound disparities in social and community supports, which contribute to continued social exclusion and health inequalities (Davidson, 2019). In Canada, this systemic exclusion is evident in the structural organization of the healthcare system, which limits access to essential and specialized medical services for geographically dispersed communities (Conway et al., 2024; Olugbuyi et al., 2022). In these rural, remote, and northern communities, critical tertiary health

specialties such as obstetrics, oncology, and acute stroke care are frequently unavailable (Rural Ontario Institute, 2019). Consequently, many individuals do not have access to primary or tertiary care and often have to rely on emergency evacuation, as many communities are fly-in-only with very few land links, including train tracks or ice roads in the winter months (Rural Ontario Institute, 2019). Although Canada has strong inclusion policies and human rights laws, significant gaps remain in ensuring equitable access to fundamental human rights for people who are marginalized by systems of oppression (Davidson, 2019). These gaps highlight that a universal right does not always translate to universal access (Drazenovich, 2025). Institutional neglect results in systemic resource inequities and a lack of health care structures for marginalized groups, especially those residing in geographically dispersed areas (Drazenovich, 2025).

Systemic racism directly influences social and community exclusion, reinforcing marginalized groups' unequal standing under current societal and political ideologies (Davison, 2019). Unfortunately, within Canada and its current societal structures, colonization and continuing colonialism have had lasting effects, further perpetuating racism, which impacts individuals' access to health care, employment, education, and overall mental and physical well-being (National Collaborating Centre for Aboriginal Health, 2014). From a life-course perspective, ensuring healthy and supportive environments for all children can lead to increased population health outcomes and decreased impacts on negative societal behaviours and the healthcare system (Santrock et al., 2020).

1.4 Significance for Children and Families Living with CHD

In the above section, I have discussed how key SDOH intersect with and impact populations across the lifespan, through a rural, remote, and northern lens. I will now discuss

how key SDOH have significant implications for children and families, particularly those living with CHD in rural, remote and northern regions. Any child with an acute illness requires immediate medical attention. This is not always possible for children who reside in rural, remote, or northern communities due to the distance from hospitals, generally and specifically from those providing specialty care such as children with CHD (Amram et al., 2015; CIHI 2026; Olugbuyi et al., 2022).

The limited population and infrastructure within the north pose unique challenges that impact employment creation and economic growth (Government of Canada, 2019). Conversely, limited employment and economic growth adversely affect mental and physical health and wellbeing (National Collaborating Centre for Aboriginal Health, 2017; Yang et al., 2024). Due to the demands of and challenges to accessing care, caregivers of a child with CHD may have to make additional employment adjustments, including using sick time, vacation days or unpaid leave. This often causes a significant financial burden due to missed work time, significant travel expenses, and additional healthcare costs (Dalir et al., 2021; Ludomirsky et al., 2021; McClung et al., 2018), impacting the child with CHD, the caregiver(s) and the family as a whole (Dalir et al., 2021; Kankaya et al., 2025; Moorman et al., 2025; Li & Lee, 2020).

In addition, food and housing insecurity which as discussed is often more pronounced in rural and northern communities, have implications for the growth and development of children, which is especially challenging for children living with CHD, who often require special nutritional treatment and are more sensitive to adequate housing as their risk for acquiring respiratory infections is intensified (Capra et al., 2021; Geskey & Cyran, 2012). Increased rates of illness places children living with CHD at increased risk of missing school, which is critical for their development (Knowles et al., 2014).

Families who include a child with a chronic illness are often in need of additional support systems. Having support systems can help parents and/or caregivers more easily access education and employment. Support systems can also help parents and/or caregivers more easily accessing guidance and advice, and increase empowerment, which can impact the child's overall care (Robinson et al., 2022). Having support systems can afford people a sense of community belonging, which has strong ties to health and wellbeing (Davidson, 2019)

Social exclusion is evident in health and social program policies for populations residing in Canada's rural, remote, and northern communities (Davidson, 2019; Wilson et al., 2020). These policy and system gaps disproportionately affect indigenous peoples (Phillips-Beck et al., 2020). Indigenous people already face the ongoing impacts of colonialism and systemic racism in their interactions with health and social services (Phillips-Beck et al., 2020).

In relation to the population in this study, which includes children and families living with CHD in NWO, this background information provides a critical understanding of the diverse challenges they may face. Children and families living with CHD need specialized and timely health services and community support to address child and family needs.

2.0 Chapter Two: Literature Review

There appears to be limited work, especially using a qualitative lens that describes the experience of living with CHD in rural, remote, and northern regions from the perspectives of children and their families. An initial search was undertaken to explore the impacts and experiences faced by children and their families living with CHD in rural, remote, and northern communities, which elicited minimal articles. The literature review was then expanded to include all geographical regions with a similar aim: to identify peer-reviewed articles exploring the impacts and generalized experiences of children and their families living with CHD. Below, I describe my original and updated literature review search strategies and results, which explore and critique the literature on the impacts and experiences of children and their families living with CHD.

2.1 Search Strategy

The search strategy was developed with assistance from Debra Gold, Lakehead University Librarian. Search terms included "family impact" OR "experiences" OR "perceptions" OR "impact" AND "congenital heart disease" OR "paediatric heart disease" AND "child*" OR "family."

Searches were undertaken through Lakehead University library using various health databases, including PubMed, Nursing and Allied Health Database (ProQuest), Cumulative Index to Nursing and Allied Health Literature (CINAHL), and Web of Science. The Canada Commons database was also explored to ensure that grey literature was reviewed. Despite applying limitations to publications containing the search terms in the title or abstract, a substantial number of articles were identified, so further limitations were applied to limit the review to the most current and relevant articles. Limits included articles published within the last

10 years, peer-reviewed, in English, and with age restrictions from birth to 18 years. A hand search was also completed; no grey literature was found, although n=3 additional hand-selected articles were added to the review. A PRISMA flow diagram depicting the original literature search process and results appears in Appendix A. In total, 70 references were thoroughly reviewed.

To ensure the review remained current, the search was updated to include literature published from the start of the previous review in 2023 to the end of 2025. The updated search was conducted using the same databases, search terms, and inclusion criteria as the original search, again, with assistance from Debra Gold. Applying the same approach ensured consistency across both search periods. Covidence was used to screen titles and abstracts, conduct full-text reviews, and extract data. A PRISMA flow diagram outlining the updated search process is provided in Appendix B. A hand search was also completed; no grey literature was found, although n=2 additional hand-selected articles were added to the review. The updated search yielded 47 additional articles, all of which were comprehensively reviewed. In total, 117 articles were included in this literature review.

This literature search was intentionally broad. As stated above, when geographic terms such as “rural”, “remote” and “northern” were added to the search, only a few articles were identified. As a result, geographical limitations were not applied to capture a wider body of literature examining the lived experiences and impacts of CHD on children and their families.

2.2 Literature Review: Theoretical Frameworks

All articles that mentioned the use of a theoretical framework whether obliquely or directly (n=4) were qualitative in research design and included theories such as (1) critical

disability studies, (2) appraisal and coping model of Lazarus and Folkman, (3) Afaf Meleis's transition theory and (4) Bronfenbrenner's ecological systems theory.

Critical Disability Studies (CDS) underpins Moola's (2020) study, which aimed to explore physical activity spaces and how children and youth living with CHD experience them through arts-based research. This theory critiques the biomedical lens and considers how disability is impacted by social factors (Goodley, 2013). It also argues that both social and bodily aspects need to be taken into account to achieve a more holistic understanding of what disability means within current cultural and political ideologies (Goodley, 2013). Using this theory, the authors developed a deeper understanding of the complex nature of a child living with CHD. CDS allowed for various concepts to be explored, including how children living with CHD within this study experienced pain as well as how they experienced stigma while participating in physical activity settings (Moola, 2020).

The Stress, Appraisal, and Coping model by Lazarus and Folkman (1984) was used and adapted as a guide to explore the coping and stress experiences of mothers of infants undergoing surgery for CHD (Nakazuru et al., 2017). The model was adapted, and the major source of stress was defined as the infant's surgery. The appraisal accounted for mothers' psychological preparedness, specifically three appraisal areas: time of diagnosis, time awaiting corrective surgery for CHD, and reappraisal (Nakazuru et al., 2017). Additional initial factors in the mother's appraisal included demographics, personal factors such as readiness to be a mother, religion and beliefs, and situational factors such as social status, health history, and timing of the infant's diagnosis (Nakazuru et al., 2017). Coping was defined as the mother's practical preparedness (Nakazuru et al., 2017). The adapted model was an excellent guide to underpin the

research process, and it examined the coping process mothers experienced while living with an infant awaiting or having CHD surgery.

Afaf Meleis's transition theory considers transition periods of increased risk and overall vulnerability (Elliott et al., 2021). Afaf Meleis's transition theory is a middle-range theory originating from the nursing discipline; it identifies transition periods, such as changes in health or times of illness, as periods of vulnerability for clients, which can impact health outcomes (Meleis et al., 2000). This non-sequential model describes the three key responses of transitions accounting for the patterns, conditions and nature of transitions (Elliott et al., 2021). The study used this theory to underpin its research process to explore parents' experiences, specifically during the interstage period following cardiac palliative surgeries (Elliott et al., 2021). The authors highlighted that transition periods are complex, with various social, personal, and environmental factors that can pose challenges, aligning with Meleis's (2000) transition theory (Elliott et al., 2021).

The final study that explicitly stated the use of a theoretical framework was by Bichard et al. (2022), who used Bronfenbrenner's Ecological Systems Theory to underpin their research. The authors state that this model has benefits because it accounts for multiple domains that impact the child's growth and development. This includes those closest to the child, such as family, extended family, and school, and extends to other domains, including broader systems such as health care interactions, cultural and political influences, and recognizing that these changes are influenced by time (Bronfenbrenner, 2001).

The four theoretical frameworks each have strengths, accounting for different areas to consider when understanding children and families' experiences living with CHD. However, the drawbacks to utilizing the Appraisal and Coping Model of Lazarus and Folkman and Afaf

Meleis's transition theory are that they tend to focus on specific situations or time-limited transitions. Whereas CDS and Bronfenbrenner's ecological systems theory are considered more grand-range theories and, therefore, can attempt to explain the phenomenon under study comprehensively (LoBiondo-Wood et al., 2018).

2.3 Results

Of the articles reviewed, the majority (n=65) were conducted outside of North America and geographically diverse (e.g., Australia, New Zealand, Asia (China, India, Japan, Saudi Arabia, Taiwan, Jordan, Syria), Europe (Italy, Sweden, England, Denmark, Poland, Netherlands, Turkey), Africa (Egypt, South Africa), and other international regions. There were 20 from the United States and 11 from Canada.

The majority of studies in the reviewed articles (n117) were quantitative in design (n=60), followed by qualitative (n=33) and mixed-methods studies (n=6). There were (n=16) systematic reviews, and (n=2) literature reviews. Studies from Canada used qualitative (n=4), quantitative (n=6), and mixed methods (n=1) methodologies.

Four overarching themes emerged from the literature review: families' challenges in care, children and family quality of life (QOL) outcomes**,** child growth and development, and family-unique needs. Several subthemes were also identified within the literature and will be discussed below. The sub-themes and concepts that emerged from the literature were often threaded throughout the five overarching themes. Gaps within the literature and recommendations related to CHD will be discussed at the end.

2.31 Families' Challenges in Care

Families of children with CHD face a range of day-to-day challenges that extend beyond the child's cardiac diagnosis and shape the family's broader lived experience. This section

examines how caregiving demands, parental vigilance, and cultural context influence children and their families. It will also introduce subthemes related to shifts in role in routines, financial hardship, and environmental burdens. Stressing these challenges is important for the present study, as they are likely intensified in rural, remote and northern communities where access to specialized pediatric cardiac services is limited, and travel demands are greater.

The first theme identified across the literature was the challenges of care experienced by children with CHD and their families. CHD affects not only the child but the entire family system, including routines and relational dynamics (David Vainberg et al., 2019; Knecht et al., 2015). Children with more complex CHD require greater support, often causing heightened stress among families (Cole et al., 2024; Dahlawi et al., 2024; Lee et al., 2021; Scearbo et al., 2025; Sprong et al., 2024; Zhu et al., 2022). Recent studies further emphasized that caregiving demands extend beyond medical management; over time, these demands affect long-term family planning and ultimately impact the emotional stability of the caregiver (Cole et al., 2024; Dalir et al., 2021; David Vainberg et al., 2019; Kankaya et al., 2025; Nayeri et al., 2021; Vasilescu et al., 2024).

A constant pattern of heightened parental vigilance emerges across the literature, with parents closely monitoring symptoms, including cyanotic spells and breathing patterns (Dalir et al., 2021; Nayeri et al., 2021), and perceived risks, even during periods of clinical stability (Sprong et al., 2024). This vigilance frequently manifested as difficulty relinquishing care to others (Sprong et al., 2024), and in overprotective parenting behaviours (Dahlawi et al., 2024; Sprong et al., 2024), sometimes resulting in sibling jealousy (Dahlawi et al., 2024). Adolescents experienced parental protection as both supportive and, at times, constraining (Savaş et al., 2024), it has been described by Hsiao et al. (2024) as “overcontrol disguised as love” (p. 209).

Adolescents particularly felt their parents' overprotective behaviours when their restrictions limited autonomy and peer interactions (Hsiao et al., 2024; Knowles et al., 2016; Savaş et al., 2024).

Cultural context shaped how these dynamics were experienced. Within the Saudi Arabian context, parental disclosure of the child's CHD condition was developmentally guided. It was also guided by privacy-centred cultural values, which, while protective, may limit the child's own understanding of their condition and contribute to fear or uncertainties (Dahlawi et al., 2024). Localized cultural patterns underscore the importance of accounting for context when interpreting caregiving practices, a consideration directly relevant to northern Canadian communities. Recognizing unique contextual influences is essential for interpreting families' experiences and developing place-based supports.

Overall, findings within this theme suggest that caregiving demands associated with CHD can contribute to parental vigilance and parenting practices, which can also impact siblings' dynamics (Dahlawi et al., 2024). These practices can also impact children's psychosocial adjustments (Hsiao et al., 2024; Knowles et al., 2016; Savaş et al., 2024) as well as broader, long-term family functioning (David Vainberg et al., 2019; Knecht et al., 2015).
Within this theme, subthemes related to shifts in roles and routines (Cruz et al., 2022; Dalir et al., 2021; David Vainberg et al.,2019; Mombach Barreto et al., 2016; Sood et al., 2019), financial hardship (Cole et al., 2024; Cruz et al., 2022; Mombach Barreto et al., 2016; Sood et al., 2019) and environmental burdens (Dalir et al., 2021) will be discussed.

2.311 Financial Hardship. The financial hardship of CHD is substantial and multidimensional, documented across a wide range of international contexts (Choi et al., 2021; Cruz et al., 2022; Kankaya et al., 2025; Kolt et al., 2020; Ludomirsky et al., 2021; McClung et

al., 2018; Mombach Barreto et al., 2016; Moorman et al., 2025; Peterson et al., 2022; Scearbo et al., 2025; Sood et al., 2019). Employment disruption was a consistent finding; many parents reduced their workforce participation, including missed work hours, to accommodate complex caregiving demands (Cruz et al., 2022; Dalir et al., 2021; 2021; Kankaya et al., 2025; McClung et al., 2018; Moorman et al., 2025). In the qualitative findings, both financial and employment strains were stressed, with some caregivers reporting complete job loss due to their child's medical needs (Cruz et al., 2022; Kankaya et al., 2025; Moorman et al., 2025).

Kankaya et al. (2025) highlighted the disproportionate impact on mothers, noting that many had to quit their jobs entirely or work remotely to accommodate the significant demands of caregiving. For single mothers, this strain extended to daily necessities, such as transportation to and from the hospital, as well as to longer-term commitments, including maintaining employment and educational goals (Sood et al., 2019).

Medication costs (Choi et al., 2020; Cruz et al., 2022; Sood et al., 2019) and additional financial challenges, including gaps in insurance coverage and out-of-pocket costs for subspecialty care, further compounded families' financial pressures (McClung et al., 2018 & Peterson et al., 2022). Children with complex ongoing medical management that was not fully covered by insurance, or who lacked total health coverage, were found to face adverse health outcomes (McClung et al., 2018; Peterson et al., 2022). Broader socioeconomic impacts extended to food insecurity, with some families struggling with financial hardship having to rely on food assistance programs (Ludomirsky et al., 2021; Peterson et al., 2022). These findings collectively suggest that the financial burden of CHD is not only shaped by medical costs but also intersects with broader socioeconomic factors that shape an individual family's stability and a child's outcomes.

2.312 Shifts in Family Roles and Routines. Shifts in family roles and routines were consistently identified across the literature as families adapt to the realities of caring for a child with CHD (David Vainberg et al., 2019; Simeone et al., 2019; Sprong et al., 2024). Care challenges were described from both mothers' and fathers' perspectives (Cruz et al., 2022; Dalir et al., 2021; Nayeri et al., 2021; Sprong et al., 2024; Watkins et al., 2022; Vasilescu et al., 2024), and from the perspectives of other members of the family, including siblings (Bichard et al., 2022; Dalir et al., 2021; Schamong et al., 2021). Substantial evidence indicates that heightened caregiving demands precipitate profound shifts in parental roles (De Stasio et al., 2019; Sood et al., 2018; Sprong et al., 2024; Watkins et al., 2022). Specifically, intensive caregiving demands disrupt traditional nurturing behaviours; while some parents experience emotional exhaustion that manifests as psychological distancing between parent and child (De Stasio et al., 2019), others undergo a gendered role fragmentation within the family system (Sood et al., 2018). These role alterations extended beyond caregiving tasks to include acute psychological distress (Watkins et al., 2022), disrupting social relationships and everyday life (David Vainberg et al., 2019; Moorman et al., 2025; Sprong et al., 2024).

Several qualitative pieces of evidence, conducted across diverse sociocultural contexts, deepen the understanding of families living with a child diagnosed with CHD (Dalir et al., 2021; Hejl et al., 2020; Jackson et al., 2018; Kankaya et al., 2025; Nayeri et al., 2021; Sprong et al., 2024). Two phenomenological qualitative studies conducted in Iran found that parents and family members described the experience as a "catastrophic burdens of care," with significant time taken away from routine household duties and from other family members (Dalir et al., 2021; Nayeri et al., 2021). This caregiving strain was echoed in an Australian qualitative study in which interviews with 17 parents revealed intensifying caregiving demands and the strain of

balancing the needs of the child with CHD alongside those of siblings and partners (Jackson et al., 2018). Across these global contexts, caring for a child with CHD was consistently described as extending well beyond typical routine parenting responsibilities. This was characterized by parents closely monitoring symptoms such as cyanotic spells or breathing patterns (Dalir et al., 2021; Nayeri et al., 2021), physical limitations, and environmental precautions, contributing to persistent worry and additional stress (Dalir et al., 2021; Dahlawi et al., 2024; Nayeri et al., 2021; Sprong et al., 2024).

Although few studies have specifically examined sibling experiences, available research suggests that siblings undergo notable shifts in roles and responsibilities. Bichard et al. (2022) found that siblings of children with CHD in the UK attempted to take on additional caregiving and household duties to maintain family functioning. These additional roles negatively affected their emotional wellbeing and schooling, which may have been further intensified by the COVID-19 pandemic. Some siblings, however, also reported positive outcomes of the lockdown, noting that it meant more time together as a family unit (Bichard et al., 2022).

International research highlights that geography further amplifies these challenges for families of children with more complex CHD (Vasilescu et al., 2024; Watkins et al., 2022). In these contexts, families are often required to travel to distant tertiary or, in some cases, international surgical centers for access to care. This travel can result in prolonged separation from home, employment, and established support networks, thereby intensifying emotional, logistical, and financial strain (Vasilescu et al., 2024; Watkins et al., 2022). These findings reinforce the need for family-centred approaches to care and for additional economic and social supports (Dalir et al., 2021; Watkins et al., 2022) that address the holistic health needs of all patients and families with CHD (Dalir et al., 2021; Watkins et al., 2022).

Although these studies provided valuable insights, several limitations should be considered. Two studies were conducted within a specific geographical area in Iran, which may limit the transferability of their findings to other cultural and health care contexts (Dalir et al., 2021; Nayeri et al., 2021). In addition, many studies included predominantly mothers and relatively few fathers, underscoring the need for more inclusive research that reflects the experiences of the wider family unit (Dalir et al., 2021; Hejl et al., 2020; Jackson et al., 2018; Sprong et al., 2024). Further limitations identified by Dahlawi et al. (2024) and Nayeri et al. (2021) where only the number of participants was reported, with no accompanying demographic data. This lack of data restricts the understanding of participants' characteristics, including whether perspectives may be disproportionately influenced by one gender.

2.313 Environmental Burdens. Environmental factors present a distinct caregiving challenge for families of children with CHD. Respiratory infections are common in this population: a cross-sectional study of 180 children with varying degrees of CHD found that 25% had recurring respiratory infections (Azhar et al., 2016). These infections can lower blood oxygen saturation (Keenan-Lindsay et al., 2022) and can increase the frequency and length of hospital stays, significantly impacting QOL for children and their families (Azhar et al., 2016). As a result, parents spend considerable effort each day shielding their children from potential germs (Sood et al., 2019), environmental exposures, including crowded spaces, cigarette smoke, allergens, humidity, and conditions that might trigger or exacerbate respiratory distress (Dalir et al., 2021). Some families living in harsher conditions, including households with high humidity and those living close to animal waste disposal, reported that these environments could exacerbate respiratory illnesses such as asthma (Nayeri et al., 2021). Dalir et al. (2021) discussed the strategies families used to modify their living conditions, including removing allergens from

the home and installing humidifiers. The literature emphasizes the need for increased support and research for children with CHD and their families residing in underserved and widely dispersed regions. It has been shown that many families are burdened with environmental concerns, including extreme cold. Parents of children with CHD, specifically those with Fontan circulation, described how cold weather and outdoor sporting environments increased their worries regarding fatigue and overexertion, ultimately impacting the child's participation (Leo et al., 2023). The findings emphasize how environmental factors and parental perceived vulnerability intersect in shaping caregiving decisions (Leo et al., 2023).

2.32 Children and Family Quality of Life Outcomes

QOL is a central component in peadiatric CHD, capturing how children and their families experience the cumulative impact of medical, psychosocial and contextual factors over time. This section reviewed evidence on child and family QOL, including the tools used to assess it and factors associated with poorer outcomes. It will first discuss children and families' QOL generally, and then examine the four subthemes, which include (1) child QOL, (2) family QOL, (3) child psychosocial Impacts, and (4) family psychosocial impacts. These domains reflect both functional and psychosocial dimensions of everyday life. Understanding these patterns is critical for this current study, as children living in remote northern communities may face additional barriers that shape their everyday well-being.

Across the literature, studies incorporating both child self-reports and parent proxy reports consistently demonstrate that children living with CHD experience lower QOL and reduced well-being compared to their healthy counterparts (Dardas et al., 2024; Knowles et al., 2014; Lee et al., 2021; Marshall et al., 2024; Raj et al., 2017). Similarly, studies relying solely on parent proxy reports also found reduced QOL scores among children with CHD, although these

findings reflect parental perceptions rather than the child's direct experiences (Azhar et al., 2016; Mussatto et al.,2023; Jaschinski et al., 2022; Liu et al., 2022; Licht-Ardila et al., 2024). Additionally, research examining parents' own self-reported QOL indicates that caregivers themselves experience diminished wellbeing (Azhar et al., 2016; Khoshhal et al., 2019; Lopez et al., 2016; Mamasoula et al., 2024; Jaschinski et al., 2022; Schnellmann et al., 2022). Across both child and parent-reported measures, lower QOL is most consistently found among children with severe forms of CHD (Knowles et al., 2014; Liu et al., 2022; Raj et al., 2017).

Several factors contributed to lower QOL for children with CHD, driven by cumulative burdens such as time away from school, frequent cardiac interventions or surgeries (Pillay et al., 2020), medications, and non-cardiac comorbidities, including longstanding illness, vision, and hearing loss (Knowles et al., 2014). Additional evidence linked lower QOL to reduced functional capacity, greater disease severity (Lee et al., 2021), and socioeconomic and contextual factors, including poverty, lower parental educational attainment, and maternal caregiving roles (Lopez et al., 2016). These findings were consistent across studies, despite variations in QOL measurement tools. In the original literature search, almost half of the articles (n=27) reported on child and/or family QOL; the majority were quantitative in design, with only two systematic literature reviews, one mixed-methods study, and one qualitative study. In the updated literature search, over half (n=26) examined child and family QOL, again with the majority (n=22) being quantitative in design. The majority of the quantitative studies were cross-sectional designs, limiting causal interpretation and restricting understanding of how QOL changes over time for children and families.

2.321 Child QOL. The child QOL literature reviewed examines how children living with CHD experience everyday functioning and wellbeing across physical, emotional, social and

school-related domains. Within the studies reviewed, children's perspectives are typically addressed through standardized QOL questionnaires, which ultimately shape what is measured and how their everyday lives are captured and interpreted.

Across studies, the Paediatric Quality of Life Inventory (PedsQL) and the PedsQL 3.0 cardiac model are the most widely used validated tools for assessing health-related quality of life (HRQOL) in children with CHD. The generic PedsQL scale evaluates broad, everyday dimensions of health for children aged 2-18 years (Varni et al., 2001). It includes four dimensions: physical, social, emotional, and school functioning (Varni et al., 2001). The PedsQL cardiac module explicitly targets distinct condition-related stressors across five areas: heart symptoms, treatment anxiety, perceived cognitive and physical limitations and communication for children 8-18 years, with a corresponding parent proxy report section (Grimaldi Capitello et al., 2021; Uzark et al., 2003).

Across instruments and study designs, children and adolescents with CHD consistently report significantly lower HRQOL compared to their healthy counterparts (Bulbul Oztoprak et al., 2024; Licht-Ardila et al., 2024; Marshall et al., 2024). Reductions in QOL are evident across multiple domains of the PedsQL generic core scales, including physical, emotional, social and school functioning (Bulbul Oztoprak et al., 2024; Licht-Ardila et al., 2024; Marshall et al., 2024). However, findings varied regarding which domains were most affected. Using parent proxy reporting, Licht-Ardila et al. (2024), found physical functioning to be the most impaired HRQOL domain across all age groups. Whereas Bulbul Oztoprak et al. (2024), using the same PedsQL instrument but in a child self-report study, found that only adolescents scored lowest on physical health, whereas younger children aged 5-7 years scored lowest on psychosocial health (Bulbul Oztoprak et al., 2024).

Differences in reporting methods were noted and may have contributed to some of the variations observed. For example, Licht-Ardila et al. (2024) relied solely on parent proxy reports, whereas Marshall et al. (2024) included both child and parent proxy reports. Although Bulbul Oztoprak et al. (2024) was designed as a child self-report study, the authors noted that children under 7 years old may receive assistance from their parents. However, the study did not clearly state how many of the 60 younger children aged 5-7 required parental assistance in completing the questionnaire. This may have influenced the lower psychosocial health scores in this age group, as responses could partly reflect parents' fears and perceptions instead of the children.

Similar patterns have been reported using a validated oral health-related quality of life (OHRQOL) instrument, with child-reported data, demonstrating significantly poorer emotional, social, and functional well-being among children with CHD compared to healthy peers (Bessa et al., 2023). A systematic review and meta-analysis further found that children with CHD scored lower than healthy peers in the school functioning domain of the generic PedsQL and in the cognitive problems subscale of the PedsQL cardiac module (Mamasoula et al., 2024). These standardized QOL assessments indicate that lower scores imply a higher frequency of daily difficulties. As the pedsQL cardiac module specifically captures disease-specific burdens, these lower scores indicate that children with CHD experience more heart disease-related cognitive difficulties, such as problems with concentration and memory, compared to healthy peers.

The relationship between parental psychological distress and child QOL is complex. Using the PedsQL 3.0 cardiac model, Grimaldi Capitello et al. (2025) found that higher maternal anxiety and depression were associated with poorer child-reported cardiac-specific QOL in several domains. However, Marshsall et al. (2024) found that even significant parental stress, anxiety and or depression reported by parents did not predict child self-reported QOL. The

contrast in findings indicates that the association between parental psychological distress and children's perceived QOL is complex and likely influenced by multiple interacting factors, including disease severity, socioeconomic context, methodologies, and measurement tools used.

Access to surgical intervention also appears to shape QOL. Children awaiting cardiac surgery in Tanzania reported significantly lower HRQOL than those who had undergone surgical intervention, particularly in physical functioning domains (Koster et al., 2025). The study pointed to the influence of symptom burden and socioeconomic factors, including access and affordability of treatment for children living with CHD (Koster et al., 2025). While Canada's publicly funded cardiac surgery system differs substantially, access-related challenges persist for geographically dispersed families, including travel costs, time away from work, and distance from specialized centres. Findings suggest that although contexts differ, there are comparable implications for HRQOL in rural, remote, and northern regions.

Although QOL is consistently lower among children with CHD, the degree of variation across studies indicates that socio-environmental contexts and clinical factors, including the complexity of cardiac defect, age at surgery, and the number of surgeries performed, may play a role in outcomes. Frequent reliance on proxy reports also limits the extent to which the child's lived experiences are captured in this body of literature. Across studies, age-related differences, parental psychological functioning, and family well-being more broadly are associated with variations in child-reported QOL. These factors are best understood as part of broader interconnected systems, and QOL findings should be interpreted within the psychosocial context of the family unit as a whole. For this reason, the next section examines family QOL, which provides a broader understanding of how CHD affects the wellbeing across the family unit.

2.322 Family QOL. Psychological distress and lower perceptions of QOL have frequently been reported among parents of children living with CHD (Catapano et al., 2024; Khoshhal et al., 2019; Mussatto et al., 2023). Mothers of children with CHD have been shown to have significantly lower QOL than mothers with children with minor illnesses, not related to CHD, yet not listed by the authors (Sileshi & Tefera, 2017). Children with more complex CHD report lower HRQOL, a pattern also observed in parent proxy reports (Lee et al., 2021; O'Connor et al., 2023). Recent evidence from children with tetralogy of Fallot variants (moderate to severe CHD) suggests that higher BMI is associated with lower child and parent HRQOL, particularly in the physical and social functioning domains, underscoring that modifiable health factors (beyond CHD) can contribute to QOL outcomes.

However, some cross-sectional studies suggest that although HRQOL often declines with increasing CHD complexity, the condition's severity alone may be insufficient to explain these findings. Instead, the child's neurodevelopmental (e.g. stroke and/or seizures resulting from complex surgical and interventional histories), psychosocial comorbidities (e.g., learning difficulties, mental health concerns), and cumulative care challenges can shape the child and parent-reported QOL (Dardas et al., 2024; O'Connor et al., 2023). A prospective study found that surgical risk classification as a standardized indicator of CHD severity failed to show a significant association with parental psychological well-being (Lopez et al., 2016). Rather, social and environmental burdens, including socioeconomic strain, caregiving demands, and the maternal figure, might play a greater role (Lopez et al., 2016).

Correlations between financial hardship and emotional impacts on QOL have also been reported in two studies conducted in the United States (McClung et al., 2018; Moorman et al., 2025). A cross-sectional survey by McClung et al. (2018) found that parents experiencing

financial difficulties were twice as likely to express the need for mental health support compared to those without financial hardship. Additional contributing factors included lack of health insurance, having a child living with CHD, and also co-occurring physical, developmental or physical limitations (McClung et al., 2018). Qualitative work by Moorman et al. (2025) further illustrated how financial strain and mental health needs are experienced and embedded in families' everyday lives.

In contrast, another cross-sectional study conducted in Germany found that children with CHD had similar or even higher HRQOL compared to healthy peers (Reiner et al., 2019). Family support, coping strategies, and positive home and social environments were identified as possible explanatory factors (Reiner et al., 2019). These findings challenge a purely deficit-oriented reading of the literature and point to the protective role of contextual factors. Overall, across the literature, there was variability in instrument selection, a lack of CHD-family-specific measures, and inconsistent psychometric evaluations. These methodological inconsistencies complicate the interpretation of findings and likely contribute to the variability observed in reported QOL outcomes in the CHD literature (Eagleson et al., 2023; Reiner et al., 2019).

Overall, the literature suggests that children with CHD and their families experience lower QOL than healthy peers and families, and it is shaped by more than just disease severity. The outcomes are influenced by several factors, including disease complexity, socioeconomic strain, parental psychological functioning and access to care. However, inconsistencies in measurement, heavy reliance on proxy reports from parents, and limited research on factors such as geography make it challenging to fully capture and understand how QOL is shaped across diverse settings. These gaps further underscore the need for qualitative, child-centred research, particularly in underserved areas such as northern, rural, and remote communities, where access

and environmental stressors are more pronounced. Building on the broader understanding of QOL, the next section examines psychosocial impacts in greater depth, as these experiences are closely intertwined with overall well-being for both children and parents.

2.323 Child Psychosocial Impacts. Beyond QOL scores, children and youth with CHD experience a range of psychosocial challenges that affect their emotional, behavioural, social, and academic functioning. This section synthesizes the literature on emotional and behavioural difficulties, social relationships, self-concept and adaptive coping among children living with CHD. The psychosocial dimensions are key within the study, as it seeks to understand how children experience their lives while living with CHD in a northern community.

Children and youth with CHD consistently experience a range of behavioural and emotional challenges across the literature (Dahlawi et al., 2020; Millen et al., 2025; Oliver et al., 2020). These commonly included internalizing behaviours such as high levels of anxiety, social withdrawal, somatic complaints, and broader emotional difficulties within their daily lives (Millen et al., 2025; Oliver et al., 2020). However, the extent to which these challenges are directly attributable to CHD rather than to contextual factors, such as peer social situations or repeated environmental changes associated with hospitalizations, remains unclear. This uncertainty underscores the need for further qualitative research to better understand the children's lived experiences (Millen et al., 2025; Oliver et al., 2020). Behavioural challenges are frequently discussed alongside cognitive and motor difficulties, with overlapping impairments further increasing the risk of academic and social difficulties (Millen et al., 2025).

Quantitative synthesis further supports these patterns. A systematic review of eight studies found that children and young people with CHD experience greater emotional and behavioural difficulties, including depression and social withdrawal, with more severe or

complex conditions associated with greater challenges (Dahlawi et al., 2020). Similarly, a systematic review and meta-analysis of 16 studies examined psychosocial outcomes among 916 children and adolescents with severe CHD (Abda et al., 2019). The review found higher rates of behavioural challenges, including increased internalizing and externalizing difficulties, as well as lower social cognition, compared to healthy peers (Abda et al., 2019). Together, these findings emphasize the complex and multidimensional nature of psychosocial impacts while living with CHD, particularly among those with greater disease severity (Dahlawi et al., 2020; Abda et al., 2019). This underscores the importance of integrating routine psychosocial assessment into routine cardiac care (Abda et al., 2019).

Longitudinal research provides further insight into how these challenges develop over time. A Canadian study following 66 children with moderate to severe CHD from ages two to five found that, using repeated parent-completed Child Behaviour Checklist ratings, was used to examine patterns of behavioural and emotional functioning across early childhood (Lepage et al., 2025b). Although three-quarters of children's scores fell within normative ranges at each time point, a smaller group of children demonstrated early behavioural and emotional concerns that emerged at age two and persisted into the preschool years (Lepage et al., 2025b). Within this smaller subgroup, children who showed greater difficulties in early toddlerhood were associated with more pronounced challenges over time (Lepage et al., 2025b). Lower gestational age was also linked to persistently higher anxious/depressed symptoms (Lepage et al., 2025b). These findings underscore the importance of early screening and identification within peadiatric cardiac care (Lepage et al., 2025b). However, the study's small sample size and single-centre design may limit the broader generalizability of these findings in other regions or healthcare systems.

Medical complexity also shapes psychosocial outcomes. Children who undergo multiple surgeries (Jaschinski et al., 2022) and require implanted devices, such as permanent cardiac pacemakers (Allam et al., 2018), have been shown to experience poorer mental health outcomes, including elevated levels of anxiety and depression. In addition, visible physical changes following surgery can influence children's self-perception and social experience. Postoperative chest scars have been identified as a source of distress for some children, contributing to feelings of emotional discomfort (Savaş et al., 2024) and social vulnerability (Knowles et al., 2016; Savaş et al., 2024). While many children associate scars with negative experiences, such as feelings of social exclusion, one child in the Knowles et al. (2016) national cohort study demonstrated more positive feelings, viewing their scar as ‘special’ and ‘lucky’.

Beyond individual factors, children with CHD often experience broader social and academic disruptions. Frequent medical appointments, physical limitations and prior traumatic hospital experiences contribute to feelings of exclusion (Knowles et al., 2016; Savaş et al., 2024) or experience of bullying within the school setting (Hsiao et al., 2024; Savaş et al., 2024). Despite these challenges and recognizing their day-to-day differences, such as taking medication or being more aware of their health risks, children expressed a desire to maintain normalcy and to be perceived as similar to their peers (Knowles et al., 2016).

Notably, inconsistencies remain across the literature (da Silva et al., 2013; van der Watt et al., 2017). A cross-sectional study reported that male adolescents with CHD or acquired heart disease described fewer behavioural problems than healthy peers, while no significant difference was found among females (da Silva et al., 2013). Discrepancies were also noted between child and parent reports, with parents indicating more severe behavioural problems (da Silva et al., 2013). These differences may reflect adolescents’ tendency to minimize challenges and/or lack

of awareness of their own medical condition and how it affects them (da Silva et al., 2013). Da Silva et al. (2013) also noted that parents may be overestimating the severity of problems due to the emotional weight of their child's illness and can often skew their perception of their child's behaviours. The authors acknowledged that the results were not consistent with other literature on children with CHD, which often reports greater psychosocial issues among this group (da Silva et al., 2013). Findings from this research suggest that children and adolescents with CHD may adapt to their condition over time through positive coping strategies and consistent family support (da Silva et al., 2013). These findings are similar to those of Reiner et al. (2019), who reported similar findings and attributed adaptation to living with CHD, as well as social and family supports, as factors influencing improved health outcomes.

Similarly, a qualitative study conducted in South Africa found that some children aged 8 to 14 demonstrated unexpectedly high levels of cognitive self-regulation in managing their condition (van der Watt et al., 2017). Van der Whatt et al. (2017) define cognitive self-regulation as the ability to use mental skills to guide decision-making, which aids in adaptive and health-protective behaviours in children. These findings contrast with typical developmental expectations and the broader literature, which suggest that children in this age group have a limited cognitive understanding of illness and are not typically expected to independently manage their health-related behaviours (van der Watt et al., 2017). Such variability suggests that psychosocial outcomes are shaped by a combination of developmental, contextual, and cultural factors rather than CHD alone.

Various limitations were noted across the studies included. Many studies rely on cross-sectional designs, which restricts the ability to infer causal relationships or examine changes in outcomes over time (da Silva et al., 2013; Im et al., 2017). Small sample sizes and single-site

recruitment further constrain generalizability (Dahlawi et al., 2024; Knowles et al., 2016; Savaş et al., 2024; da Silva et al., 2013; van der Watt et al., 2017). Geographical location further limits the generalizability of findings due to the differences in cultural and healthcare contexts (van der Watt et al., 2017). Limited participant demographic data and reliance on single measurement tools restrict the depth of interpretation (da Silva et al., 2013). While most studies identified psychosocial challenges, da Silva et al. (2013) and van der Watt et al. (2017) identified more specific differences across age groups and genders, suggesting some variability in how these outcomes are presented.

Overall, children and adolescents with CHD face a wide range of psychosocial and cognitive impacts that are shaped by disease severity, age and development stage (Abda et al., 2019; Im et al., 2017; Millen et al., 2025). To respond to these complex needs, children and adolescents across the CHD spectrum require developmentally appropriate education and psychosocial support to promote self-empowerment and active engagement in their care (da Silva et al., 2013; Im et al., 2017; van der Watt et al., 2017). Age-appropriate information and family support around the illness can foster greater self-reliance, resiliency and QOL. Strategies for child coping include normalizing their experience with peers, recognizing and working within their physical capacities, and reframing their condition in a positive and meaningful way (Knowles et al., 2016). Children may also benefit from seeking information and taking an active role in managing their own health (Knowles et al., 2016). Importantly, studies that incorporate children's own perspectives on living with CHD suggest that their voices contribute uniquely to understanding psychosocial impacts and to developing child-specific outcome measures (Knowles et al., 2016). Despite a substantial body of research on psychosocial outcomes, there remains a limited in-depth understanding of children's lived experiences, indicating a clear need

for more qualitative work that meaningfully centres children's voices (Dahlawi et al., 2020; Knowles et al., 2016). Future qualitative research that centres on children's own perspectives and life experiences across their various environments may provide a deeper understanding of how these challenges are experienced and managed in everyday life (Dahlawi et al., 2020).

2.324 Family Psychosocial Impacts. Parents and families of children with CHD also experienced significant psychosocial impacts. This section reviews evidence on parental distress, coping, social support, and health service use, and how these factors intersect with children's psychosocial and broader outcomes.

The complex and often unpredictable nature of CHD exposes families to multiple stressors that can contribute to significant psychological impacts among parents (Cepuch et al., 2023; Dahlawi et al., 2020; David Vainberg et al., 2019; Jaschinski et al., 2022; Khoshhal et al., 2019; Lisanti et al., 2021; Nakazuru et al., 2017). Identified stressors include the child's need for cardiac surgery (Golfenshtein et al., 2021; Lin et al., 2024), the number of surgical operations (Jaschinski et al., 2022; Nakazuru et al., 2017), hospital admissions, including intensive care stays and separation from the child during hospitalization, particularly during NICU admission (Catapano et al., 2024).

Beyond acute medical events, parents frequently describe difficulty regaining a sense of normalcy due to the constant unpredictability and uncertainty surrounding their child's health trajectory (Kankaya et al., 2025; Moorman et al., 2025). Parental distress during hospitalizations is often shaped by loss of control, disrupted bonding, environmental stressors and role disruption (Besley et al. 2025; Catapano et al., 2024; David Vainberg et al., 2019; Kankaya et al., 2025; Moorman, 2025). Reflecting this, a cross-sectional study conducted in Australia (Besley et al., 2025) found that mothers of infants with CHD reported a strong association between maternal

stress and mother-infant bonding difficulties. These challenges were further exacerbated by prolonged family separation and heavy reliance on staff for infant care (Besley et al., 2025). Collectively, these findings make clear that parental distress and bonding challenges are not only a product of the child's diagnosis but are heavily shaped by care systems and environments.

From the moment of diagnosis, families experience a wide range of intense and often fluctuating emotions (Davey et al., 2023; Dandy et al., 2024; Jones et al., 2024; David Vainberg et al., 2019; Kankaya et al., 2025; Nayeri et al., 2021; Watkins et al., 2022; Vasilescu et al., 2024). A meta-synthesis of 26 qualitative studies exploring parents' psychological experiences at diagnosis suggests that families often felt unprepared and overwhelmed (Dandy et al., 2024). Parents described an ongoing process of mourning multiple losses, including the loss of a 'normal pregnancy', the 'imagined healthy child', and hopes for a typical lifespan for their child (Dandy et al., 2024). Families continue to face a wide range of, often fluctuating, emotions starting with the initial diagnosis and continuing through their child's cardiac journey. Feelings of anxiety (Mombach Barreto et al., 2016; Bruce et al., 2014b; Catapano et al., 2024; Dandy et al., 2024; Davey et al., 2023; Kankaya et al., 2025; Lopez et al., 2016), hopelessness (Bruce et al., 2014b; Dandy et al., 2024; Kankaya et al., 2025; Lopez et al., 2016; Mombach Barreto et al., 2016), fear and uncertainty about their child's future are key parental emotions reported across the literature (Bruce et al., 2014b; Catapano et al., 2024; Dandy et al., 2024; David Vainberg et al., 2019; Kankaya et al., 2025; Leo et al., 2023). Shock and sadness (Bruce et al., 2014b; David Vainberg et al., 2019) and intense fear, especially during moments perceived as near-death experiences (David Vainberg et al., 2019). With parents describing profound fear of losing their child and finding decision-making especially challenging during these critical events (Bruce et al., 2014b; Kankaya et al., 2025).

The hospital-to-home transition represents a distinct period of heightened vulnerability. Gaskin et al. (2024) conceptualize it as a "liminal" phase in which parents feel suspended between the perceived safety of the hospital environment and the uncertainty of managing complex care independently at home. This transition involves a complex emotional duality for parents. Parents experience an element of joy and excitement as they celebrate leaving the hospital, alongside a terrifying sense of lost support, fear and anxiety regarding independent clinical management at home (Gaskin et al., 2024; Simeone et al., 2018).

Significant psychological impacts on parents, such as post-traumatic stress (PTS) disorder, have been reported at various high-risk points, including diagnosis, hospitalization, discharge (Jones et al., 2024) and following a child's cardiac surgery (Davey et al., 2023; Golfenshtein et al., 2021). A scoping review of 31 articles found that while the majority of parents experienced decreased PTSS over time (post-traumatic stress symptoms), 16-25% of parents experienced persistent PTSS, extending longer than 16 months (Jones et al., 2024). These worsening PTSS have been linked to increased use of hospital services, including emergency room and unplanned cardiologist visits for their child (Golfenshtein et al., 2021). For some parents, the accumulated weight of these experiences progressed to significant distress, including depression, and in severe cases, suicidal ideation (Dandy et al., 2024; Jackson et al., 2018). Many caregivers also reported feelings of isolation (David Vainberg et al., 2019; Jackson et al., 2018; Kankaya et al., 2025; Mombach Barreto et al., 2016; Nayeri et al., 2021), lack of sleep, and self-care (Jackson et al., 2018).

Although both parents of children with CHD experience significant psychosocial impacts, emerging evidence suggests these are intensified among mothers (Cepuch et al., 2023; Kruszecka-Krówka et al., 2024; Lisanti et al., 2021; Nakazuru et al., 2017). Mothers of children

with CHD experience elevated rates of depressive symptoms and anxiety (Cepuch et al., 2023; Kruszecka-Krówka et al., 2024; Lisanti et al., 2021; Nakazuru et al., 2017) and are exposed to myriad stressors, especially pre- and postoperatively (Lisanti et al., 2021; Nakazuru et al., 2017). Timing of diagnosis (e.g., pre vs postnatal), changes in roles and routines (especially when the child is admitted to a peadiatric intensive care unit) (Lisanti et al., 2021), infant age, symptoms, and the chromosomal abnormalities present had a significant influence on the mother's anxiety, coping, and stress levels (Kruszecka-Krówka et al., 2024; Nakazuru et al., 2017). Fathers, while experiencing psychological distress across various cultures, often suppress it to conform to traditional gendered expectations of strength (Dandy et al., 2024). Despite the literature on this psychological burden, families' psychosocial needs are frequently not addressed by healthcare teams (Franklin et al., 2023; Jackson et al., 2018; Zhu et al., 2022). When parents lack adequate psychosocial support within their child's cardiac care, they are at increased risk for ongoing psychological distress and decreased well-being (David Vainberg et al., 2019; Franklin et al., 2023; Watkins et al., 2022). Importantly, Canadian evidence suggests that parental stress may impact not only parental well-being but also neurodevelopmental outcomes in toddlers with CHD (Lepage et al., 2025a). This retrospective cohort study of 100 toddlers with moderate to severe CHD found that parenting stress during infancy was associated with poorer cognitive, receptive language, and gross motor developmental outcomes at 24 months (Lepage et al., 2025a).

In summary, parental psychological distress, limited social support, and difficulties accessing mental health and practical resources are common. These challenges can compound the everyday demands of caring for a child with CHD. The psychosocial strains have direct implications for both parents' and children's QOL, reinforcing the importance of interpreting

QOL within broader relational and contextual environments. However, critical gaps remain in understanding these experiences. Future research across varying points in time, using diverse methodologies, especially qualitative approaches and a gendered lens, is crucial to deepening our understanding of the complex factors that shape families' experiences, caregiving responsibilities, and overall well-being. A deeper understanding could inform and enhance the support that health professionals and environments provide to help address the challenges that families and children living with CHD face.

2.33 Child Growth and Development

Children living with CHD may experience issues related to physical growth (Azhar et al., 2016) as well as broader developmental challenges that can affect everyday functioning, such as participation in education and leisure activities (Farr et al., 2018; Spillmann et al., 2021). The following subthemes are discussed: physical activity, functional and cognitive abilities.

2.331 Physical Activity. Physical activity and functioning play an essential role in overall QOL, physical and emotional outcomes, and in preventing comorbidities for children with CHD (Blais et al., 2020; Pillay et al., 2020). However, engagement in physical activity is shaped by a web of intersecting barriers. Adolescents living with CHD consistently report feeling "different" from peers (Hsiao et al., 2024) and describe limited physical activity and/or restricted participation in sports due to parental concerns (Hsiao et al., 2024; Leo et al., 2023; Venna et al., 2025). A rapid review identifying barriers and facilitators of physical activity among children and adolescents with CHD found parental fear and uncertainty about safe activity as a key barrier to engagement (Venna et al., 2025). It also emphasized sociocultural barriers, including unclear exercise guidance from health care providers, social misunderstandings among peers, and limited knowledge within schools (Venna et al., 2025). In school-aged children with CHD, higher

parent-perceived child vulnerability has been associated with lower moderate to vigorous physical activity (MVPA), suggesting that parental beliefs around their child's body and fragility may meaningfully impact children's participation in sports (Sprong et al., 2023). Interestingly, this study did not find significant associations between MVPA and parental overprotection, indicating that parents' perceptions of vulnerability may be more influential than their apparent protective behaviours (Sprong et al., 2023).

Several studies revealed a mix of factors that shape physical activity for children with CHD, including social exclusion (Blais et al., 2020; Desai et al., 2013; Knowles et al., 2016; Moola, 2020), fatigue, reduced physical endurance (Dahlawi et al., 2024; Knowles et al., 2016), pain, and fear of failure (Blais et al., 2020; Knowles et al.,2016; Moola, 2020). Some children experience frustration, anger, and sadness when unable to keep up physically with peers (Savaş et al., 2024). Despite these challenges, among those who did participate in physical activity described feeling excitement and enjoyment, emphasizing positive peer interactions and inclusion as important aspects of their experience (Blais et al., 2020). These findings point to the need for a broader social and cultural shift in how physical ability is perceived (Blais et al., 2020; Moola, 2020). Targeted educational interventions and tailored exercise programming can enhance disease-specific knowledge and build the self-efficacy required for safe, confident participation in physical activity (Blais et al., 2020; Moola, 2020).

2.332 Functional and Cognitive Abilities. Children with CHD demonstrate typical overall intelligence compared with those without CHD, while experiencing specific neurodevelopmental and functional challenges (Spillmann et al., 2021; Millen et al., 2025). These challenges are particularly evident in executive functioning, working memory, and processing speed (Spillmann et al., 2021; Millen et al., 2025). A systematic scoping review

found that children with CHD scored significantly lower in the cognitive domains of concentration, expressive language, and receptive language (Millen et al., 2025). A prospective cohort study of 134 children similarly found that factors beyond cardiac complexity, including SES and postoperative complications, contributed to prolonged hospital stays and significantly affected cognitive functioning outcomes (Spillmann et al., 2021).

Cognitive challenges (Spillmann et al., 2021; Millen et al., 2025), particularly in executive functioning and attention (Farr et al., 2018; Millen et al., 2025), appear to shape broader functional difficulties (Farr et al., 2018; Flemming et al., 2024; Pfitzer et al., 2019; Spillmann et al., 2021). These difficulties span across multiple areas of daily living, including motor skills, self-care and independence, endurance, communication, task performance and social participation (Farr et al., 2018; Millen et al., 2025). Children with CHD generally participate in leisure activities; however, lower cognitive functioning has been associated with reduced participation, suggesting that neurocognitive difficulties may limit opportunities for everyday engagement (Spillmann et al., 2021).

Children with CHD also experienced significant challenges in school participation that extend beyond academic performance to include attendance, engagement, and extracurricular and social involvement. Researchers suggest that children with CHD are more likely to have increased missed school days (Farr et al., 2018; Flemming et al., 2024; Pfitzer et al., 2019; Savaş et al., 2024), perform lower in academics and require additional educational supports compared to healthy peers (Farr et al., 2018; Flemming et al., 2024; Millen et al., 2025; Spillmann et al., 2021). Children with severe CHD were found to have deficits in metacognitive functioning (Millen et al., 2025), which had a substantial impact on school performance and were more likely to repeat a school year (Pfitzer et al., 2019). In contrast, the Millen et al. (2025) scoping review

identified limited direct evidence (two studies) specifically linking CHD to reduced school attendance, suggesting that variations in findings may reflect contextual differences in child age, CHD severity, and study design. School-related difficulties are not attributable to a single factor; they are part of a complex, multifactorial interplay of cognitive (Millen et al., 2025; Spillmann et al., 2021), functional, health-related and social limitations that directly impact classroom engagement, task completion and overall educational attainment (Farr et al., 2018; Flemming et al., 2024; Millen et al., 2025).

Qualitative evidence conducted in Europe suggests that functional and developmental concerns are often overlooked during periods of acute, unpredictable medical care (Clarke et al., 2025; Sprong et al., 2024) and are typically more pronounced early in a child's life. These concerns become more apparent as a child grows older and their condition stabilizes, allowing parents to prioritize developmental concerns (Clarke et al., 2025; Sprong et al., 2024). Several studies stress the critical need for anticipatory and routine developmental monitoring given the evolving needs of children living with CHD (Clarke et al., 2025; Farr et al., 2018; Sprong et al., 2024).

Overall, several methodological limitations were noted across the included studies. The majority of the articles were quantitative in design, thereby limiting understanding of the lived experience of children with CHD. Both Farr et al. (2018) and Pfitzer et al. (2019) were cross-sectional in design, so cause and effect cannot be fully understood; both studies were also conducted as parent proxy. A further limitation of Farr et al. (2018) is the reliance on data from the National Survey of Children's Health to identify children with special health care needs. Although the majority of children with CHD fall within this category, not all children with CHD do, and so it may not be generalizable to the broader CHD population. The findings also stress

the various challenges children living with CHD face, underscoring the need for increased support, timely screenings, and continued research that attends to their lived experiences and the relational and contextual factors shaping their development.

2.34 Family Unique Needs

Children and families living with CHD have reported a wide range of unique and evolving needs. The following subthemes are discussed: (1) the need for family resources and supports, and (2) child-specific resources and supports. Both are essential for enhancing the overall care experience, within the hospital setting and following discharge into their home environment.

Families of children with CHD frequently described general fear and uncertainty, and more specifically fear related to a lack of specialized peadiatric cardiac support and services (Cruz et al., 2022). Concerns included their child's overall health status, the potential need for surgery, challenges with referrals and wait times, and whether timely intervention and follow-up would be available (Cruz et al., 2022). Families also reported challenges navigating fragmented health care systems, in which mental health needs and services are often perceived as separated from cardiac care for children with CHD (Hejl et al., 2026). This fragmentation can delay recognition of children’s mental health difficulties and make it harder to access timely, holistic supports that address both cardiac and mental health needs together (Hejl et al., 2026).

Families and caregivers across geographically diverse settings also reported substantial barriers to care, including challenges in navigating complex healthcare systems and service limitations due to geographic constraints (Choi et al., 2021; Lopez-Barreda et al., 2024). Evidence from a large, multi-country study in Latin America found that perceived barriers to care are shaped not only by individual and family socioeconomic characteristics but also by

structural and country-level health care system factors (Lopez-Barreda et al., 2024). During the COVID-19 pandemic, a cross-sectional study out of the United States found that although therapy access for children with CHD was maintained, the shift to virtual or hybrid delivery models was associated with decreased parent satisfaction (Donovan et al., 2023). Findings emphasize mode of delivery as a key determinant of families' service satisfaction (Donovan et al., 2023).

Geography plays a critical and specific role in shaping health outcomes for children with CHD (Pinto et al., 2021). A retrospective cohort study conducted in the United States found that greater distance from specialized cardiac surgical centres was associated with fewer unplanned readmissions to the surgical hospital (Pinto et al., 2021). This could be related to families seeking care locally or experiencing delays in accessing the surgical center. However, when readmission did occur among those living farther away, it was associated with longer hospital stays, higher costs, and increased complications, suggesting greater acuity (Pinto et al., 2021). Rural residence, independent of distance, was also associated with an increased likelihood of readmission, reflecting the limited availability of specialized local services and greater reliance on tertiary centers for care (Pinto et al., 2021). A key limitation of this study was that data captured only readmissions at major cardiac surgical centres, likely underestimating total service use among individuals seeking care at local hospitals (Pinto et al., 2021). In particular, those living in more geographically isolated areas (Pinto et al., 2021). These findings emphasize the need for increased research and service development in geographically dispersed and under-resourced areas, especially those living with chronic and potentially life-threatening illnesses, such as children and families with CHD (Pinto et al., 2021).

2.341 Family Resources and Supports. Families require clear, regular and ongoing communication and reassurance from health care providers about their child's health (Cruz et al., 2022; Catapano et al., 2024; Dandy et al., 2024; Franklin et al., 2021). This helps build trust and effective collaboration between families and the healthcare team, leading to better health outcomes for families and children with CHD (Cruz et al., 2022; Franklin et al., 2021). The lack of information and continuity in care often leaves parents actively coordinating their child's appointments, medications, and follow-up visits to mitigate gaps in a fragmented system (Cruz et al., 2022). Parental knowledge construction extends beyond formal provider education. Confidence in managing their infant's care grew through experiential and relational learning (David Vainberg et al., 2019; Gaskin et al., 2024), active engagement with the medical team, and learning from other parents' experiences (Gaskin et al., 2024). Recommendations from families for closing these gaps include frequent, open, up-to-date, and transparent communication between healthcare teams and families (Azhar et al., 2016; Schnellmann et al., 2022; Sood et al., 2019). Communication and information delivered should go beyond specific care for the child's illness and trajectory to include anticipatory guidance. Areas for anticipatory guidance should include the child's developmental and social health needs to empower parents, so they feel better prepared and more confident in their child's care (Bruce et al., 2014b; Sood et al., 2019).

Additional educational supports, such as institutionally supported online platforms (Yang et al., 2025), digital videos or mobile applications, have been reported as beneficial and positively received by families in managing complex caregiving demands (Jackson et al., 2018; Liu et al., 2022). Frequent phone calls and health promotion counselling have also been identified as feasible modes of ongoing support, even in specialized areas such as preventive oral health (Karikoski et al., 2022). Enhanced education on CHD, including treatment pathways, was

reported as essential regardless of family background (Animasahun et al., 2015; Azhar et al., 2016).

All family resources and support must consider the critical component of time. Families have described caregiving across illness phases as particularly vulnerable, as information and emotional needs shift in response to evolving medical and developmental demands (Jackson et al., 2018; Pridham et al., 2018; Sprong et al., 2024). Therefore, parental concerns are not static but change across phases of the child's condition (Sprong et al., 2024). Stress and worry frequently intensify at key vulnerability points, such as the initial diagnosis, peri-operative years, hospitalizations (Cruz et al., 2022; Elliott et al., 2021; Pridham et al., 2018; Sprong et al., 2024), discharge, early home care and adaptation (Gaskin et al., 2024). Parents' needs for information, guidance and reassurance differ at diagnosis, during preoperative preparation, and postoperative recovery, and again at later developmental stages, reflecting the dynamic and ever-changing nature of caregiving demands (Pridham et al., 2018; Sprong et al., 2024; Yang et al., 2025). Multiple studies suggest the need for continued support, follow-up guidance, and developmentally appropriate education across the transition phases of the CHD journey (Elliott et al., 2021; Im et al., 2017; Sanker et al., 2022; Sprong et al., 2024; Yang et al., 2025).

Relational and community supports are foundational to family coping. Families describe coping through striving for normalcy and becoming experts in their child's health (Lumsden et al., 2019). Sources of support included friends, family, partners, peer support groups, and interdisciplinary health team members like social workers (Azhar et al., 2016; Bruce et al., 2016; Bruce et al., 2014b; Dandy et al., 2024; David Vainberg et al., 2019; Franklin et al., 2021; Lumsden et al., 2019; Mombach Barreto et al., 2016; Sood et al., 2019). Religious or spiritual supports were also identified as important resources for helping parents cope with the emotional

and psychological challenges associated with their child's condition (Bruce et al., 2016; de Morais Almeida et al., 2024; Dandy et al., 2024; David Vainberg et al., 2019; Lin et al., 2024).

Formal government and public health care programs were also described as helpful resources (Stood et al., 2019). Organized programs, such as therapeutic camps, were also described as particularly valuable, offering children with CHD opportunities to participate in typical camp activities alongside peers who also live with CHD (Desai et al., 2013; Moola et al., 2015; White et al., 2016). These camping experiences provided meaningful benefits for both parents and children with CHD (Desai et al., 2013; Moola et al., 2015; White et al., 2016). External supports and respite care were recognized as important in enabling families to recharge and continue meeting complex daily needs (Bruce et al., 2014b; White et al., 2016).

The literature supports the need for individualized, family-centred care that addresses the specific needs and well-being of the whole family unit, including parents and siblings (Sprong et al., 2024). To ensure that parents' psychological concerns are being addressed, it is imperative that the child's health care team also provides screening and family-centred interventions (Franklin et al., 2023; Lepage et al., 2025; Sprong et al., 2024). This approach facilitates early conversations and recognition of parental stress and well-being concerns, allowing the health care team to provide appropriate and timely psychosocial and multidisciplinary support and to coordinate referrals, if needed (Franklin et al., 2023; Lepage et al., 2025).

2.342 Child Specific Resources and Supports. While the majority of the literature has emphasized parental information needs and caregiver supports, emerging evidence increasingly supports directing resources specifically to children living with CHD. This includes multidisciplinary approaches to ensure appropriate and timely follow-up programs and to monitor key developmental milestones (Sprong et al., 2025). Early and ongoing developmental

and emotional assessments and screenings should be integrated into the cardiac care treatment pathway (Dahlawi et al., 2024; Licht-Ardila et al., 2024). Physiotherapy assessment has been found to help health care providers identify and address motor developmental challenges earlier (Clarke et al., 2020). A recent randomized controlled trial conducted in China further found that a supervised, individualized home-based exercise program with telehealth follow-up significantly improved gross and fine motor development in children aged 0-5 with simple CHD within 6 months of cardiac catheterization (Du et al., 2024). This study also found that, in addition to improved child health outcomes, parental QOL was enhanced (Du et al., 2024).

Child-friendly preoperative preparation, including arts-based approaches and age-appropriate explanations, helps children feel comfortable and supported (Dahlawi et al., 2024). Health care providers should engage adolescent patients as active participants in their own care through shared decision making, ensuring their emotional needs are also met by identifying supports and addressing past or current trauma related to their cardiac journey (Savaş et al., 2024). Discrepancies have been reported between children and adolescents' self-perceived confidence in readiness for transition to adult cardiac services and adult assessments. These findings highlight gaps in knowledge and healthcare navigation that require continued specialized, developmentally appropriate programming (Sanker et al., 2022).

In the context of peer bullying and social exclusion, children often turn to their parents as their primary source of comfort, as they value the feeling of being completely understood (Hsiao et al., 2024). Beyond the family, teachers, nurses and social workers emerge as trusted and stable supports, playing a critical role in fostering inclusive and responsive environments for children with CHD (Savaş et al., 2024). These professionals are particularly important for children who missed school due to illness, as they facilitate reintegration into academic, social, and physical

activities while reducing associated stress (Dahlawi et al., 2024). Alongside these supports, supportive peers (Venna et al., 2025) and teacher relationships have been shown to positively influence physical activity engagement (Savaş et al., 2024; Venna et al., 2025). Collectively, the literature underscores the importance of coordinated relational support across home health care and educational contacts, highlighting the need for integrated systems that attend to the multifaceted and complex lives of children living with CHD.

2.4 Gaps and Recommendations Within the Literature

Although this literature search provided a well-rounded, international view of children and families living with CHD, important limitations remain regarding its generalizability to the Canadian and northern contexts. These limitations are shaped by political, organizational, and societal variations across geographical landscapes. Notably, only one article (Pinto et al., 2021) mentioned children and families living in rural, remote, and northern areas with CHD, and as shown in the literature, populations living in these regions face unique living and healthcare challenges. This gap points to a critical need for research conducted in geographically diverse settings to develop a deeper understanding of the specific realities faced by populations these regions.

Across the literature, several key recommendations related to care delivery, knowledge creation and future research were identified. These included enhancing family-centred approaches to care (Bruce et al., 2014b; Cruz et al., 2022; Silva et al., 2013; Franklin et al., 2021), increasing research conducted in geographically dispersed regions (Pinto et al., 2021; Raj et al., 2018), and increasing the meaningful inclusion of children's voices, including younger children in both care and research (Dahlawi et al., 2020). There is also a clear call to broaden the use of qualitative methodologies generally to enhance understanding of the complex lived

experiences of children and families living with CHD. Given the reported impacts on QOL across all family members, family-centred approaches are particularly needed among those living with socioeconomic challenges (Lopez et al., 2016). The literature further emphasizes the need for routine mental health screening across family members (Golfenshtein et al., 2021; Jaschinski et al., 2022; Lisanti et al., 2021; McClung et al., 2018) and for interventions that are responsive to families' diverse and context-specific needs (Llewelyn-Williams et al., 2022).

Methodologically, the literature is dominated by quantitative, primarily non-experimental designs that rely heavily on standardized questionnaires and predetermined measures. While valuable, these approaches may limit deeper understanding of children's and families' perspectives and the contextual factors shaping their experiences. Most of these studies relied on parent proxy responses rather than children's, which also limits knowledge in this area (Azhar et al., 2016; Jaschinski et al., 2022; Mussatto et al.,2023; Liu et al., 2022; Licht-Ardila et al., 2024; Spillmann et al., 2021). Additionally, studies examining parental perspectives predominantly included only mothers completing questionnaires and may therefore limit the diversity and generalizability of the findings (Golfenshtein et al., 2021; Jaschinski et al., 2022; Lopez et al., 2016).

Across the literature, it is often noted that there is poor correlation between parent and child accounts; parents often report lower QOL scores, reflecting poorer overall functioning than their child (da Silva et al., 2013; Dahlawi et al., 2020; Knowles et al., 2016; Lee et al., 202; Mamasoula et al., 2024; Patel et al., 2017). This highlights the importance of capturing children’s perspectives, which cannot be fully represented through proxy reporting. Although discrepancies have been cited throughout the literature between parent and child QOL reporting, some studies found general agreement between child and parent reporting on QOL (Mamasoula

et al., 2024; O'Connor et al., 2023). One study still found differences in the social domains, with parents reporting lower functioning (Koster et al., 2025). Together, these inconsistencies, along with the limited inclusion of children's perspectives, further strengthen the case for including their voices in research.

Finally, quantitative studies differed in terms of measures, sample sizes, participant demographics, and CHD severity, further limiting the generalizability of the findings. To address current knowledge gaps, a qualitative study was conducted to explore the lived experiences of children and families living with CHD in rural/remote/northern settings.

3.0 Chapter Three: Research Questions and Objectives

3.1 Research Purpose

Drawing on Bronfenbrenner's Bioecological Theory and van Manen's hermeneutic-phenomenological approach, this qualitative study explored the lived experiences and overall perceptions of children diagnosed with CHD and their families living in rural, remote, or northern communities within NWO. This will aid in a better understanding of the experiences and needs of children and their families living with CHD.

3.2 Research Questions

The main question explored within this study was:

1. What are the experiences of children diagnosed with CHD and their families living in rural, remote, and northern areas of Northwestern Ontario?

The following four sub-questions were posed to guide the research process and are underpinned by Bronfenbrenner's Bioecological Theory, as it considers the child and family as a unit and the complex bidirectional influences of the multi-layered environment that shapes their world. The research questions also align with van Manen's existential four lifeworlds methodology: *lived space, body, time,* and *other* (van Manen, 2007). These existentials provide a framework for exploring the various dimensions of the lived experiences of CHD. The following questions broadly address both the child and the family, the specific existential and were further broken down and tailored to the child's developmental age and stage, utilizing Piaget's Cognitive Theory of Development within the interview guide (refer to Appendix C). Although each question was broadly associated with a particular existential, the lifeworld existentials are deeply interconnected and were not treated as distinct categories.

1.1 How does your home environment impact your experiences of living with CHD or caring for a child with CHD?

1.2 How does living with a diagnosis of CHD or caring for a child with CHD affect activities of daily living and routines?

1.3 Since the diagnosis of CHD, what have been your experiences living with or caring for your child with CHD?

1.4 What are your experiences and relationship perspectives with your family, school, work, community, and the health care teams?

4.0 Chapter Four: Methodology and Conceptual Framework

This section will discuss my philosophical assumptions and how they might have influenced this research project. An in-depth exploration of both my chosen theoretical framework and methodology will be provided, including a consideration of the seminal and historical literature that has shaped the current works of both Bronfenbrenner's Bioecological theory and van Manen's hermeneutic phenomenology.

4.1 Positionality

Reflexivity is a guiding principle in much qualitative research, particularly in hermeneutic phenomenology. It enhances data analysis and the interpretation of themes that emerge from the research process (Solan et al., 2014). Engaging in self-reflexivity allows for a deeper critical consciousness, which helps the researcher to position themselves within their research (Creswell and Poth, 2018). I am a white, healthy, able-bodied female residing in an urban area of NWO. My experience as a Registered Nurse includes nursing education, working with children and families, and emergency care. I previously worked as an RN at BC Children's Hospital in Vancouver and the TBRHSC. My current full-time position is as a Lecturer in the School of Nursing at Lakehead University.

While working as an RN at BC Children's Hospital, I gained knowledge and skills across various acute care areas; my final area of work and passion was the cardiac unit. While working on this unit, I gained advanced skills in caring for children with varying degrees of CHD. The most acute cases were awaiting cardiac transplants with life supports such as left ventricular assist devices (LVAD) or Berlin Heart machines. While working as an RN in the local NWO context, it was hard for me to be face to face with the real lack of specialized paediatric cardiac care and support for children and families in this region. I acknowledge I am an 'insider' to my

research topic due to my past nursing experiences and recognize my values, beliefs, and biases when collecting and analyzing the data. My personal and professional values and beliefs align with the College of Nurses of Ontario (CNO) (2023) professional standards. These standards mean prioritizing respect for client's dignity, integrity, inclusivity, and culturally safe care to ensure I can provide care that is in the clients best interest (CNO. 2023).

In addition to my past professional experiences, during this research project, I experienced a significant personal transition as I became pregnant with my first child and later entered early motherhood. I feel fortunate to be married to a very supportive partner and to be surrounded by an extremely supportive family, a close circle of friends, as well as social support systems, including childcare. These supports played a crucial role in enabling me to navigate early motherhood while completing this PhD and working full-time. Without them, this journey would have likely been a far more challenging journey. This experience added additional layers to my reflexive practice, especially during family interviews, where parents shared learning of their child's CHD diagnosis during their prenatal screening. At this time, I was approaching my prenatal anatomy screening, and later, within the research, I was caring for a newborn. These personal experiences significantly heightened my emotional awareness and required ongoing reflexive engagement to ensure that my experiences and emotions did not overshadow or shape the participants' experiences and interview responses.

I maintained a reflexive stance throughout the research process, critically considering how my pre-assumptions and prior experiences (both professional and personal) could influence my perceptions and interpretations of the data. Acknowledging my current and past experiences in acute care nursing within the specialized field of paediatric cardiology, alongside personal experiences, allowed me to engage in critical self-reflection (Heinonen, 2015; van Manen, 2007).

For example, my familiarity with typical clinical trajectories and medical terminology sometimes led me to anticipate particular concerns, such as worries about surgical outcomes or hospital readmissions, before participants explicitly raised them in interviews. My reflexivity practices are discussed in detail below in section *4.5 Phenomenology of Practice: Implications for Child and Family Health.*

Strong awareness of positionality enhanced transparency and rigour, helping ensure that my perceptions did not misrepresent the data (Ibrahim & Edgley, 2015). Throughout the research process, I remained aware of potential power imbalances. As an RN and the primary researcher, I critically considered the dynamics between myself and participants to ensure I created an open, comfortable environment for discussion (Ibrahim & Edgley, 2015). In practical terms, this meant clearly introducing myself as the researcher rather than in a clinical role, inviting participants to ask questions about the study, emphasizing that there are no right or wrong answers and that we can stop at any time. When interviewing parents, I used plain non-technical language when discussing their child's condition or treatment. When interviewing children, I adapted my language to their developmental stage, drawing on Piaget's Cognitive Theory of Development to ensure the interview guides aligned with their level of understanding. I observed body language and regularly checked in with participants to ensure questions were understood. I allowed participants to set the pace of the interview, I offered pauses and took breaks when participants appeared confused, reflective or had emotional moments. Across the interactions, I continually aimed to be respectful, empathetic, and non-judgmental, with the intention of reducing any perceived hierarchies and fostering a sense of safety and mutual respect during our conversations.

4.2 Philosophical Assumptions

The philosophical underpinnings that guided this research project were shaped by a blend of idealist ontological assumptions and interpretive epistemological assumptions, which will be further discussed below (Creswell and Poth, 2018; Giacomini, 2010).

The idealist ontological lens aligns with the interpretive paradigm, guiding this research, recognizing that reality is understood through individuals lived experiences and the meaning they attribute to these experiences (Creswell and Poth, 2018). This interpretive orientation aligned with van Manen's hermeneutic phenomenological approach, which seeks to understand and interpret the meanings embedded in the complexities of lived experience (Creswell and Poth, 2018; Lincoln et al., 2018). This paradigm provided a deeper understanding of the intricacies and intersecting issues children and families experience while living with CHD in their home communities within NWO (Creswell and Poth, 2018; Giacomini, 2010). This included historical and cultural elements that shaped and influenced their societal views, experience of health, healthcare services and access to care within the context of NWO (Creswell and Poth, 2018; Giacomini, 2010).

The interpretive paradigm shaped the research process. For example, the study included children and families across Northwestern Ontario and intentionally included all eligible children, including young children, to create space for voices often underrepresented or excluded in research. Questions were broad, open-ended, and centred around van Manen's lived existentials (Creswell and Poth, 2018). This allowed participants to describe their lived experiences in their own words and explore meanings they attributed to living with or caring for a child with CHD (Creswell and Poth, 2018). During analysis, the study also considered the broader context in which participants' experiences occurred, including geography, access to

healthcare services, institutional practices, and other factors that shape families' experiences of accessing cardiac care in Northwestern Ontario. As the researcher's interpretations were shaped by the participants' findings, yet also by professional and personal background, which aligns with the study's hermeneutic phenomenological methodology (Creswell and Poth, 2018). The guiding philosophical assumptions supported in-depth exploration of children and families lived experiences in NWO, which helped uncover their healthcare needs and complex family experiences. These findings will aid in informing health care practice and policy changes that better address the unique needs and experiences of children living with CHD and their families in NWO. Particularly relating to challenges associated with health care access, family care, and the intricacies of living in geographically underserved regions.

4.3 Theoretical Framework: Bioecological Theory

The Bronfenbrenner Bioecological Theory provides a comprehensive and holistic understanding of child and family health and served as the guiding theoretical model throughout this research project (Bronfenbrenner & Morris, 2006; Bronfenbrenner, 2001). The theoretical underpinnings of this theory shaped the research questions and overall research design.

The Bioecological Theory was developed by Uri Bronfenbrenner, a leading scholar in developmental psychology (Bronfenbrenner, 1977; Rosa & Tudge, 2013). Bronfenbrenner's original work included *Toward an Experimental Ecology of Human Development* (1977) and *The Ecology of Human Development* (1979), in which he believed that individuals are products of their environment and time. His work continued to evolve in the 1990s into the Bioecological Theory, also named the Bioecological Model of human development it included recognition of the biopsychological characteristics of the person (Bronfenbrenner, 2001; Rosa & Tudge, 2013). The Bioecological Model has several defining properties that encompass new elements and

fundamental tenets from its earliest form (Bronfenbrenner, 2001). They are described by Bronfenbrenner as a series of seven critical propositions (Bronfenbrenner, 2001).

With the Bioecological theory, Bronfenbrenner defines development as "the phenomenon of continuity and change in the biopsychological characteristics of human beings both as individuals and as groups. The phenomenon extends across the life course, across successive generations, and through historical time, both past and present" (Bronfenbrenner, 2001, p. 3). The Bioecological theory views family and child health development as a complex interplay among various levels of environmental and social influences (Boyel et al., 2019). The Bioecological Model views the individual's health as influenced by various environmental factors. The influence of environmental contexts is bidirectional, so a shift in one area may positively or negatively affect another, altering the life course and development (Santrock et al., 2020).

Critical proposition (I) consider human development to involve a reciprocal interaction between individual characteristics and elements of the environment in which they live (Bronfenbrenner, 2001). This comprise the subjective and objective elements; together, they are suggested to be influential in the life course of human development. Subjective elements involve an individual's unique genetic and personal characteristics and experiences. Objective elements refer to immediate and broader environmental and social contexts. Bronfenbrenner was influenced by Kurt Lewin and believed that the ecological environment in which people live could be understood from the field of phenomenology (Bronfenbrenner, 2001; Rosa & Tudge, 2013). Although Kurt Lewin influenced Bronfenbrenner, this theory does not directly align with phenomenology, as it moves beyond understanding an individual's worldview to include a

framework encompassing multiple, complex, intersecting systems that shape human development (Bronfenbrenner, 2001).

Critical proposition (II) discusses the impacts of proximal processes (Bronfenbrenner, 2001). The experiential world of individuals is highlighted as having a significant influence on the second key proposition, which is foundational within the Bioecological Model: the *proximal processes*, which are frequent bidirectional interactions between individuals and the microsystem part of their environment. The context a person finds themselves in, along with their personal characteristics and temporal and spatial aspects, directly influences proximal processes and ultimately shapes an individual's development (Bronfenbrenner & Morris, 2006; Rosa & Tudge, 2013).

Critical proposition (III) addresses the Process-Person-Context and Time (PPCT) model, highlighting the importance of all the component that influence human development (Bronfenbrenner & Morris, 2006; Rosa & Tudge, 2013), which are viewed as the driving 'engines' within child and family development (Bronfenbrenner, 2001; Bronfenbrenner & Morris, 2006; Rosa & Tudge, 2013). Human development occurs through reciprocal interactions between individuals, between individuals and symbols such as gestures or other forms of communication, and between individuals and objects, including the physical or material aspects of the environment (Bronfenbrenner, 2001). Proximal processes refer to these regular interactions in an individual's immediate and external environment and extend over time (Bronfenbrenner, 2001).

Proposition (IV) addresses child development by encouraging active participation in complex activities at a progressive rate (Bronfenbrenner, 2001), underscoring the importance of strong parental-child mutual bonds and attachment for positive child internalization. Having

supportive and nurturing environments helps shape a child's positive values, beliefs, and behaviours. Both propositions (IV) and (V) align with one another, as the model suggests that for a child to develop cognitively, morally, and emotionally consistently, parents or caregivers must encourage regular participation in progressively challenging activities. This can establish mutual attachment, influencing and motivating a child's developing behaviours.

Proposition (VI) suggested that the continued emotional attachments and interactions between the caregiver and child depend on third-party involvement and degree of availability (Bronfenbrenner, 2001). This proposition was added to the model due to the rise in single-parent households in the 1990s and research suggesting that lone-parent households had behavioural and emotional impacts on the developing child. Bronfenbrenner (2001) highlighted that these findings are not generalizable to all single-parent households. Studies showed that single-family households that had additional support, whether that be friends, community groups, or another adult in the home, were beneficial for both child and parent. In addition to parent and child support, this proposition highlights the influential research for the Bioecological model conducted by Bronfenbrenner and Ceci in 1994 (Bronfenbrenner, 2001). Bronfenbrenner and Ceci (1994) discuss the interactions and synergistic effects of both genetics and the environment; they state it is through the proximal processes "through which genetic potentials for effective psychological functioning are actualized" (p. 568). Highlighting proximal processes, including the child's environments and relationships, has vast implications for actualizing genetic potentials, ultimately shaping a child's developmental competence and behaviours (Bronfenbrenner, 2001; Bronfenbrenner and Ceci, 1994).

Proposition (VII) highlights the importance of the family unit (Bronfenbrenner, 2001). The Bioecological Model addresses caregivers, parents, and children, and this proposition notes

that parental psychological development is strongly influenced by their child's overall emotional, physical, and behavioural development.

4.31 PPCT Model: Implications for Child and Family Health

Bronfenbrenner's Bioecological theory is guided by the *Process-Person-Context and Time (PPCT) model* and has influenced the research methodological approach and design (Bronfenbrenner, 2001). Within this study, *proximal processes* were explored and illuminated through the lived experiences of children and families living with CHD. The immediate environments and interactions experienced by both the child and the caregiver were found to shape their unique life courses significantly. Developing a deeper understanding of the complex processes that occur within the family unit and across broader systems and environments helped address existing gaps in the literature. Although children and families shared the common phenomenon of living with CHD, their experiences were all unique. Variations in coping mechanisms, emotional responses, and everyday experiences differed depending on the family unit, systemic, social, and environmental influences.

The *person*, including the child and family, will exhibit varying beliefs, perceptions, and behaviours regarding their spatial environment and interactions. These factors influenced child health development, as well as family resilience, behaviours, and management while living with CHD.

The *context* refers to five interconnected systems that shape the ecology of a family's health (Rosa & Tudge, 2013). The inner component of the model consists of the microsystem; most direct interactions occur within this domain, which includes the child's and families' closest relationships and social interactions (Santrock et al., 2020). The second domain is the mesosystem, which refers to the connections and relationships between families' microsystems,

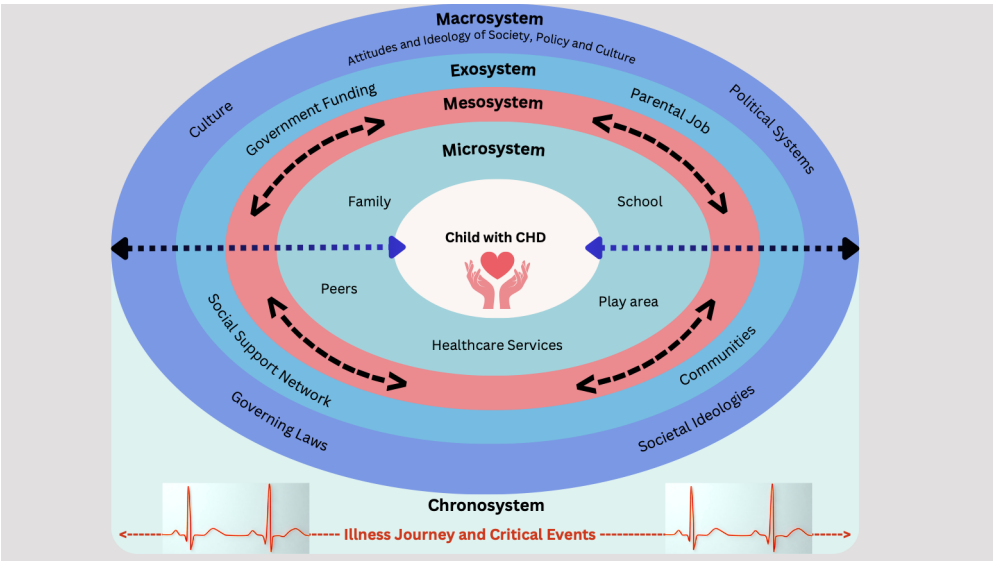
such as interactions between home, school and healthcare providers (Santrock et al., 2020). The third domain is the exosystem, which includes social settings and structures which the child may not participate in directly such as legal services, parental jobs, or media, yet still influence the child's experiences and development (Bronfenbrenner, 1979). The macrosystem refers to 'consistency' among broader community cultural and belief ideologies that shape and influence institutions within our environments, and indirectly children and families (Bronfenbrenner, 1979). The final domain of human ecology is the chronosystem; it is related to time and influenced by environmental, sociohistorical, and critical life-course events that can be planned or unplanned (Santrock et al., 2020).

The final component of the PPCT model is the dimension of *time,* which is further broken down into micro, meso, and macro time (Bronfenbrenner & Morris, 2006). Micro time refers to the immediate interactions within an individual's life; it accounts for the continuing experiences of proximal processes (Bronfenbrenner & Morris, 2006). Meso time extends beyond the immediate day-to-day events to transitions or events that occur over longer periods, including weeks or months (Bronfenbrenner & Morris, 2006; DiSanti & Erickson, 2021). This could include repeated clinic appointments, follow-up visits or transitions in school. The final aspect of macro time encompasses one's life course, which is influenced by broader societal and historical events and can span generations (Bronfenbrenner & Morris, 2006). Macro time involves understanding how developmental processes affect large-scale changes across domains of human development and broader societal and environmental contexts (Bronfenbrenner & Morris, 2006; DiSanti & Erickson, 2021). These may include events like wars, economic recessions, pandemics, chronic illness, parental divorce and bereavement.

The multi-level environments and supports are ever-changing for children and families living with a critical illness such as CHD. This overarching theoretical model allows for a deeper understanding of micro- and macro-environmental and social influences within local contexts, helping clarify the factors influencing children and families living with CHD. Systemic inequalities and social injustices can be explored by examining various influential domains in children's and families' lives. See Figure 1 below for an adapted version of Bronfenbrenner's Bioecological Model developed for this study, based on Santrock et al. (2020) and foundational concepts within Bronfenbrenner's Bioecological Theory (2001).

Figure 1

Adapted Bioecological Model of Human Development



Note. Figure adapted by the author from Santrock et al. (2020), based on Bronfenbrenner's Bioecological Theory (2001)

4.4 Phenomenology Historical Perspective

Phenomenological research emerged at the beginning of the 20th century to deepen understanding of consciousness as perceived and experienced by subjects (Solan et al., 2014).

Qualitative methodologies aim to explore several forms of the human experience; what sets phenomenology apart from other methodologies is that "phenomenology is the study of the primal, lived, pre-reflective, pre-predicative meaning of an experience" (van Manen, 2017, p. 776). Aligning with van Manen, this means phenomenology is concerned with how experiences are lived through before they are analyzed or conceptualized, even though in research we work with participants' reflective descriptions as a way of accessing and interpreting these pre-reflective, lived experiences (van Manen, 2017). For example, a parent's immediate and initial reaction upon hearing their child's diagnosis is a pre-reflexive experience, which they later recount and reflect upon during the interview process. Phenomenology can be used both as a research method and as a philosophy (Dowling, 2007). Phenomenological research aims to examine participants' reflective texts to further explore and develop the meaningfulness of specific human experiences and events; it is the study of essences (van Manen, 2017). Since the beginning of the 20th century, phenomenological research has developed with various perspectives from different philosophers, all of which focus on a phenomenon experienced by a group of participants to aid in developing a deeper understanding of the lived experience (LoBiondo-Wood et al., 2018; Solan et al., 2014; van Manen, 2016). Key philosophers include Maurice Merleau-Ponty, who expanded phenomenological views to include the role of the body in perception and experience (van Manen, 2016). Other philosophers included Jean-Paul Sartre, who contributed to existential phenomenology; and Paul Ricoeur, who made significant contributions to phenomenology through his work on 'human will' and development of hermeneutics, emphasizing the importance of interpretation (van Manen, 2016).

Although these key individuals added to the knowledge and critical work of phenomenology, Edmund Husserl and Martin Heidegger, who will be further discussed below,

paved the way for groundbreaking phenomenological movements in the early 20th century (van Manen, 2016). Hans-George Gadamer and Max van Manen are also addressed as they were key leaders within interpretive (hermeneutic) phenomenology (van Manen, 2016).

4.41 Edmund Husserl

Phenomenology has strong ties with the social sciences and was established as a philosophical framework by Edmund Husserl, a German philosopher in the 1900s, who sought to better understand people's original essence of experience without interpreting them (Patton, 2015; van Manen, 2017). Although Husserl is known as the founder of phenomenology, other figures such as Franz Brentano and Immanuel Kant were instrumental in developing key components of phenomenology. Their work provided important philosophical background for the later development and understanding of phenomenology (van Manen, 2016). Husserl developed phenomenology as a theoretical lens to offer a different perspective and challenge the dominant positivist paradigm and theoretical perspectives of his time, that were often rooted in 'Cartesian philosophy' (Sloan et al., 2014). Epistemologically, Cartesian philosophy is grounded in deductive reasoning to ensure clear findings which are beyond any doubt (van Manen, 2016). In his early works Husserl's expressed the belief that phenomenology is a rigorous science. He was motivated by the idea that his work would lead to absolute truth or science beyond dispute (van Manen, 2016). Husserl's original descriptive phenomenology is also known as transcendental phenomenology (Sloan et al., 2014). Husserl believed in the rigorous science of phenomenology; he held that phenomenology is the study of how knowledge comes to be, which is uncovered through an individual's consciousness (van Manen, 2016). Husserl understood individuals' lived experiences as new knowledge gained through a non-biased and objective lens (Racher & Robinson, 2003). Husserl's descriptive phenomenology focused on a particular

phenomenon and they appear in participant's consciousness, within the context of their real-world experiences, which aid in developing a deeper, enriched understanding of their lived reality (Sloan et al., 2014). Husserl "defines phenomenology as a descriptive philosophy of the essences of pure experiences. He aims to capture experiences, without interpreting, explaining, or theorizing" (van Manen, 2016, p. 89). To achieve his aims of descriptive phenomenology, Husserl introduced the core principles of epoché, also known as bracketing, and reduction, as foundational methods within phenomenology (van Manen, 2016). Husserl's bracketing approach is usually the first step in research. It holds the researcher accountable for putting aside personal experiences or beliefs about the phenomena under study so that they do not affect the data collection and description process (Patton, 2015; van Manen, 2016). Reduction remains a key component across various forms of phenomenology. It refers to the process of repeatably returning to the descriptions of their lived experience and focusing on their essential structures (van Manen, 2016). Through this process of uncovering the essential structures of consciousness and experience, reduction allows new phenomenological meanings to be illuminated (van Manen, 2016). Together, epoché and reduction will enable the meaning of a phenomenon under study to be discovered (van Manen, 2016)

4.42 Martin Heidegger

Heidegger was a 20th-century German philosopher who continued the development of phenomenology as a methodology. He "applied hermeneutics as a research method founded on the ontological thesis that lived experience is an interpretive process" (Racher & Robinson, 2003, p. 472). As such, and compared to Husserl's epistemological emphasis, Heidegger's approach to phenomenology focused on the study of 'being' (van Manen & van Manen, 2021). A key difference between Husserl and Heidegger's phenomenological approach lies in their beliefs

about 'reduction' and 'bracketing': where Husserl believed it to be possible for the researcher to remain objective in their analysis, Heidegger held that the researcher cannot separate data description from the analysis and interpretation of data (Parahoo, 1997). Where Husserl believed it to be possible to uncover the essential structures of consciousness and experience, Heidegger disagreed. In his hermeneutic approach to reduction, Heidegger recognizes that omitting one's pre-understanding or past experiences is not possible; therefore, the researcher must engage with critical self-reflection, openness, and reflexivity throughout the process (van Manen, 2016). Reflectivity remains a fundamental principle in hermeneutic phenomenology. It can enrich data and theme interpretation when the researcher is conscious and reflective throughout the research design, questioning, and overall process (Solan et al., 2014).

4.43 Gadamer

Hans-George Gadamer was a German philosopher who studied under Martin Heidegger (van Manen, 2016). Although Heidegger paved the foundations for hermeneutics, Gadamer's work was key in developing the philosophical movement for hermeneutic phenomenology (van Manen, 2016). The work of Gadamer and Ricoeur, which preceded Max van Manen in the 1990s, remain key historical influences within hermeneutic phenomenology (Sloan et al., 2014; Streubert & Carpenter, 2011). The hermeneutic approach moves beyond the interpretation of data to include perspectives from both historical and cultural contexts, which provide a deeper understanding of their socially constructed worldview (LoBiondo-Wood et al., 2018; Solan et al., 2014; van Manen, 2007). Hermeneutic phenomenology is focused on a particular phenomenon, though it differs from Husserl's descriptive approach in that the researcher interprets the participant's lived experience, co-constructed with the research participants (Creswell and Poth, 2018; LoBiondo-Wood et al., 2018). Gadamer believed that through understanding our

prejudices, we, as researchers, can make sense of the world (Koch, 1999). If researchers understand their own prejudices through critical self-consciousness and the broader impacts of social, gender and cultural factors, intellectual dialogue is enabled (Koch, 1999). Gadamer further developed the concepts within the hermeneutic circle to ensure researchers revisit discussions and feedback with study participants (Fleming et al., 2003).

4.44 Max van Manen

Max van Manen is a Dutch-Canadian researcher who has become a prominent leader in hermeneutic phenomenology. Max van Manen believed that the foundations of phenomenology are practical and, therefore, believes that hermetic phenomenology can be applied across various disciplines, including nursing (Errasti-Ibarrondo et al., 2019). Max van Manen's hermeneutic phenomenology combines both the historical aspects of descriptive and interpretive phenomenology in that the interpretive element includes the description of the phenomena (Dowling, 2007). In congruence with Heidegger, van Manen does not follow Husserl's approach to 'bracketing.' Van Manen holds that the researcher cannot put aside what is already known or forget past experiences (Dowling, 2007; van Manen, 2007). Rather, van Manen acknowledged that he had assumptions and preunderstandings, noting that:

> "It is better to make explicit our understandings, beliefs, biases, assumptions, presuppositions, and theories. We try to come to terms with our assumptions, not to forget them, but rather to hold them deliberately at bay and even to turn this knowledge against itself, as it were, thereby exposing its shallow or concealing character" (van Manen, 2007, p. 47).

van Manen's approach to hermeneutic reduction center on openness (Heinonen, 2015; van Manen, 2007). He believes that as researchers, that we can't ignore our preunderstanding and

biases but should acknowledge them, and practice critical self-reflection to deepen our understanding of the phenomena we explore (Heinonen, 2015; van Manen, 2007).

Van Manen lists six steps for the research process, including: (1) turning to the nature of the lived experience, (2) investigating experience as we live it, (3) engage in phenomenological reflection, which includes isolating themes and revealing themes among lifeworld descriptions, (4) engaging in the phenomenological art of writing by writing and rewriting, (5) maintain a strong and orientated relation to the phenomena and (6) balancing the research context by considering both parts and the whole (Streubert & Carpenter, 2011; van Manen, 2007). This framework provides researchers with a guide to ensure appropriate steps within the hermeneutic-phenomenological approach are undertaken throughout the research process.

Hermeneutic phenomenology, according to Van Manen (2007), incorporates four fundamental existential themes as aids throughout the research process. They encompass the "*lifeworld of all begins, regardless of their historical, cultural or social situatedness*" (p. 101). These four existential themes guide phenomenological researchers in their writing, reflection, and analysis (Dowling, 2007). The four existential themes are "*lived space (spatiality), lived body (corporeality), lived time (temporality), and lived human relation (relationality or communality)*" (van Manen, 2007, p. 101). The first existential of lived space refers to felt space; it is often preverbal and has significant implications for how individuals feel (van Manen, 2007). Lived body refers to an individual's physical being and bodily presence in the world (Rich et al., 2013; van Manen, 2007). Lived time is subjective and understood by one's experience (Rich et al., 2013; van Manen, 2007). "*The way we feel can influence how we experience time and moments, and conversely, constraints, freedoms, and demands placed by time can also affect how we feel*" (Rich et al., 2013, p. 12). The final existential is lived other (human relation); this

relates to the relationships and experiences individuals have with those around them within their lifeworld (Heinonen, 2015; Rich et al., 2013; van Manen, 2007). Although the four existentials can be described and interpreted as separate lifeworld existentials, they cannot be separated as they interrelate to form the lifeworld in which humans exist (van Manen, 2007).

4.5 Phenomenology of Practice: Implications for Child and Family Health

This research was underpinned by Bronfenbrenner's Bioecological Theory and van Manen's hermeneutic-phenomenological approach. Together, the theoretical model and methodological approach enabled the research questions to extend beyond the individual and their immediate microsystem to consider the broader environmental contexts and temporal dimensions shaping the lived experiences of children and families living with CHD.

As the research activities were dynamic and characterized by continuous interplay across each step, reflexivity remained central throughout the research process. I engaged in ongoing reflective practice, supported by critical self-awareness and the use of field notes and a reflective journal. For example, I documented my emotional responses (such as sadness or anxiousness when parents described receiving the diagnosis), my emerging assumptions (for instance, all families would experience challenges or frustrations within the system), and reflections on how these reactions may have shaped my questioning and interpretation of the participant's narrative. Returning to the entries during analysis was particularly valuable, as it prompted me to examine when I might be drawing on my personal and professional experience and to guard against imposing these assumptions within the stories of children and families. Navigating this was especially challenging while I was pregnant and in the early months of motherhood with a newborn; I became acutely aware of the need to distinguish my own feelings from those expressed by parents and from interpretations of their accounts. In addition, I used the

observational tool during and after each interview to record details about the environment and interactional dynamics (e.g., signs of distress, ease, home environment, and verbal and nonverbal responses). These notes also became an important resource during analysis, alongside the transcripts and audio recordings. I would frequently return to them, re-reading my notes, observations, and transcripts, and re-listening to the interview audio recordings. This helped me to situate myself within the research encounters and consider how the context of each interview influenced the generation and interpretation of the data. These practices were fundamental across all phases of the study, drawing on Van Manen's (2007) steps: (1) turning to the nature of the lived experience; (2) investigating experience as we live it. Van Manen's remaining research activities will be discussed in detail within the following methods section.

Utilizing the Bioecological theory and the selected methodological approach, this study explored the unique lived experiences of children with CHD and their families living in NWO by examining the intersecting layers that shaped their realities. The data illuminated the essence of the lived experiences through in-depth interviews with children and parents. The findings will inform health policy, support health practice considerations, and advance health system transformation in Northern Ontario.

The methodological approach of hermeneutic phenomenology focuses on the individual's lived experiences and gaining a deeper understanding of the subjective and personal life events within their worldview, which is socially constructed from their cultural and historical context (Giacomini, 2010; Solan et al., 2014). Van Manen's lifeworld existentials guided the research process, specifically during research reflection (van Manen, 2007). Within the existential of lived space, van Manen (2007) describes how "*children probably experience space in a different modality than adults*" (p. 103). Drawing on this idea, both the draw-and-tell method and

qualitative interviews with Children living with CHD were planned (Angell et al., 2015; Goodwin et al., 2023; Søndergaard & Reventlow, 2019). However, there was minimal uptake among the children during interviews for the draw-and-tell methods. Although this represented a limitation, interviews with both parents and children provided rich, experiential accounts that illuminated diverse experiences (van Manen, 2007).

Lived space emerged as a central component of this research. This is significant. As noted in the literature review, there is a gap in understanding and research focusing on children's and families' experiences living with CHD in rural, remote and northern regions. The concept of their lived environment was fundamental to understanding the complex world in which they live. Van Manen (2007) also noted the differences between children's and adults' experiences of lived time and body. Within this study, these differences were also true for lived others as children's relationships and conversations vary depending on their developmental age and stage, which is further impacted by their illness. Collectively, the four lifeworld existentials were influential in deepening understanding of children and their families living with CHD in NWO.

Findings from this study highlighted that healthcare challenges were often compounded by geographical context (Campbell et al., 2019). Gaining a deeper understanding of the barriers and challenges faced by parents concerning the health and development of their child with CHD contributes to informing health policy and practice. Central to this work was providing a voice to children and their parents, who are often underrepresented in Canada's current societal structures and political ideologies.

The theoretical framework of the Bioecological theory and the chosen phenomenological methodology utilized in this study acknowledge the social, cultural, political, and environmental factors that impact and shape the subject's construction of their current reality and lived

experience (Bronfenbrenner, 2001; Patton, 2015). The discourse around health care structure and access for children and families living in NWO's rural, remote, and northern regions was highlighted in the findings through critical inquiry into power differentials and their influence on children's and families' constructions and perspectives of their reality (Patton, 2015).

5.0 Chapter Five: Research Methods

Chapter 5 describes the research methods used within the study to better understand the experiences and perceptions of children and families living with CHD in Northwestern Ontario. The research methods were underpinned by Bronfenbrenner's Bioecological theory and Van Manen's phenomenological design and supported by the core principles of the TCPS 2 (Government of Canada, 2022a). In this chapter, I outlined the study design, research setting, participants, sampling and recruitment, and the data collection methods used.

5.1 Research Setting

As outlined in chapter 1, this study was situated within the broader geographic and healthcare contexts of Thunder Bay and Northwestern Ontario. Families in this region often navigate long distances limited local subspecialty services and referral pathways to southern tertiary centres for pediatric cardiac services. More specifically, the immediate research setting was situated within the context of the Thunder Bay Regional Health Sciences Center (TBRHSC) paediatric cardiology clinic. Families are seen at the clinic while navigating their ongoing care and remains a central point of local care access. The setting is important as it reflects a layered and complex web of care that families have to navigate in Northwestern Ontario. This is due to the fact that local services are intertwined with various points of care often spread out across the province.

5.2 Ethical Considerations

Ethical considerations include concepts already discussed, such as positionality, reflexivity, transparency, and trustworthiness throughout the research process (Creswell and Poth, 2018; Tracy, 2006). As a Ph.D. student at Lakehead University, procedural ethics was first sought through the Lakehead University Research Ethics Board (REB), which referred the study

for ethical approval to the TBRHSC research office. It was through TBRHSC that ethical approval was granted.

Following the principles of TCPS 2, all participants were provided with detailed information about the study, including its purpose, potential risks and benefits (Government of Canada, 2022a). All participants were made aware of the time commitment and resources required for the research project to make an informed decision before signing consent (Creswell and Poth, 2018; Government of Canada, 2022a). Participants were also informed that their child's pediatrician would not be made aware of their decision to partake or not in this study and that their participation or choice not to participate would have no impact on their child's current or future care.

All participants were informed that their consent was voluntary and that they could withdraw from the study or end the interview at any time during the research process (Government of Canada, 2022a; Tracy, 2006). Participants were also informed, and the researcher ensured, that their identity would be kept confidential throughout the research process, including the dissemination of the research findings (Government of Canada, 2022a).

In accordance with procedural ethics, participants were informed of the potential risks of the research study, including the minimal risk of emotional distress (Government of Canada, 2022a; Tracy, 2006). The researcher was to maintain respect for human dignity in the event of such distress, including stopping the interview if requested and directing participants to their primary healthcare provider. Fortunately, this never occurred during the research process.

This research was completed in kind, with no conflicts of interest to disclose. The participants were informed of the study's intent, which was to provide a voice to children and families living with CHD, as part of my doctoral work. Participants were given a small gratuity

for their time in the study. Per the TCPS 2 (2022) guidelines, this incentive does not intend to exert undue influence on the potential participant; the $60 sum was appropriate, as it is for the whole family unit (Government of Canada, 2022a).

During my PhD, key ethical considerations for writing and knowledge translation were reviewed using tools such as the Canadian Institutes of Health Research (2012) Guide to Knowledge Translation and compliance with REB approval, which follows the tenets of the Tri-Council (Government of Canada, 2022a). A clear knowledge translation plan was included in the research REB submission, with target audiences considered throughout the research process to ensure appropriate knowledge translation tools (Bowen & Graham, 2013; CIHR, 2012). The research findings will be first disseminated to the research participants for review before being shared with professional nursing bodies, the academic community, and conferences to help inform the political agenda. A clear knowledge translation plan will follow in Chapter 8.

The anonymity of the taped data was ensured by removing direct identifiers. All research data, including transcripts, consent forms and audio recording devices, are securely stored in a locked cabinet in the office of the primary investigator (A. Dampier) for seven years, in accordance with Lakehead University's ethics policy. After seven years post-project completion, and in line with Lakehead University's and TBRHSC ethics policy, all raw data stored as encrypted computer files will be deleted, and paper copies will be shredded.

Consent for this research project adhered to the TCPS 2 (2022) articles 3.3 and 3.9. Article 3.3 states that consent shall be an ongoing process and that, especially in cases involving children, the researcher should continue to seek the child's assent (Government of Canada, 2022a). Article 3.9 addresses individuals who lack the capacity to decide for themselves (Government of Canada, 2022a). To ensure Article 3.9 conditions were met, this research project

involved children and their parents in all decision-making processes (Government of Canada, 2022a). The researcher also ensured that the research project had minimal risk and minimal burden on the children participating in this study (Government of Canada, 2022a).

The intent of the research project is not to highlight the characteristics of Indigenous people; therefore, this study adhered to Article 9.2, listed example 7 (Government of Canada, 2022a). In practical terms, this meant I did not purposefully sample on the basis of participants' self-identification as Indigenous, and that cultural data was not collected as part of the demographic questionnaire. However, if a participant self-identified as Indigenous during data collection, the researcher was to inquire if culturally appropriate assistance was needed within the research project (Government of Canada, 2022a). Although the study does not specifically target Indigenous populations, the researcher recognized that the sample may include some Indigenous children and families, given the study's geographic area (Government of Canada, 2022a). During the study, no participants self-identified as Indigenous.

5.21 Family Consent

For the parents enrolled in this study, informed consent forms were emailed at least one week before the interviews. Please refer to Appendix G to view the parent information and consent form. If their child was also participating, a separate consent form for the child was also provided. This allowed families time to review, ask questions, or address any concerns about the study. Once signed, the participants returned the signed consents to the researcher via email, fax, or mail. Prior to conducting the interviews, the researcher's written permission was always reviewed with both the child and family participants for final verbal confirmation. The researcher also reiterated participants' rights and allowed time to address any additional questions about the study.

5.22 Child Consent

From an ethical standpoint, vulnerability is considered a spectrum and research participants all exist somewhere on that spectrum depending on the nature and context of the research itself. As there is no age of consent for research in Canada, consideration must be given to the child and their decision-making capacity regarding the research for consent (Government of Canada, 2022a). In this study, children underwent a two-phase consent process. First, parents were asked whether they consented to their child's involvement in the study. When consent was granted, as previously stated, they were provided with an age-appropriate consent form to review and sign at least 1 week before the interviews. The second phase involved the child's assent, which included verbal and/or signed consent from the child participant, depending on their developmental stage. As previously mentioned, the study included a script for research assent for children, tailored to the child's level of understanding, which guided this process. For some children who were unable to sign their name, there was also a simple 'yes' or 'no' selection box for them to mark. Please refer to Appendix F for the child assent documents. The researcher did not involve the child as a participant in the study if the parents or legal guardian did not approve.

5.3 Recruitment

A purposive recruitment approach was used to recruit participants who could provide an in-depth, rich understanding of the phenomena under study (Creswell and Poth, 2018; Patton, 2015; Streubert & Carpenter, 2011). Participants were offered a small token, either cash or a grocery gift worth $60, to acknowledge the time and effort they provided for the research project. Following ethical approval, recruitment was conducted through multiple avenues. Participants were recruited from organizations located in Thunder Bay through the methods described below.

Laminated posters (see Appendix D) were displayed in several community and health care settings, including the paediatric and POP unit at TBRHSC, Children's Center Thunder Bay, and Thunder Bay District Health Unit. Posters provided information about the project and contact details for potential participants. The poster was also advertised and shared on social media platforms such as Instagram and Facebook.

Snowball recruitment was also used; participants were invited to share study information with other eligible families (Creswell and Poth, 2018). Specifically, the study's poster was shared by families in NWO via Facebook groups supporting children living with chronic illness. This was helpful because these online groups only allowed certain members, so families who saw the poster reached out to ask if they could share.

Clinical leaders were instrumental ‘gatekeepers’ within the recruitment process. Dr. Bruni, A. Halverson & C. Edwards, along with other nurses from the Pediatric and POP units, generated a list of potential participants and mailed invitations on my behalf. Please refer to Appendix E to view the participant information letter. This ensured the research study adhered to section 44 (6) of the Personal Health Information Protection Act, as the researcher cannot access personal health information or contact potential participants directly (Ontario Government, 2022). The information letters instructed potential participants to contact the researcher for more information about the study. The nurses working on the POP unit were also used as 'gatekeepers' within the study. During discharge teaching, nurses informed potential participants about the study and provided their contact information (Creswell and Poth, 2018).

5.4 Participants Demographics and Characteristics

Participant inclusion criteria were families with children between the ages of newborn and 17 years with a primary diagnosis of CHD, ranging from mild to severe. Eligible participants

included families and children seen in the paediatric outpatient (POP) clinic or referred to a paediatric cardiologist and on file at the POP TBRHSC. Additional participants were recruited through posters placed at various community organizations and through online social media platforms. All participating families had to reside within NWO and speak English.

For this study, the term ‘f*amily*' consists of the child diagnosed with CHD and their parents and or caregivers. There are several gaps within the literature around children with CHD and their families living in northern, rural and remote regions, especially within the local context of now. To narrow the focus and ensure an in-depth and rich understanding of the participants' experiences, I chose to focus on children and their parents living with CHD and not include the siblings of the children living with CHD. Following recruitment, the final participants comprised 14 families (27 participants) and will be discussed in detail in the following chapter.

5.5 Data Collection Tools

To address the research questions, data collection was initially designed as a three-pronged approach that included interviews, 'draw and tell,' and field notes. During this process, data was collected through semi-structured interviews with children and their families, along with field notes. Interviews provided rich, unique, and individualized data (Creswell & Poth, 2018; Ravitch & Carl, 2016).

The 'Draw and tell' method was originally proposed as a child-centred approach to support younger children’s participation by inviting them to draw what they consider a significant event or experience from their lifeworld (Søndergaard & Reventlow, 2019). This demonstrates an age-appropriate, fun, and engaging method in peadiatric research (Driessnack, 2006; Martin, 2019; Søndergaard & Reventlow, 2019; Rollins, 2005). In this study, “draw and tell” was incorporated as an optional activity to facilitate expression among younger children.

However, while attempting the method, it had little uptake among the children, with only one participant being successful during data collection. The limitations of this will be addressed below.

5.6 Interview Guide: Piaget's Theory of Cognitive Development

Piaget's Theory of Cognitive Development (CDT) informed the creation of the interview guide and child research assent scripts used during interviews with the participating children. The interview guides were developed with age-appropriate language and questions, including prompts and probes underpinned by Piaget's Theory to ensure the children's cognitive level is met (see Appendix C). The ages and stages, according to Piaget, included pre-operational ages 4-7, concrete operations ages 7-11 and formal operations ages 11-16 (Keenan-Lindsay et al., 2022).

Guided by Piaget's CDT and informed by my nursing knowledge and skills, I assessed each child's developmental level during my initial interaction to guide the selection of the appropriate interview approach. Piaget's CDT and the correlating assessment are outlined in Table 1 below. The child's overall cognitive level and skills were not measured within this study. Piaget's theory was used in this study only to facilitate age-appropriate conversations.

Table 1

Piaget's Developmental Stages and Assessments

Cognitive Development (Piaget)	**Language & Cognition**	**Assessment**
Pre-operational (2-7 years)	***Age 4:*** Has a word vocabulary of 1500 words or more, can use sentences of four or five words, names one or more colours, comprehends analogies, such as "if ice is cold, fire is?", understands time better in terms of sequence of daily events, may count correct yet	***Age 4:*** Ask the child to: →Say how they feel to assess their use of words within sentences (at least four or five). →Finish this statement: "If ice is cold, fire is?" → Sing a simple song.

	poor mathematical concept of numbers, knows simple songs. ***Age 5:*** Has a vocabulary of 2100 words, uses sentences of six to eight words, with all parts of speech, names coins, names four or more colours, describes pictures with comments and elaboration, knows days of week, month, and other time associated words, can follow three commands in succession, knows composition objects such as an "a shoe is made of?", uses time orientated words with increase understanding. ***Age 6:*** Develops concept of numbers, able to count 13 pennies, describes objects in a picture rather than counting them, understands time and timing in the day, e.g. morning or afternoon, obeys three commands in succession ***Age 7:*** Can accurately copy a diamond, repeats three numbers backward, develops the concept of time, can read a watch or clock	***Age 5***: Ask the child to: →Name coins, e.g. nickel, dime → List four or more of their favourite colour → say what day it is, month or year. → to follow three commands in a row following the game of 'Simon says.' ***Age 6:*** Ask the child to: →Ask what day it is and what time of day, e.g., morning/afternoon → To follow three commands in a row following the game of 'Simon Says ***Age 7:*** Ask the child to: → Repeat numbers backwards e.g.3,2,1 →State the time when asked.
Concrete operations (7-11years)	***Age 8-9:*** Counts backwards from 20 to 1, repeats days of the week and months in order; knows the date; describes common objects in detail, not just their use; more aware of time can be relied on to get to school on time, produces simple painting or drawings, understands concepts of space, cause and effect and conservation (permanence of mass and volume) ***Age 10-11:*** Can write brief stories, read for practical information or enjoyment, and write short letters to friends and family.	***Age 8-9:*** Ask the child to: →Repeat numbers backwards from 20-1 →Repeat the days of the week, list five consecutive months and state the current date, including year. →Ask the child to draw a clock. ***Age 10-11:*** Ask the child to describe the following task (testing the child's ability to conserve)

		→ Show the child two identical sheets of paper with the same number of stamps and the same amount of uncovered space; the researcher will rearrange the stamps on one sheet of paper →The child should recognize that the amount of uncovered area remains the same on each sheet.
Formal Operations (11- 15 years)	***Ages 12-15:*** Develops capacity for abstract thinking, increasing ability of scientific reasoning and formal logic, has the capacity to think beyond the present without having to focus on the immediate situation, e.g., plan for college, occupational possibilities, relationships, and consequences of their decisions, e.g. dropping out of school.	***Ages 12-15:*** To assess abstract and logical thinking, the child could be asked to answer the following questions. → What would happen if there was no gravity on earth? →If I gave you X number of candies and your parents x number how many candies did I give out in total?

(Keenan-Lindsay et al., 2022)

5.7 Data Collection Methods & Process

Once ethical approval from the TBRHSC ethics board was obtained, data was collected from March 2024 until June 2025.

5.71 Interviews

Following initial contact, interested participants were screened for eligibility to ensure they met the inclusion criteria. Once eligibility was confirmed, detailed information about the study was provided to participants to ensure an informed decision and to obtain informed consent from parents and/or caregivers. This process also occurred for the children who participated in this study, yet it was tailored to an age-appropriate literacy level for understanding. Please see Appendix F for the child assent scripts, tailored to the pre-operational, concrete, and formal

operations stages of development. Assent was attained from all children who participated in the study.

Data was collected through semi-structured interviews with children diagnosed with CHD and their parents/caregivers, alongside the use of field notes. Semi-structured interviews ensured that questions were tailored to the research while allowing for a conversational approach (Ravitch & Carl, 2016). As previously discussed, interview guides were developed, consisting of open-ended questions with prompts and probes to engage participants in discussion and develop a deeper understanding of children's and families' experiences (Ravitch & Carl, 2016).

The use of both in-person and virtual settings for interviews reflects the geographically dispersed nature of this population. As such, the research was conducted across multiple settings, including participants' homes, the researcher's office at Lakehead University, the Zoom virtual platform, and, at the request of one family, a local park. To support participants' participation and needs, each family was asked which environment would be most comfortable and best suited to their busy lives and schedules. Often, families were juggling many commitments in their lives, including work and family needs, and other challenges would arise, such as illness, so interviews were scheduled and rescheduled outside of work hours, including evenings and weekends. This ensured a family-centred approach.

Van Manen (2007) addresses the difficulty in engaging in conversation when interviewing children and states:

> To gain access to the experiences of young children, it may be important to play with them, talk with them, puppeteer, paint, draw, follow them into their play spaces and into the things they do while you remain attentively aware of the way it is for children (p. 68).

As previously shared the method of ‘draw and tell’ was attempted but used only by one child participant. However, I always brought paper and crayons and asked children if they wanted to colour or draw before we began our interview. I also took the time to ask simple non-health or interview-based questions beforehand, such as what they like to do for fun, favourite games, or about their pets, to help them feel more relaxed and comfortable. I would try to follow their lead on conversations and ask questions about their described interests. In some cases, children and teenagers, whether at the park, in my office, or at their home, would show me their favourite toys, books or artwork. In some of the child participants’ homes, we would spend the first half an hour playing with their family pets. This again helped create a safe and comforting space for the child.

Conducting interviews in participants' homes created a relational, comfortable environment, where the researcher gained an intimate glimpse into the families' lived spaces and the relationships within them. Interviews conducted within the researcher's office, although not a reflection of the participants' daily home environment, provide a private and neutral space which allowed for relational engagement and open dialogue. The Zoom online platform was mainly used by families living outside Thunder Bay’s city limits, offering a flexible option for busy families and families geographically dispersed. Finally, one family used a park's open space for interviews. This was unique, as the whole family came to the park to play while the interviews were being conducted. It allowed the researcher to observe the families’ dynamics and interactions throughout the process, in a ‘fun’ environment outside the family home.

Parent interviews ranged from 40 minutes to over 1 hour. Children’s interviews were significantly shorter, ranging from 5 to 32 minutes. It is important to note that 2 interviews were

short in time (around 5 minutes) and will be discussed in the limitations. The majority of child interviews were 15-20 minutes on average.

The interviews were audiotaped and transcribed verbatim. Data collected and all transcribed interviews were stripped of any links to personal identification, direct identifiers. Participants were given a name of "transcript #' to ensure all data is nonidentifiable and kept confidential (Creswell and Poth, 2018). No information from the electronic medical record (EMR) was obtained, although family demographics were collected at the end of each interview. Once all transcripts were reviewed and analysis was completed. I sent follow-up emails to participants to confirm any missing demographic information.

During the interview process, I paid attention to participants' behaviours, emotional expressions, body language, physical appearance, family dynamics, and physical environment, and made field notes about these observations during and after the interviews as described next.

5.72 Field Notes

Field notes were taken during and immediately following each interview using an observational tool (see Appendix G) to support rich, contextualized and detailed descriptions. The observational tool was adapted from Creswell and Poth (2018) and Rollins (2005). Field notes also included reflexive observations that sought to capture the research participants' responses and reactions throughout the process. During these very emotional and often heavy interviews, I intentionally slowed the questioning pace and allowed pauses in the conversation. When appropriate, I built in brief periods for participants to sit with a question and reflect on their experiences, allowing them to respond in their own time. Ongoing reflection on my role within the research process supported continued reflexivity. In line with van Manen, experiential

anecdotes recorded in my field notes from child participants allowed for a deeper understanding of their lived meanings and experiences (van Manen, 2007).

5.8 Data Analysis

Data were analyzed using Van Manen's hermeneutic-phenomenological approach (van Manen, 2007). The analysis was an ongoing and interactive process (Miles et al., 2020). van Manen's six research steps were engaged throughout the study as part of the dynamic, interactive hermeneutic circle, and the final steps underpinned the research's analytical process. These research steps include (3) engage in phenomenological reflection, which includes isolating themes and revealing themes among lifeworld descriptions, (4) engaging in the phenomenological art of writing by writing and re-writing, (5) maintain a strong and orientated relation to the phenomena, and (6) balancing the research context by considering parts and whole (Streubert & Carpenter, 2011; van Manen, 2007). I have addressed each step separately below, yet it is important to note that this interactive process was not linear, rather it involved a continual back-and-forth movement throughout the analysis.

The research study's aims were two-fold: it explored the lifeworld experiences of children diagnosed with CHD and to understand the experience of their families. As such, parent and child interview data were analyzed separately. Parent transcripts were analyzed first and then the child transcripts. This allowed for an in-depth understanding of the family as a whole while also interpreting parents and children as distinct sources of experiential meaning.

In line with van Manen's third step, analysis began with immersion into the data to gain familiarity. This was achieved through repeated readings of all interview parent and child transcripts and field notes. I also re-listened to the audio recordings to help recall the tone of the participant's voice and the interview environment. During the initial readings and listening to

recordings, I approached the transcripts openly, seeking an overall sense of each participant's experiences rather than isolating themes at this time. I made brief notes on both paper and NVivo to capture early impressions and initial reactions. These early notes documented key phrases and emotional responses that appeared significant (Oorsouw et al., 2022; van Manen, 2007). These early detailed notes helped inform later emergent themes, which were grouped into clusters of experiential meaning (Oorsouw et al., 2022).

Van Manen (2007) suggests three analytical approaches to isolate thematic statements; 1. the wholistic or sententious approach, 2. The detailed or line-by-line approach, and 3. The selective or highlighting approach to uncovering the phenomena under study. Throughout this process, NVivo supported organization and continued engagement with the data. NVivo was used from the beginning stages throughout the analysis to provide descriptive labels and then further group meaningful clusters together, keeping track of recurrent experiential descriptions. This allowed me to keep track of these descriptions, keywords, feelings, and phrases across transcripts and capture my evolving interpretations of the lifeworld existentials of children and parents.

Following the initial immersion in the data, I used the line-by-line approach, reviewing and reflecting on both the child and parent transcripts in detail. After each sentence or line, the researcher asks, "What does this reveal about the phenomena under study?" (van Maen 2007). After this, an initial set of key meaningful descriptive labels was identified that illuminated the experiences of children diagnosed with CHD and their parents caring for them in rural, remote, and northern areas of NWO. During the initial analytical phase in NVivo, the parents' transcripts generated over 500 meaningful descriptive labels, while the child transcripts generated just over 200.

This line-by-line approach was repeated twice more, each time supporting deeper reflection of thematic meanings as a whole. The second review allowed for greater depth of meaning and understanding, and 17 overarching themes began to take shape, each with its own subthemes. During the final review within NVivo, these 17 overarching themes were retained, while the many subthemes and similar descriptive labels within them were further refined, combined or renamed. This enabled a more comprehensive reflection on participants' lived experiences.

From here I moved into Van Manen's step 4, the phenomenological art of writing and rewriting, which underpinned the analytical process. I began writing and clustering related themes together, continually circling back to my research questions. This process took many months of writing, rewriting, and involved multiple drawings and visual maps to piece together the core essential structures of the phenomenon. Many of the core themes overlapped, and the existential structures of lived body, lived time, lived space, and lived relations were also deeply interconnected, so considerable reflection was completed to ensure the essential core structures were illuminated. Through this in-depth process, the essential structures of the phenomena began to take shape, finally illuminating the core overarching theme and the structures that will be discussed in the findings section.

The essence or meaning of a particular phenomenon is described by van Manen (2007) as 'multi-dimensional'. He emphasizes that making meaning from human experience is not simple; it involves complex layers, necessitating the researcher to continually engage in writing and reflection to understand meaning (van Manen, 2007). As the researcher, I employed continual phenomenological reflection, openness, and engagement with the data to ensure the meaning and themes of the lived experience of children and families were 'reflectively analyzed' (van Manen,

2007). As stated above, this was done through an interactive process of moving back and forth between the transcripts, field notes, audio recordings and written reflections. I also continued to write and rewrite ongoing reflections, notes on the data, and transcripts. This allowed deeper meaning to unfold throughout the analysis.

In relation to step 5, maintaining a strong, orienting relation to the phenomena, I remained focused on the central purpose of the study throughout the analytic process. This involved frequently reflecting on the research questions to ensure I stayed focused and grounded on the participants' lived experiences. Bronfenbrenner's Bioecological model and van Manen's key lifeworld existential were used as guiding lenses to support reflection and interpretation within the broader contextual dimensions of participants' experiences. This includes integrating micro-, meso-, and macro-level influences with the four-lifeworld existential (Rich et al., 2013; van Manen, 2007; Wiersman & Dupuis, 2010). I regularly returned to these lenses when interpreting thematic clusters, this was done through frequently revisiting the research questions which were formulated based on Bronfenbrenner's Bioecological systems and van Manen's lifeworld existentials. Questions around the child and families' everyday environments (micro), relationships with systems of care (meso), broader structural systems (macro), and the influence of time and major life events influenced the families devolvement (chrono) were considered. These reflections were also considered in relation to the lived body, space, time, and relations. This process helped ensure that themes remained grounded in the theoretical and methodological frameworks, rather than in abstract categories.

The sixth step of van Manen's research process included balancing the parts and the whole. I achieved this through continually moving back and forth between participant excerpts, thematic understandings, full transcripts, and field notes. While specific parts were considered in

detail, these interpretations were also examined within the broader context of the participants as a whole and across all interviews, including the parent and child groups separately. The iterative process ensured that the emerging themes reflected the overall meaning of participants' experience rather than isolated parts of the data (van Manen, 2007).

In conclusion, this interactive and in-depth analytical process was completed over many months. Rigour within the analysis was supported by sustained engagement with the data, transparent documentation of the analytical process through the use of NVivo and written reflections. Throughout the research process, reflexivity was maintained, further strengthening the trustworthiness of the findings. Overall, this study demonstrates strong methodological rigour and credibility, among other key criteria for ensuring quality in qualitative research, as discussed in detail below.

5.9 Assessment of Qualitative Data

To ensure quality within this qualitative research study, the conceptualization of the key 'big-tent' criteria, which include a worthy topic, rich rigour, sincerity, credibility, resonance, significant contribution, ethics, and meaningful coherence for excellent qualitative research, served as a foundational guide to ensure validity, trustworthiness, and reliability throughout the research process (Tracy, 2010). Confirmability is addressed through transparency about my positionality and through ongoing reflexivity throughout the research process to help minimize bias and be inclusive of the multiple viewpoints, perspectives, and experiences that participating children and families shared with me (LoBiondo-Wood et al., 2018).

5.91 Worthy Topic: Significant Contributions to the Field of Child Health

This research contributes to a deeper understanding of the lifeworld experiences of children diagnosed with CHD and their families living in NWO's rural, remote, and northern

areas. Through in-depth interviews, the findings provide rich data on children's families' experiences of living with and navigating CHD within a geographically unique context. To date, there is a gap in general and qualitative research that focuses on children's and families' experiences and perspectives while living with CHD in rural, remote or northern communities, especially within the context of NWO. This area is unique and faces many barriers to equitable healthcare services; this research will help illuminate issues around health and social injustice and inequity for children and families living with CHD in under-resourced settings.

This research will also contribute to qualitative and phenomenological methodology. As noted throughout the literature, there is minimal use of research conducted with younger children and children in general. This study provides a voice for children, closing the gaps noted in the literature, as a parent proxy often reported children's experiences around CHD. The findings from this research has implications for healthcare practice reform, can inform health policy, and can contribute to health system transformation, bridging the gaps in care within NWO (Patton, 2015). As children with cardiac conditions often require specialized care outside Thunder Bay, these findings highlight opportunities to strengthen local support services within NWO.

5.92 Rich Rigour

Key steps are employed throughout the research process to ensure rich rigour, including a sound research design, member checking, triangulation, reflexivity, and transparent reporting, including the return of transcripts to participants (Creswell and Poth, 2018). A sound research design involved selecting an underpinning theoretical and phenomenological approach aligned with the research questions and the population (Creswell and Poth, 2018). I also ensured detailed and rich data was collected and further reviewed with an analytic method utilizing van Manen's hermeneutic phenomenological approach (Tuval-Mashiach, 2017; van Manen, 2007), as

described above. Member checking involved returning transcripts and findings to participants so they could clarify, confirm, or elaborate on their accounts (Castleberry & Nolen, 2018). This not only provides transparency but also enhances the credibility of the findings (Castleberry & Nolen, 2018). Triangulation was achieved through multiple data sources and methods, including semi-structured interviews with children and parents and observational field notes (Carter et al., 2014). This combination of narrative accounts and observational records supported a more comprehensive understanding of the phenomenon. Reflexivity was maintained through ongoing self-reflection on my assumptions, positionality, and influence on the research process, documented in field notes and personal journaling (Creswell and Poth, 2018; Solan et al., 2014; Tuval-Mashiach, 2017). Transparent reporting included a detailed description of the research methodology, context, participants, and analytic processes, as well as the return of transcripts to participants (Tuval-Mashiach, 2017; Castleberry & Nolen, 2018). This supports a clear trail of the research process and findings. It also reinforces the study's rigour and allows the reader to assess the trustworthiness (Tuval-Mashiach, 2017).

5.93 Sincerity

Tracy (2006) identifies sincerity as a key tenet within qualitative research, achieved through self-reflexivity, data auditing, and transparency. Reflectivity is a fundamental principle of the methodological approach utilized within the research study. Self-reflexivity was embedded throughout the research process, supporting ongoing awareness of my perspectives, assumptions, and positioning to enable objectivity (Tracy, 2006). Data auditing was completed through member checking, rigorous coding and analysis process as described above, and clear transparency throughout research findings and documentation (Creswell and Poth, 2018). In addition, challenges, limitations and unexpected findings are acknowledged later in this

document and discussed with rationale to enhance the overall transparency of the research study (Tracy, 2006).

5.94 Credibility

Credibility is supported through the use of van Manen's methodological and analytic approach, ensuring that participants' experiences are represented in a rich and meaningful way (Tracy, 2006). Triangulation of the data is also critical to ensure credibility in the qualitative study and can be achieved using two or more data collection methods (Carter et al., 2014; Streubert & Carpenter, 2011). In this study, the environmental scan, field notes and semi-structured interviews have enhanced its comprehensiveness, depth, and breadth (Carter et al., 2014; Polit & Beck, 2006; Streubert & Carpenter, 2011). Field notes, recorded interviews, and transcripts were frequently reviewed and compared to enhance the study's trustworthiness.

5.95 Resonance

In line with the concept of resonance, Tracy (2006) discusses aesthetic merit, transferability, and generalizability to enhance quality within qualitative writing. The findings incorporate rich descriptions and narratives from families living in Northwestern Ontario, highlighting their lived realities within this unique context. Their experiences and findings form the study's aim to evoke understanding and contribute to improvements in care and support for children and families living in NWO (Tracy, 2006). Data from this study may be transferable and generalizable, inferred across interdisciplinary sectors to inform clinical practice, and utilized within political governance when reviewing healthcare policy and structure for Northern Ontario.

5.96 Significant Contributions

Significant contributions from this research will be made through theoretical, heuristic, and practical significance (Tracy, 2006). The findings offer insight that deepens understanding of

social and health-related experiences in a northern, rural context, which may be relevant nationally and internationally for populations in similar geographical contexts. This research particularly contributes to the limited qualitative research in this area of focus and limited research overall that include the voice of children.

5.97 Meaningful Coherence

Meaningful coherence refers to alignment between viewpoints, theoretical perspectives, and methods (Tracy, 2006). The relationship between views, theoretical perspectives, methodological design and how they have underpinned data collection methods has been previously described. As such, the research process has been congruent in a meaningful manner (Tracy, 2006).

5.10 Limitations of Methods

Although this study demonstrated several strengths and strong theoretical and methodological underpinnings, it also had several limitations that must be addressed to ensure ethical transparency and rigour.

Firstly, the use of purposeful recruitment may limit the generalizability of findings beyond those who participated in the study. The findings are specific to the unique geographical and healthcare context of NWO and may therefore not reflect the experiences of other northern regions, as these areas are not homogeneous. Recruitment occurred through a specific cardiac clinic within NWO and may not have captured the experiences of other families who are not connected to these services. Specifically, those still living in northern and or rural areas of NWO who are closer to the Winnipeg catchment area. Although recruitment posters were displayed at various organizations throughout the city, they did not include all of them. This could have limited the diversity of families and the range of perspectives represented.

Additionally, this study excluded non-English speaking families, again highlighting the potential for diversity gaps. The majority of parent participants within this study were mothers, reflecting only a small number of fathers. This may limit the depth and breath of parental perspectives and experiences and thus understanding of the same.

Unfortunately, in this study, challenges arose with the proposed child-centred data collection method, the draw-and-tell method. Before the interviews began, the researcher explained and demonstrated how the activity would unfold as we 'chatted' about their 'special heart', yet only one child participated. For those limited to Zoom, I ensured families had a pen/marker and paper before the interview, yet participation remained limited. As a result, children's opportunities for different modes of expression, especially among younger participants, may have been reduced.

Interview duration differed between child and parent participants. Child interviews were significantly shorter, ranging from five to 32 minutes. While only two interviews were short (around five minutes), the majority were 15-20 minutes. The shorter interviews may be due to several factors, including the child's health and mood that day, willingness to participate, and their developmental capacity. Additionally, the researcher is relatively new to this approach and research. As a result, the depth and richness of the lived experiences captured in these two interviews may be limited. Recognizing this gap, the researcher invited the child participants to participate in a follow-up interview. However, only one participant responded and completed a second interview, lasting 17 minutes, which provided an opportunity to address questions and further elaborate on their initial discussion.

Early memory recall for parents may be limited, especially during acute, often traumatic medical periods. Similarly, normal age- and development-related factors influence memory gaps and recall in children.

Finally, virtual interviews may have limited the researcher's ability to observe all nonverbal cues and to fully engage with participants in their home environment, including observing relational interactions within the space. Although face-to-face interviews were the preferred method for data collection (and the majority), the online platform ZOOM ensured the ethical principle of justice (Government of Canada, 2022a) in that all the participants had the opportunity to share their experiences, even when it was not possible for them to meet face to face.

5.11 Chapter Five Research Methods Summary

In conclusion, this study explored the lived experiences of children diagnosed with CHD and their families living in rural, remote and northern regions of NWO. This study employed a hermeneutic-phenomenological approach, guided by Max van Manen, to gain a deeper understanding of the participants' lived-world experiences and the core structures within them. The theoretical underpinning of Bronfenbrenner was also used as a guide when reflecting and interpreting the meaning as a whole among participants. It was integrated alongside van Mane in the creation of the research questions and interview guides.

Children diagnosed with CHD, aged 4 to 17 years and their parents and or caregivers were recruited for this study. Purposeful sampling was used to recruit families through various platforms, including the TBRHSC cardiac POP clinic and other community-based recruitment methods, resulting in 14 families comprising of 27 participants.

Data was collected through semi-structured interviews, conducted in various environments, including the researcher's work office at Lakehead University, participants' homes, a park, and zoom to accommodate families' busy schedules and those in geographically diverse areas. Interview guides for children were developed at various developmental levels to ensure child-centred language in interviews. Other child-centred methods, such as draw-and-tell, were proposed in this study but did not achieve the anticipated engagement among children.

Data analysis was rigorous and followed van Manen's hermeneutic phenomenological approach. This involved an interactive process of reflection, thematic exploration, and continued writing and rewriting. The researcher was actively engaged with the data and the hermeneutic circle throughout the analysis phase, which was supported by a reflective process.

Ethical approval was obtained from both Lakehead University Research Ethics Board and TBRHSC. Informed consent and child assent process were implemented and adhered to the strict TCPS 2 (2022) guidelines, specifically articles 3.3 and 3.9.

Overall, this methodical approach supports an in-depth exploration of the rich lived experiences of children with CHD and their families living in NWO. These in-depth accounts provided the findings and overall core essential structures of the phenomena, which will be presented in the following chapter.

6.0 Chapter Six: Findings

This study was designed to explore the lived experiences of children diagnosed with CHD and their families living in rural, remote, and northern areas of Northwestern Ontario. Guided by Bronfenbrenner's Bioecological Theory and Van Manen's phenomenological design, the study sought to illuminate the deeper meanings embedded in families' lived space, lived time, lived body and lived relations. The analysis considered the intimate, micro-level realities of the child and family, as well as the complex interplay of broader systems and environments that shaped their experiences across the continuum of time.

The findings from this research are complex and intersecting. While the themes depart from Van Manen's four existential categories of time, body, space, and relation, these 'divisions' are not reflected in participants' lived realities. Rather, the participating families' experiences are interwoven. Families' experiences are characterized by intricately interconnected elements that constantly shift between moments of crisis and ordinary life, leaving families suspended in a liminal state. The liminal state families experience creates unstable rhythms of time. The journeys of families caring for their child with CHD have many challenges; there are, however, also positive stories to highlight. The themes stress the complex interplay between a family's immediate environment and the complex broader systems that have shaped their entire experience.

In the following, I first present the participant and demographic data. I then outline the findings on parents', introduce the families, provide an overview of the findings, detail the caregivers' experiences, followed by those of children.

6.1 Participants' Demographics and Characteristics

Following recruitment, the final study sample included 14 families, comprising a total of 27 participants: 13 mothers, 4 fathers, and 10 children. Initially, there were 29 participants enrolled and completed interviews. Following data collection, it was identified that one family (comprising of one parent and one child) had been inadvertently recruited through TBRHSC despite not meeting the studies CHD inclusion criteria. The family had received a recruitment letter while the child was undergoing investigation for CHD however clinical assessment confirmed the child did not have a confirmed diagnosis. As a result, both participants were excluded from the final group of participants.

As presented in Table 2, the children who participated ranged from 4 to 17 years of age and represented a range of CHD diagnoses type. Note that one child was referred from the cardiac clinic as a child under investigation for CHD and an underlying inherited arrythmia.

Table 2. ***Children Participant Demographics and Characteristics (N=10)***

Category	**N**
Child Participant Age (Years)	
2-6	0
7-11	4
12-17	6
Total	**10**
Child CHD Diagnosis Type	
Acyanotic increased pulmonary blood flow	2
Acyanotic obstruction to blood flow from ventricles	2
Cyanotic mixed blood flow	2

Cyanotic decreased pulmonary blood flow	3
Inherited arrhythmia	1
Total	**10**

Table 3 illustrates the demographics and characteristics of the 14 families that participated in the study. The age at diagnosis category reflects 15 children with CHD (n=15*), rather than the 14 participating families, as one family had two children diagnosed with CHD. I had several discussions with the family around protecting their anonymity as this could be an identifiable characteristic, yet the family felt comfortable and provided permission to disclose this information. Categories including geographic location, family structure, parental employment impact and household income reflect family-level data (n=14). Parental age and education category reflect all parents across participating families (n=28), as demographic data was collected on the family, regardless of interview participation.

Table 3. ***Family Participant Demographics and Characteristics***

Category	
Age at Diagnosis	
Prenatal	4
Neonatal (0-28 days)	7
Infancy (1-12 months)	2
Childhood	2
Total	**15***
Geographic Location	
Northern urban centre	13

Northern rural community	1
Total	**14**
Family Structure	
Two Parent Household	11
One Parent Household	3
Total	**14**
Parental Age (years)	
30-39	7
40-49	17
50-59	4
Total	**28**
Parental Education Level	
Less than high school	2
High school diploma	4
College diploma	9
University degree	10
Graduate degree	3
Total	**28**
Parental Employment Impact (Care-Related)	
No employment disruption	5
Reduced to part time	4
Quit job entirely	5
Total	**14**

Household Income	
< $60,000	1
$60,000-$100,000	5
>$100,000	8
Total	**14**

6.2 Family Descriptions

Within this section, each of the 14 families will be briefly described and given a pseudonym. These short descriptions, along with the use of names within the family, help provide context and a sense of humanity to the reader. To protect the anonymity and confidentiality of the families, all identifying details have been removed from each account.

Family 1: The Anderson Family. This family includes parents, Sarah and Mark, and several other siblings. Five people live in the house with some pets. Child, Noah, aged 12-17 years, has undergone cardiac surgery within the past few years. Remains to have continuous monitoring as a condition, over time, will determine the potential need for interventions or additional surgery.

Family 2: The Samson Family. This family includes Ali and Roger and their child, Arnold, aged 2-6 years. Continuous monitoring as the condition over time will determine the potential need for interventions or surgery.

Family 3: The Tremblay Family. This family has divorced parents, Sophie and Julian. There are other siblings and pets within the family. Child Leo, aged 12-17, lives between both homes. Previous cardiac surgery when young requires continuous monitoring and most likely will need further intervention at an unknown time.

Family 4: The Chen Family. This family includes parents Mei and David. The family consists of multiple siblings and pets living in the home. Child, Renna, aged 12-17, has had multiple surgeries, the last of which was in their younger years. Continuous monitoring is required as there is a potential for corrective surgery in the future, yet no set date.

Family 5: The O'Connor Family. This family includes the parents, Erin and Liam. The family has multiple siblings living in the home, close in age, and a child, Emma, 2-6 years. No corrective surgery is needed currently, but continuous monitoring remains.

Family 6: The Smith Family. The family consists of divorced parents, Jasmine and Hank. Child, Charlie, 12-17 years, lives between both homes, with several siblings and pets. Multiple surgeries were required when young. Continuous monitoring as condition over time will determine the potential need for interventions or additional surgery.

Family 7: The Wilson Family. The family consists of parents Jennifer and Jeramy. Child, Mason, aged 12-17 years. Cardiac surgery was performed in the early years; currently, no further cardiac intervention is needed. While this can never be guaranteed, Mason will have continuous lifelong monitoring.

Family 8: The Brown Family. The family consists of parents Jessica and Tyler. There are several children in the home. Children, Sally and Tim, both aged 7-11 years, both requiring cardiac surgery and awaiting a date based on their clinical presentation while being closely monitored.

Family 9: The Gagnon Family. The family consists of parents Melissa and Frank. There are multiple siblings in the home as well as pets, along with child, Riley, aged 7-11 years. No surgery was needed in younger years, but continued monitoring will be required to ensure stability.

Family 10: The Kowalski Family. The family consists of parents Anna and Peter. Child, Harrison, aged 7-11, has had cardiac surgery when young, and will need monitoring to ensure no need for future surgery.

Family 11: The Harrison Family. The family consists of parents Ben and Marcy, who, although they are separated, remain living together. Child, Fran, aged 7-11, has no other siblings and lives with their parents. Continuous monitoring is required. No surgery has been required yet. The family is awaiting to see if surgery is needed; there is no current time or date.

Family 12: The Nguyen Family. The family consists of parents Lina and Bob. There are multiple siblings in the home with various pets. Child Lance, aged 12-17 years, has had cardiac surgery when young, and will need monitoring to ensure no need for future surgery.

Family 13: The MacLeod Family. The family consists of parents Shena and Matt. There are multiple siblings in the home with multiple pets. Child Nate, aged 12-17 years, has had multiple surgeries, the last of which was in their younger years. Nate will need continued monitoring as they are a potential candidate for corrective surgery in the future, yet no set date.

Family 14: The Garcia Family. The family consists of divorced parents, Sofia and Miguel. There are other siblings and pets in the homes. Child Lucia lived between both parents' houses. They are aged 12-17 years and have had multiple surgeries in their younger years. Continuous monitoring requires the potential for corrective surgery in the future, with no set date.

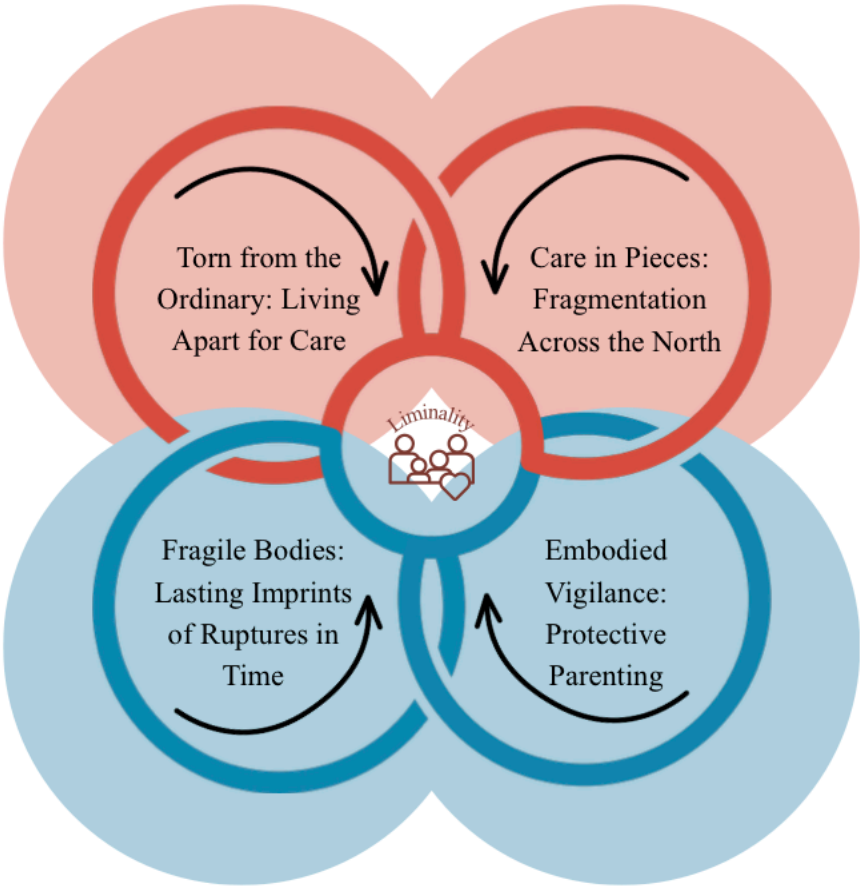
6.3 Findings Overview

The findings of this study are organized around a central, underpinning concept of liminality, with four additional themes that reflect the different aspects of families' experiences.

Each theme includes related subthemes that further illustrate the patterns and complexity within the findings.

Figure 2 below provides a visual overview of the core parent findings and themes. The figure shows that families experiences are not separate but deeply interconnected. At the centre of the findings is the core concept of liminality, which captures how families describe living in an ongoing state of in-between, navigating uncertainty, disruption, and shifting rhythms of time across the northern context. The sense of living between crisis and ordinary life was intricately woven across all parents' experiences. The figure metaphorically depicts the four chambers of the human heart, with red and blue colours woven between to represent the flow and mixing of oxygenated and deoxygenated blood. This attempts to illustrate how families move through periods of acute instability and attempt to restore ordinary life. Liminality at the center of the heart, represents the core 'heartbeat' of these experiences, shaping the unsteady rhythms of time, that pulsates through each of the themes and subthemes. Critical ruptures in time that will be discussed throughout, causing families to be suspended in unsteady and unpredictable 'heartbeat' rhythms in time, contributing to the ongoing state of liminality. The four themes (heart chambers) build on the core finding, reflecting how these liminal experiences are lived and shaped within Northern Ontario. Figure 2 is a roadmap of the findings, and below also includes the various sub-themes that will be discussed in this chapter. Throughout this chapter, Figure 2 will be presented before each of the four themes to provide a visual reminder of the interrelatedness and to orient the reader to where the analysis will move next**.**

Figure 2. ***Overview of Parent Themes***



Core Finding: Liminality

- Suspended in Liminality: Families living in unsteady Rhythms of time across Northern Contexts
- **Torn from the Ordinary: Living Apart for Care**
    - Shifts in family life: parenting severed across fragmented spaces
    - Fractured family rhythms: impacts on siblings
    - The intersection of gendered caregiving and disrupted employment
    - The hidden costs of care at a distance

- **Care in Pieces: Fragmentation Across the North**
    - Discontinuity and conflicting messages
    - Parents as health care coordinators
    - The importance of an anchor in a sea of chaos
- **Fragile Bodies: Lasting Imprints of Ruptures in Time**
    - Disrupted bodies: lasting imprints of interrupted beginnings
    - Acute ruptures in time: witnessing the child's fragile body
    - The lasting imprint on parental well-being
- **Embodied Hypervigilance: Protective Parenting**
    - Differing experiences: shielding children from the weight of illness
    - Protecting Children within everyday and medical environments
    - Parental healing overtime

While circumstances vary between families, shared experiences nonetheless bind them together. Despite differences in varying CHD diagnoses, age and cardiac journeys, ongoing uncertainty surrounding the child's health emerges as a central unifying condition. It is within this ongoing uncertainty that families' experiences of living in-between become most apparent. In the next section, I explore the core findings of families suspended in liminality, living in unsteady rhythms of time across the northern context.

6.4 Suspended In Liminality: Families Living in Unsteady Rhythms of Time across Northern Contexts

Within this study, liminality refers to an ongoing state in which families experience being suspended between periods of acute medical instability and efforts to restore ordinary family life. Liminality was initially explored by anthropologist Van Gennep through the concept of

transition in his original work of rites of passage (Little et al., 2022; van Gennep, 1960). In this work, he argued that across various cultures, rituals had similar structures, and he separated them into three phases: separation, transition (liminal) and incorporation (van Gennep, 1960). Building on Van Gennep, Turner (1979) further conceptualized liminality as a state of being "betwixt and between" ordinary social roles, where individuals are in a period of ambiguity, unsure of who they will become (Turner, 1967). Building on the anthropological history and foundation, contemporary illness research as applied liminality to describe the lingering uncertainty, disruptions, and altered perception of time that accompany serious illness (Bruce et al., 2014a; Little et al., 2022), also among children (Carter, 2017; Janusz, & Walkiewicz, 2023).

Families within this study remained suspended in liminality, as their lives were continually disrupted by their child's illness trajectory and shaped by persistent uncertainty. Endless periods of waiting created an unsteady rhythm of time that permeated everyday life for families. This was characterized by cycles of anticipation, interruption, and prolonged pauses as families waited for the next appointment, test results, or changes to their child's condition. This disrupted temporality made it difficult to establish predictability or routine, as periods of relative stability were often abruptly interrupted by new and ever-changing medical developments. The ongoing uncertainty seeped into all facets of the families' life, ultimately shaping how parents made decisions, organized family routines, and navigated the complex demands of their child's care.

For many families, the liminal state began the moment of diagnosis. With only a few small words from a doctor confirming their child's CHD diagnosis, parents described their worlds being immediately turned upside down, some families sharing their feelings of "complete shock". One mother reminisced, "When he was first diagnosed, we were…completely stressed out, it sounds so dramatic, but almost like having a breakdown" (Ali Samson). In many cases,

the diagnosis was followed by an urgent air ambulance transfer to a tertiary center due to the child's critical condition. Another mother said that she would "never forget" their doctor's "raspy voice" when telling them their child's diagnosis, "there's something going on with his heart and we just don't know what it is. So we're gonna have him air ambulanced to London. We're gonna have to go as soon as possible" (Jennifer Wilson). This moment in time marked the beginning of the family's cardiac journey that was both fragile and highly acute for the newborn. Another mother echoed similar memories around their doctor's voice when delivering the diagnosis, saying "it just there was no hope in his voice" (Sarah Anderson). It is within these ruptures in time that families all described being catapulted into liminal space, suspended between the life they had and an uncertain future. What could have been a contained period of crisis was intensified by geographical distance, forcing families to make impossible decisions while separated from family, friends, and support systems.

Although the crisis periods lessened over time, the fragile nature of their child's condition remained. Parents described living with a persistent undercurrent of worry and uncertainty, aware that at any moment their lives could once again be disrupted by their child's health needs. One mother felt like she was "always in constant worry. You're always worrying about what is going to happen next. What's going to happen in the future?...when he does go for his heart surgery?" (Jessica Brown). For these families, time collapsed at the moment of diagnosis and was thereafter stretched into prolonged periods of waiting marked by uncertainty and anticipation. Jessica continued, "It's an isolating feeling. And people don't understand because it's not something that you can see. And so when you're having to go through unpredictability every six months of your life, that can be something, you know" (Jessica Brown).

Acknowledging that the biyearly medical appointment could uproot their worlds, everyday life became reoriented around medical timelines, hospital rooms, travel days and fragile bodies.

This constant anticipation became an enduring emotional burden. Uncertainty about results, clinic visits, and conversations with the specialist often created immense psychological strain. The prolonged periods of 'waiting', further exacerbated by geographical burdens and complex system navigation, further intensified the emotional toll for the majority of families. Jullian said that,

> It's just a huge emotional stress when you're already going down, always worried, waiting for that next piece of news that's not gonna be the good news. So, you add that to that, until you know what's going on, people make themselves crazy. I think we all do it. And so you're going down into that cloud and then to have those extra kind of stresses attached to it (Julian Tremblay).

Given the Northern context, many families described additional layers of logistical uncertainty. Parents waited months, and at times even a year, for their next clinic visit and/or follow-up phone call. In some cases, families had to travel to southern Ontario to receive results and/or for follow-up consultations. Families describe this experience of waiting as "scary," *with* one mother remembering, "we would just like, wait for her updates and we had to live with this kind of like dooming feeling is the hole's gonna fill in on their own, or do we have to go?" (Erin O'Connor). These prolonged and uncertain waiting periods contributed to an unstable rhythm of time, in which families' lives were organized around unpredictable medical timelines rather than typical developmental or family milestones. Living within this state of liminality meant families could no longer hold on to what they understood as their prior reality; instead, their sense of the

future was suspended, and they were unsure of what might come. A mother described what that meant,

> So they had surgeries, but what we don't have is data for life expectancy and things like that with him. So we always just kind of throw it in the back of our mind and we don't concentrate on those things. But every once in a while, that does rear its ugly head. You know that you're assuming he's going to have a regular, nice, long life-expectancy. But we don't we don't know from the data. So we just live every day to its fullest (Shena MacLeod).

Moments of crisis and continued uncertainty often clouded the family's ability to imagine the future, as they often had no control over what would happen to their child's body or the situation surrounding their child. One mother lamented, "She needed so much care…we weren't sure what the future would hold around her first birthday when she still couldn't sit up… So, the whole life plan shifted and was a question mark for a long time" (Sofia Garcia). Families described having a constant fear of the worst possible outcome; the possibility of losing their child was never absent. As Jasmine Smith (a mother) recollected, "He was pretty sick for a while. Honestly, the amount of weight he was losing and them just trying to figure stuff out, I didn't know if I was coming home with a kid". Another mother had a similar experience:

> I found that each appointment when he was young was a very, - it was very emotional. I was, you know, presented with this baby and, you know, like, I had another child at home. And it was difficult because my fear was always that I was going to lose them. I didn't know his heart. I didn't understand if his heart was going to be able to, you know - as it going to fail when I took him home, that was one of my biggest fears (Jessica Brown).

Many families also described living with the ongoing possibility that they could be required to uproot their lives and leave home abruptly for specialized care. This liminal state extended beyond the parents to affect the whole family unit. Siblings frequently experienced disruptions to routines when parents had to travel and leave home abruptly for extended periods. These abrupt shifts further destabilized families' sense of temporal continuity, as plans were changed in response to medical information, that was often given with little notice. The continued uncertainty shaped parents' everyday thoughts, layering additional stress onto already demanding routines. The back-and-forth nature of medical planning and constant unknowns became mentally exhausting and stressful. One mother described how the uncertainty became part of their everyday thought processes: "You might go to London. Oh, now you're not going to London" (Melissa Gagnon). Many families did not realize the extent of this emotional toll and underlying feeling of catastrophic fear until significant milestones occurred, such as being discharged from the cardiac clinic. One mother remembered,

> I burst out crying after the doctor left the room, like, weeping because I was living under the thought of, like, am I going to find her dead. It just was always in the periphery or are we going to London today? Is that coughing spell going to lead to a breathless spell going to lead to blue lips and blue hands going to lead to another trip to 'emerg'. Going to lead to a - someone coming in the room saying I'm sorry, you have to go to London and go have this surgery. And so those are catastrophic thoughts. I realize that, but being discharged all of a sudden, I was like, oh my gosh, I don't have to carry those thoughts (Erin O'Connor).

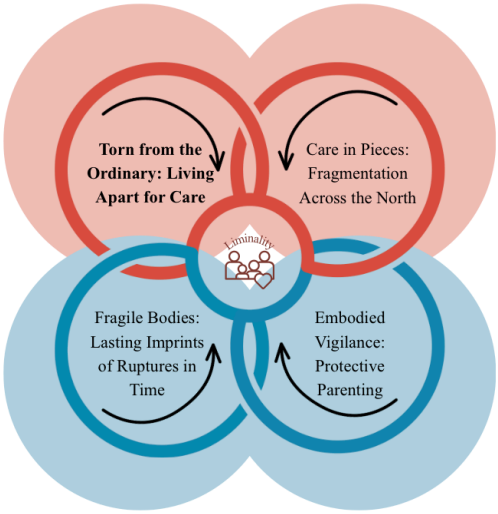
However, it was not just in conjunction with hospital admissions that families' sense of safety and predictability was disrupted or they experienced catastrophic fear. This also occurred

while the child was ‘healthy’, particularly when their child engaged in physical activities such as sport. Jasmine recalled, “It always worries me. Like I used to always have this fear. Like he's going to play basketball and have a drop and have a heart attack” (Jasmine Smith).

Across their child’s cardiac journey, families experienced repeated ruptures in the rhythms of time, leaving them in this unsteady and unpredictable state. Despite this unsteady rhythm, every time a crisis passed, parents re-engaged in the process of building stability and creating a new everyday “normal”. As outlined by Ali,

> I think it's, like it's more adjusted now, but it's still a little unsettled because of the unknown. There's always the unknown. So it's still very unsettling, but you kind of just gotta push it at the back of your mind, because then you're not present with your child because there's that stress there. And I'm trying to just be my most authentic self so I can be the best version for him…it comes in where you're like, oh, I'm doing good and out of sight out of mind, and then it comes back again where you're really thinking about it. It's kind of like a bouncy ball back and forth (Ali Samson).

Past medical crises reshaped family life, with parents navigating a liminal space where uncertainty remains the only constant. The shared experiences described above illustrate how families are continually suspended in this liminal state, living within an unsteady rhythm of time. The sweeping undercurrent of uncertainty seeps into their everyday thought processes, reorganizing their routines and, ultimately, shaping families’ life trajectories. In turn, this state of liminality influences how families navigate their child’s illness while balancing the ever-changing demands and complex care of their child with CHD alongside the needs of the broader family unit. Figure 2, bolds the next theme explored, torn from the ordinary: living apart for care.



6.4.1 Torn from the Ordinary: Living Apart for Care

The first theme (bolded in the figure above), developed within the overarching theme of liminality, focuses on families' experiences of living apart for care. It captures how families are required to leave home and stay in unfamiliar environments, often separated from other family members, support networks, and employment. These separations marked a clear break from ordinary family life and positioned families in a space between home and hospital stability and disruption.

The impacts of living apart for care were most pronounced during acute periods of illness and they shifted overtime. As children grow older and their conditions become more stable, separations tend to be shorter and less frequent, although the possibility of future disruption remains in the background. Living apart for care was not only about physical distance, but it also altered how family life was organized when families were together, including daily routines, roles, and relationships. Although families often described resuming aspects of their normal lives, these routines unfolded and were often altered to form a new normal. Daily life often felt temporarily intact, which was shaped by an ongoing awareness that another rupture and sudden change could occur at any time.

This theme is explored through three subthemes, which will be discussed next. These include 1) shifts in family life: parenting severed across fragmented spaces, 2) the intersection of gendered caregiving and employment disruption, and 3) hidden costs of care at a distance.

6.4.1.1 Shifts in Family Life: Parenting Severed Across Fragmented Spaces. This subtheme explores how living apart for care required families to reorganize the entire foundation of their life, its routines and rhythms. Ordinary family routines were reshaped around medical schedules, timelines, appointments, and travel. One mother described how, “There's less of the kind of quality time where everyone just sits around and then a funny story comes up where like things organically happen… Everything needed to be scheduled” (Sofia Garcia). Families were forced into shifts within their family life and unit due to the needs of their ill child, with many families experiencing prolonged periods of separation and being forced to parent across diverse and fragmented spaces, adding to an already stressful period. One mother felt that “what was more stress was like I had a 2-year-old at home and then I've got my newborn [here]. So now we've got that balance act [of trying to parent both well two in different places]” (Melissa Gagnon).

The early stages of the fragile and critical condition of the newborns brought profound disruption for families and often led to abrupt immersion into crisis. Infants were critically ill, requiring urgent specialized medical care, frequently requiring being flown hundreds of kilometres away to distant tertiary care centres. One mother talked about her experience of trying to navigate their child’s acute care needs while ensuring their other child is also cared for.

> We leave the hospital, we call my mom... We have a meeting at (Name)'s mom's house…because we have him and he's only two, you know? So it's like, what do we do? And I hate flying. So…he had to go on the ORNGE airplane because there's no chance, I

could go on it because it's so small and I'm way too scared. Plus, I just had a C-section. You know?... it was like terrible (Jennifer Wilson).

Families were thrown into a liminal phase where decisions were urgent and often beyond their control. Another mother discussed her experience of an abrupt transfer to southern Ontario due to the critical condition of her child. She was separated from her family and other children for more than three months. She had to stay in southern Ontario awaiting the child's surgery, although "he had that at 12 days old, but then he got a ton of complications from the surgery. He couldn't get off the ventilators…He had trouble breathing. His diaphragm was paralyzed" (Jasmine Smith). Families were often suspended in a stage of acute liminality as time was collapsed into moments of serious urgency. Families managed their sick child in an unknown environment, while also organizing care for their other children from afar, while trying to maintain ordinary life.

Many parents held that their greatest support system during these times was not only their partner but also their own parents (their child's grandparents) or other family members, including siblings or aunts. These family supports often took on caretaking roles at home while one or both parents were away. One mother shared her stress when having to leave for care, "if I didn't have family… like my younger sister to get my flight to Toronto, or like my spouse to help out with things…if he wasn't here to watch them (other children) when I'm taking (Name) to Toronto for a week" (Jasmine Smith). This experience, common for many parents in this study, highlights how access to care depended not only on the parents' ability to travel but also on the availability of a trusted family member and or friend who could step in to provide care and sustain the family's routines in their absence.

In addition to support systems at home, many families were fortunate to have extended family in southern Ontario, where they were transferred for specialized care. This support network was particularly important during critical periods when families were required to remain away from home in unfamiliar environments, such as in hospital settings in a large urban city. One mother's parents lived in southern Ontario, so accommodation was '*free,*' and she was able to bring her other children while her husband stayed home and worked. She felt that, "It was actually probably easier childcare than if they'd stayed here (at home)… Like who's staying at the house to keep after the kids, right" (Mei Chen). A few parents reported that they had the means to fly their child's grandparents to southern Ontario for support during prolonged hospital stays.

The northern context forced families to live apart for care, to have to make impossible decisions, while also being torn between being at their sick infant's bedside and remaining with their other children at home. In northern Ontario, the absence of local specialist pediatric cardiac services means that any serious condition could trigger an urgent transfer to a tertiary centre in the south, often with little warning and minimal choice. This 'specialist cardiac care desert' in the north magnified the risks of each decision as accepting care also meant accepting separation. Decisions had to be made fast, with little time to digest; one mother recalled: "4:00 that afternoon he left us and then I couldn't go with him and then by 9:00 that night, we're going to Toronto as well. So we're leaving a 4-year-old behind not knowing anything" (Sophie Tremblay*).* The father continued to reflect on this experience, adding, "We didn't know for sure he was even okay, alive, until we were on the plane, because they can't tell you, right?" (Julian Tremblay). Geography intensified the crisis among families. What could have been a short transfer in an urban setting often became a complex ordeal, involving air travel, weather-

dependent flight schedules, and long distances from home. This will be discussed in more detail throughout and within the following theme: *care in offices across a northern landscape*. Another mother talked about the agony she felt of not wanting to be separated from her other child: "I don't care if that he's got to stay at the Ronald McDonald House with us…I don't want us to be broken up. I want us to be all together. Because…I didn't know if he was going to frickin make it" (Jennifer Wilson).

The liminality imposed on families as they were forced to live apart for care left them suspended between the demands of crisis and the need for ordinary life to continue. The pull between two spaces took an enormous toll on the parents lived body and self, as they felt guilt and sadness having to make impossible choices. One mother shared her experience during this time: "It was definitely a traumatizing part in my life…I was a full-time mom, and to have me all of a sudden gone for that long…I never missed a kid's first day of school except for that year" (Jasmine Smith). For several families, this was a cruel reality; decisions about attending or missing important milestones of their other children were often made for them; living apart for care was the only way forward due to immediate crises and ongoing needs of their sick child.

For several families, what was thought to be a quick stay of only a few days turned into living apart for care, with no timeframe and often several months away from their homes and support systems, causing a collapse of normal life. A mother recalled, "I had actually, my other two kids were home, and I thought…I'm just going to Toronto for medical appointments, and I'll see you in a couple days. And then I was there for three months, so it was insane" (Jasmine Smith). Families shared their internal fears and struggles as they tried to plan for the unknown during this time. One mother reflected:

> Who's going to watch my son? How are they going to function? Do we have enough food in the freezer that they will be fed while I'm gone? Who's going to do all the things and who's going to go? Do I go, does (Name) go. Where do we stay? How do we... How do we do this? (Erin O'Connor).

Erin further shared that, above everything else, she wondered, "Is she [Emma] going to be okay?" (Erin O'Connor).

The separation was challenging for both the parent who accompanied the child with CHD and the parent who stayed at home. A father described his struggles when having to leave his wife and ill child to go home and care for their other child: "the hard part, having to leave him and you guys down there to come back to deal with her, which I was happy to do…just too far away…like have a bad day and I wouldn't have made it" (Julian Tremblay). Many of the fathers shared similar struggles. They felt the pain of having to divide their parenting, always leaving some family members behind to meet the competing demands of acute and daily life. As illustrated in Figure 2 *overview of themes*, these experiences sit in the intersection of geography, caregiving and employment, illustrating how the themes in this chapter are tightly interconnected. I return to these overlaps in more detail in subsequent themes.

For many families, long periods of time away from home, separation, and not knowing when they would end were common. Living apart for care forced families to try to live in two different places at once, parenting across severed spaces. Their physical bodies were forced into an unknown hospital environment far away from home. Yet their minds were divided and torn, thinking about, loving, missing, and caring for their other children and family life from a distance. Parenting across divided spaces and the continued uncertainties of when they would return home further contributed to the ongoing state of liminality for families.

6.4.1.2 Fractured Family Rhythms: Impact on Siblings. Parents in the study frequently reflected on the impacts that living apart for care had on siblings. Siblings experienced prolonged family separation, absence, waiting, and disruptions in their lives and routines as time often revolved around the ill sibling. Ordinary expectations of waking up to their parents' presence, returning home and knowing they would be there were no longer guaranteed. Many parents reflected on the emotional toll that repeated separation had on their other children. One mother reflected on how her child had an emotional outburst in the grocery store. To her, this illustrated how the sibling of her child with CHD had come to live with the constant possibility of disappearance.

> I turned the corner at the end of the thing with the cart and the girls, and he started to scream. He had thought I'd disappeared. And I thought, oh, because that's his reality. Like, he wakes up some mornings and I'm not there because she got sick in the night and I went to emerg, and now grandma's coming in to babysit and where's my mom? (Mei Chen).

For siblings, '*normal*' family rhythms became fractured, with ordinary family time often being marked by sudden absences, making otherwise predictable routine unpredictable. One father talked about the lasting impacts separation had on the sibling of their child with CHD following acute hospitalization periods of the child with CHD. He stated that it, "probably affected for the first two or three years after that. Every time we left, she wanted to know where we were going because we just kind of left her, right?" (Julian Tremblay). The mother added, "Well, she wasn't even awake. She woke up, and she knew it could happen, that, you know, somebody would be here, but she didn't know we were gonna go away, away. That was hard" (Sophie Tremblay). Even in ordinary moments such as leaving the house, the child sought

reassurance, revealing how the earlier separation due to their sibling's illness had altered their sense of safety and predictability.

Parents also spoke about how siblings had to adapt to a life reorganized around a sick child, and how this reorganization didn't center on the siblings' needs because of the nature of the other child's illness. One mother explained in relation to her other child, "he's essentially fine, but like he definitely needed to learn to be really tolerant because sometimes we were at the hospital for six hours on a day that the daycare was closed or, you know" (Sofia Garcia). Having to bring the other children to the hospital for long periods was a reality for many families as they were away from their home and support systems.

In addition to spending prolonged periods in a hospital setting, families shared that the critical needs of their ill child often meant that siblings received less time and attention. One mother recalled, "There was definite impacts. And (the sibling) definitely took a back seat during those earlier years. Thankfully, it was kind of during those earlier years where he doesn't remember" (Shena MacLeod). Parents also described that siblings often felt that their sibling with CHD was given "*special treatment*" or that they were "*bubble wrapped*". Many families often found themselves more protective of their child with CHD compared to other children with one mother stating, "I definitely am more protective of him. More baby him" (Jasmine Smith). Most parents acknowledged this while stating that it was never their intent. All parents reported a constant underlying fear and worry that made them increasingly more protective of their child with CHD in comparison with their other children.

6.4.1.3 The Intersection of Gendered Caregiving and Disrupted Employment. Living apart for care influenced both parental employment and caregiving roles, with responsibilities often unevenly distributed and strongly gendered. As previously described, the acuity of the

child's condition required families to navigate life between home and hospital. Parents had to balance the family's financial needs alongside often complex caregiving demands. Complex caregiving demands included feeding tubes, at-home oxygen, oxygen level monitoring, secondary illnesses, and medications. These additional challenges were often managed away from home and support, or at home without specialist support. One mother reminisced.

> He was on 14 different medications… I had this grid thing that I had it all down on because there was 14 different medications anywhere from 2 to 4 times a day…I had to have a time and which ones I gave him at that time, and I would pre-draw them all and then have them in bags…so then I would check my list to make sure that those were the right ones, and then I would give it to him. And then he also had to get needles twice a day for the first three months (Sarah Anderson).

These parents were forced into difficult, unequal roles; one parent had to remain working while the other took on the primary and complex caregiver role, frequently at the cost of their employment. Both choices and roles were uniquely challenging.

Across the 14 families, employment changes were overwhelmingly experienced by mothers. The majority of mothers had to alter their employment significantly following their child's diagnosis. Five of the mothers interviewed left their jobs entirely, and four reduced their employment to part-time. As one mother explained, "I just quit a job because it had me away from him or, you know, so I wanted to make sure that I'm home" (Jasmine Smith). Another mother had a similar experience regarding caregiving demands and employment impacts which she wrote in a text message following the interview. She explained that she did so to ensure her child could not hear the discussion. She expressed that this was to protect her child, as she didn't

want her to feel “responsible or regret for the things that were out of her control” (Sofia Garcia). Sofia further shared,

> I would say that for sure her illness did affect my career and my education trajectory. My plan had been to pursue grad school by the time my kids were born in full-time school. That kind of went out the window without question when she needed so much care and because for a long time, we weren't sure what the future would hold around her first birthday when she still couldn't sit up (Sofia Garcia).

Most mothers described these decisions not as losses they dwelled on, but rather as choices made from love and necessity. One mother changed her employment to become more flexible so she could provide full-time care and contribute financially to the family. Ali changed her employment to teaching classes that worked around her child’s nap, and also took on additional work online to become “more of a full-time worker” (Ali Samson). Ali added, “…but still, when he goes to school, I am gonna be able to drive him, and then I'm gonna be able to pick him up” (Ali Samson). The changes made by mothers underscored how caregiving demands frequently reshaped mothers’ everyday roles. In many cases, employment became secondary so that the immediate needs of their child and family were met.

Caregiving demands and employment intersected in ways that created unique challenges. The severity of the child’s condition, combined with frequent near and far hospital visits, limited families’ ability to rely on external supports such as caregivers or daycare, further restricting their ability to maintain employment. One mother recalled, “Reality is when you have a child that's sick, like you can't put them in a daycare and you can't work…like there's no way to have had two incomes on with like a severely ill child…there just was no way” (Sofia Garcia). Another mother echoed, “I started my own [blank] company after all those years of never going

back to work after she was born. There was no way you could go back to work when she was a baby… she couldn't be in daycare" (Jennifer Wilson). Other families described adopting unique, ever-changing caregiver roles to manage employment and care demands,

> We call it point parent. We don't really have a mom-stays-home or dad-stays-home. It's just we take seasons of like, okay, you're point parent, for these six months. I'm going to work really hard. I'm going to make enough money that we can survive... And then the other parent is the anchor. Oh, not point parent but anchor parent…Because at any point, you know, we got a call from daycare, which has happened. We're not sure if this is okay. And if daycare is unsure, we go pick her up. We don't mess around…Someone has to be home with her (Erin O'Connor).

Although these role shifts were co-created and shared, they still relied on one parent assuming primary caregiving responsibilities, usually the mother. This pattern highlights how caregiving demands and gender roles continued to structure parental roles in ways that were not always experienced as equal, even when both parents were involved in the care. Parents' stories also emphasized that even with help, families must have one parent at home or on call in case their child required immediate care. Flexibility was not something all workplaces could accommodate, yet it was essential when caring for a sick child.

Although they worked together to maintain ordinary family routines, being physically separated by more than 1000 km to ensure their child's medical needs were met while maintaining financial stability added pressure on both parents. However, that pressure was often experienced differently across parental roles and genders. A mother shared, "My husband had to work all the way through…He had to work…he can't take three months off work. So that was stressful for me" (Melissa Gagnon). Another family's story similarly involved the need to be

apart, due to financial and employment requirements, “Yeah. I mean, we were together, but also like someone at the hospital with (Name), somebody at Ronald McDonald House. Sometimes, depending on the season, (husband) had to go home for work. Like somebody has to make some money” (Mei Chen). The emotional toll this took on families was overwhelming. One parent described that the pressure of separating their family to return to work was not worth the emotional toll it took on both parents’ bodies and minds.

> When we were there for that long time, he tried to come - he's like, I have to go. I just have to work…The company needs me. We're broke…And he came home, and he was here for a week…And then his dad said, I put him back on a plane. This isn't going to work. He has to be there because he just wasn't okay, like, and I wasn't okay (Jennifer Wilson).

The shared experiences highlight that although caregiving and employment roles were often divided, the emotional strain of separation was not. These experiences deeply affected both parents.

Geography continued to intensify these challenges, leaving little possibility for short visits and additional support. Unlike families living closer to care, parents were unable to ‘hop in a car’ to bridge the gap between work and caregiver demands. Distance shaped families’ ability to juggle employment, support, other social connections, and the care needed. Many families felt isolated and had to live with reduced income and increased costs as described by Jessica:

> So time away from work. Like I have to take all - like I have to all days like if something happens, we have to go up the day before, now I have to take two days off work. And then, you know, plus the cost of it. I mean, everything has gone up, gas has gone up. Price of food has gone up. And, I mean, you know, for some people, it's easy to say, well,

> I'll just take one kid. Well, that's not easy to do when you don't have a support system in where you live. I can't just leave my kids here (Jessica Brown).

Employment became deeply intertwined and was impacted while living apart for care. As noted above, the majority of mothers left or adjusted their employment to assume the primary caregiving role for their child, while fathers often maintained employment to support family income. Employment could not be put on hold while families navigated the child's illness. Rather, the child's illness continuously shaped decisions about employment, family financial responsibilities, and additional expenses. It also influenced how families negotiated geographical distance, travel and caregiving responsibilities, placing them under immense stress. These stressors coupled with the continued uncertainty and unknowns around their child's illness, left families in a continual state of liminality. The loss and change in ordinary employment, with its impact extending to the financial health of the families, had major impacts.

6.4.1.4 The Hidden Costs of Care at a Distance. The vast geographical distance families had to travel for necessary care fractured families' daily routines, relationships, and overall well-being. With this, it also introduced hidden burdens that intensified ruptures over time. Families recalled the financial hardships they endured due to the urgent, frequent, and required travel for their child's care.

Even the few families who felt they could afford it spoke to the high financial cost of travel. Many families spoke to the extreme lengths they would go to "have figured out [how to pay for the additional costs]- I would have sold our house or something" (Mei Chen). Many families spoke about having to budget, deplete savings, borrow from relatives, or take on significant debt to ensure the child received the needed care. Even though "there were a lot of costs covered for sure" one family still "In the first two years of her life… incurred $30,000

worth of debt" **(**Mei Chen). Another mother recalled that "when we went through the stuff with my son we went in the poor house…And also you have a life back here. So you're paying your mortgage, you're paying your stuff, you're off work" (Melissa Gagnon). Families were torn between their crisis, the management of their ordinary lives, and financial and other responsibilities at home.

Many families needed to ask their families for support to pay for necessary and often unexpected travel, "I ended up having to catch a flight to Toronto two days later. I had to get my younger sister to pay for it because nobody helped me out here." (Jasmine Smith). Seeking financial help was very challenging for individuals and families and placed them in a vulnerable position. The families who participated in this study were already in an incredibly difficult and overwhelming position; being financially dependent on others added another complex emotional layer. The decision to travel was not an option; it is required to save their child's life, yet the financial consequences and constant worry about whether they can afford the next trip were carried entirely by the family with little external support. One family reflected, "he had an appointment like ten years ago, and I had no flight five days before his appointment because I couldn't afford it" (Jasmine Smith). This mother further shared it was through the financial support of her sister that she was able to get a flight to the appointment.

It added extreme stress for families trying to save for their often-abrupt and unplanned trips to southern Ontario, "having to pay for two plane tickets and a hotel, not expecting any of that. Like that was a shock." (Sophie Tremblay). Another mother similarly noted how "financially straining, those that like six, eight years [were] because it was like pinching every penny and saving every penny I can. And then still worrying that I'm not going to have enough for this next Toronto trip" (Sarah Anderson).

The cost of flying from one side of a province to the other was alarmingly high, particularly when there was little time to plan. Families were burdened with unimaginable costs, as Ali recalled including “flex for insurance and then you get a rental vehicle. It was like $2,800 with tax to fly”. Some families living in rural areas described even a day trip driving to Thunder Bay as financially taxing. This was due to time away from work and the expenses of bringing other children. Jessica Brown described how these pressures “all pile up”, noting that even a day trip to Thunder Bay with her family could cost $1,000.

Families described the cost of travel extending far beyond gas or plane tickets. There were hidden expenses that added up quickly, such as ensuring everyone was fed, buying groceries in unfamiliar cities, and eating out because there wasn't time or ability to cook. One parent spoke about these hidden challenges,

> The constant travel, from needing to eat, like, we're staying in a hotel. Where do we eat? We have to eat. We're downtown Toronto. It's stupid expensive… we had a kitchenette at Ronald McDonald…We can cook food in some sort of time that we have to do that. But even groceries downtown Toronto is, like, a huge chore to take all your kids, and you have to walk, and you have to carry them and you, because you don't have a car and you have to - yeah. It's expensive **(**Mei Chen).

Even with government-funded programs such as the Northern Health Travel Grant, families reported they would still not be reimbursed for the costs they incurred. Melissa shared their concerns,

> I'm telling you, travel grants don't cover. Like, they don't. They do not cover enough. They don't cover all your gas. They do not cover your stay, your food, like anything that

> goes wrong. And also you have a life back here [Thunder Bay]. So you're paying your mortgage, you're paying your stuff, you're off work (Melissa Gagnon).

The grant also fails to align with family-centred care principles, as Ali stated:

> [With the coverage of] the Northern Travel Grant, only one parent would get reimbursed. I feel like with a small child if you can it's awesome to have both parents… the child needs that support, and the mom does too… you don't get reimbursed nearly how much you spend (Ali Samson).

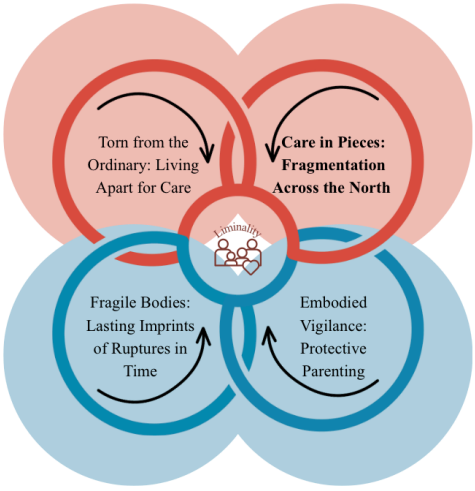
Several families discussed their issues with delayed payments and the often-significant interest rates they were left to pay due to the '*ineffective*' and '*crappy'* policy system. One mother shared,

> It's a huge expense, and we're putting the money out. And even when there's travel grants you have to like work it all over… so just like months and months and months of it sitting there on our credit card waiting for a travel grant to come back and pay it off and the interest and the like, it's tanked our - it's tanked our credit scores (Mei Chen).

Mei spoke about the letters she sent to the local government about the insufficiencies of these so-called supports. Although small changes were made, several families deemed them insufficient.

When a child became sick, families had little to no choice but to leave their homes, routines, and support systems, often for prolonged periods of time. Food and travel expenses were beyond what families would normally incur; they had to budget for them, and they added an extra cost for families that had often gone from two wage earners to one. Of course, the expenses incurred in these critical moments were not questioned. Families did what they had to for their family, but over time, the financial weight of these necessities added another layer of

stress that families were forced to carry. Across the shared accounts, living apart for care emerged as more than physical separation; it disrupted family life, altered employment and caregiving roles. This ultimately uprooted everyday routines with a new and fragile ‘normal’. Together, these experiences show how families were continually suspended in a state of liminality, where the timing, duration, and ability to afford travel for care remained unclear and challenging, perpetuating ongoing uncertainty and anxiety about the future. Figure 2 bolds the next theme explored, care in pieces: fragmentation across the north.



6.4.2 Care in Pieces: Fragmentation Across the North

The second theme, developed under the overarching theme of liminality, focused on how families experienced their child’s cardiac care as fragmented and “in pieces” across the northern landscape. Rather than receiving care in a single coordinated setting families faced many complex challenges trying to access specialized cardiac services for their child. Parents had to navigate multiple sites and systems spread across vast distances, often with different providers’ medical opinions and levels of expertise. The intersection of care fragmentation, geographical distance, and weather-related challenges was a factor largely beyond families' control. These

findings further emphasize that families remain suspended in liminality, positioned between fragmented systems of care and forced to actively bridge these gaps themselves.

Families described how this dispersed system complicated both everyday management and crisis situations, intensifying feelings of fear and uncertainty. Families frequently move between local providers, visiting specialist clinics in Thunder Bay, and tertiary children's hospitals in southern Ontario, with each site holding only part of their child's story. Within this theme, three interrelated subthemes were explored: (1) Discontinuity and conflicting messages; (2) Parents as healthcare coordinators; and (3) The importance of an anchor in a sea of Chaos.

6.4.2.1 Discontinuity and Conflicting Messages. In addition to navigating care across multiple geographically distant healthcare sites, families described how the limited availability of specialized providers in Northwestern Ontario and the infrequent visits of the cardiac clinic (twice a year) contributed to fragmented care. As a result, families often felt they received conflicting medical opinions and advice. Families reported feeling frustrated with how things were being operated. A mother expressed, “What I find is a huge struggle is each doctor tells you something different. The communication is different” (Jessica Brown). Another mother echoed, “They will give you different answers to things…So, one will say, no, he can't play hockey. This one will say, oh no, he's totally fine to play hockey…I don't have that much faith” (Anna Kowalski). Parents’ frustration was not just about differences in opinion between providers, but also about the lack of continuity and the inability to build a trusting relationship with a provider. One mother explained,

> I've also expressed my frustrations to Dr. (Name) who I have literally said like every six months you see a different doctor every, you know. So like what this doctor says is his opinion. But next, you know, in six months it could be a different opinion. So I said it's

very - you don't get to build that relationship with one particular doctor like I had with Dr. (Name) (Jessica Brown).

Several parents also questioned the capacity of the local system to meet their child specialized needs. As one mother shared, “I don't think really the healthcare system here is that supportive. I just don't think they have the resources to be.” She continued, “When he was born, there was no one here that had even seen what he has. So, like, we're so isolated, there's not the expertise” (Anna Kowalski).

Another mother described how even common childhood injuries became complicated by her child’s CHD. Mei recalled that if their child fell and dislocated their arm requiring surgical intervention, they would have to be flown to Toronto, as locally they did not have the resources to intervene due to the child's CHD. Mei stated, “They don't send kids to Toronto for arm repairs from Thunder Bay. But (Name)'s cardiac condition means anesthesiology doesn't want to touch her because there isn't a paediatric cardiologist here on call [locally]” (Mei Chen). For parents, this demonstrated how a lack of local cardiac specialist support made even minor issues feel like larger issues.

The lack of access to cardiac care made it extremely complicated for children and families residing in Northwestern Ontario. If there were an emergency or a child needed to be seen quickly, most families would have to access local care. However, many families felt discomfort that local health care providers lacked the specialist knowledge and equipment to appropriately assist with care. One mother stated that she “wasn’t feeling that comfortable. And I said, you know what, I would like, honestly, a second like opinion if you could refer us down to Toronto just to someone that deals with this” (Anna Kowalski). Another mother echoed, “If I didn't have that to lean on (London clinic/communication), then I don't know if I would feel

confident with what we have here" (Lina Nguyen). Although this mother did not feel fully confident in the general specialists' care locally, she emphasized she does "*believe wholeheartedly*" that the local pediatrician would help. This will be discussed further in the subtheme below, *the importance of an anchor in a sea of Chaos.*

In practice, families relied on a complex pattern of care spread across multiple sites. Some families rely on bi-annual clinics held in Thunder Bay with paediatric cardiologists who travel North from London's Children's Hospital. When a child's condition was more complicated and required surgery or other invasive treatment and continued follow-up, the child and their family were sent to Toronto Sick Kids Hospital. In some cases, children were transferred to London and seen at the Thunder Bay clinics for follow-up. Parents often experienced this as a complicated and disjointed process. The relational discontinuity "that the doctors from London …[was] different every single time" (Anna Kowalski) left several families feeling lost within the system. The lack of provider consistency created fear among parents about their child's symptoms or issues being missed or not appropriately followed up on. A mother whose child went to Sick Kids for check-ups twice a year said, "I feel like if he was having chest pain or an issue, and maybe there was a cardiologist here [in their home community] that could follow up with him… stuff wouldn't fall through the cracks" (Jasmine Smith). One Dad had similar feelings,

> I understand the difficulty of trying to get such a unique specialty to be in a certain place. I understand that. I just, I don't know, maybe a fuller relationship with let's say Toronto Sick Kids or London Sick Kids hospital, so there would be a little bit more regularity to – because there's the times in between those six month periods when the doctor would come or the yearly appointments that we had for many years with (Name) that we would

> be, it'd be nice if we knew that someone was here every couple of months… I'd rather just have someone I can bounce that off of much quicker [referring to discussing milestones with a specialist] and says, you know, don't worry about it, let him be him, you know (Julian Tremblay).

Julian continued to suggest a way to mitigate the challenges, which other families echoed. He said,

> I would suggest is that maybe have a, and again, I know it's about resources and staffing and availability of the right people, but, you know, it would be great for families instead of doing a big clinic, maybe doing a bunch of smaller ones every two months or something, or three months (Julian Tremblay). Families expressed a clear desire for increased frequency and continuity in care, stressing the need to consider alternative modes of clinic and service delivery tailored to the north to help health care teams and system leaders improve continuity and responsiveness in care (Julian Tremblay).

Families living in Northern Ontario also had to consider the realities of distance and climate. The families in this study described these systems as fragmented and challenging because they were spread across a vast northern landscape. As one mother noted, “I think that's one of the hard parts of living in the North is that your care can be somewhat fragmented and disjointed” (Shena MacLeod). This fragmentation of care, coupled with the northern geography and climate, disrupted families’ lives and their attempts to maintain stability, intensifying existing challenges. Several families discussed challenges brought on by snowstorms, including flight interruptions and cancellations, and fear about being able to travel during crises. One mother recalled her concerns, “This is something that I brought up with the doctors and lots of cases, I will say to them, what if something happens to (Name), and it's the middle of winter in

[town], and we can't get flown out?" (Jessica Brown). Another mother whose flight was delayed due to a snowstorm called the hospital to notify them, "we just landed, we're coming. You know, don't cancel us. We get there and people from Toronto had canceled. I'm like, are you kidding me? Like, I flew from Thunder Bay to get this kid here" (Mei Chen). Often, the hidden challenges families faced, or even the magnitude of how far Thunder Bay is from urban tertiary centers, were unknown to southern health care teams. One mother vented her frustrations about being discharged home. She tried to explain to the health care team the significant challenges around 'going home' with their child: "We're not going to North Bay. We're going to Thunder Bay" (Shena MacLeod). The assumption that 'discharge home' may have been simple for these families and that they could just return to the hospital with any concerns disregarded the significant distances and limited access to specialty supports within the North.

The COVID-19 pandemic further magnified these discontinuities. Several families felt forgotten and left without adequate care, often getting lost within the systems. A mother reminisced, "So during COVID, she [the paediatric cardiologist] went back to her country, and so we had no doctor. And then we kind of got lost in the shuffle" (Melissa Gagnon). Another mother shared a similar experience,

> COVID happened. No, it was like, honestly, like these kids just got forgotten about. And then post-COVID, they just have a rotating - we've seen a different doctor every six months since COVID, so they have no - it's like Groundhog Day, like, trying to explain things every single time (Anna Kowalski).

Families expressed that the disjointed care during this time left them feeling abandoned and unsupported during an already very challenging time, especially having to care for a sick child.

With mixed and missing information, several families felt "*confused*" when managing medical appointments, describing unclear hospital letters, conflicting phone calls and a lack of a point person. One mother emphasized, "there just isn't like a central organizing person or entity" (Sofia Garcia), and another mother echoed, "a little bit more coordination [would be helpful] because I think I had six confirmations of that appointment from different people" (Erin O'Connor). Parents recognized the critical role of communication in healthcare settings, and as particularly "critical when you are dealing with children". As Jessica noted, "they're little people. And you know, like you can't have that miscommunication because I mean one miscommunication could literally cause a domino effect" (Jessica Brown). With so many moving parts of a very complex system, families often find themselves piecing together their child's care through broken lines of communication among multiple care providers and hospital sites. "Communication gets lost and like, it's - like his pediatrician didn't know something was going on, or, you know, he's got a family doctor too, like stuff just doesn't get relayed properly…get lost in in translation" (Jasmine Smith).

The continued uncertainties around navigating their children's healthcare and ensuring important elements of their care were not overlooked contributed to families living in a liminal state. This was largely due to gaps and inconsistencies in communication, which left them suspended between knowing and not knowing, and between active care and inactive care for their child. The complex web of missing and conflicting information required parents to untangle to ensure appropriate care for their child, forcing parents into new roles, such as serving as health care coordinators.

6.4.2.2 Parents as Health Care Coordinators. Relational discontinuity, communication breakdown, and fragmented care, thrust families into the role of health care coordinator. Without

a consistent point person, families often had to follow up and track appointments. Jasmine discussed the care between the London and Thunder Bay sites, “sometimes I do feel like stuff even gets missed between the two. But she's an amazing doctor and yeah, but I do feel like it's me having to keep track of everything” (Jasmine Smith). Parents had to become their own care advocates, navigating a complex system while facing geographical barriers to care. A mother recalled,

> Last time the London team had come here…they're like, we want him to get exercise stress test or a Holter monitor…he never got any appointments or anything, and I had to follow up with it. And sure enough there was a request for him to get the Holter monitor and stuff. So it's like if I don't pay attention and don't follow up on it, some stuff gets missed (Jasmine Smith).

Missing test results and needing to follow up on results between sites to prevent their child from falling through the cracks was another major source of frustration, which also forced families to take on advocacy roles. One mother talked about a ‘huge disconnect” and continued:

> Yeah. Like, I will get CDs (compact disk), and, like, I will be mailing them to different people because, like, we went down to SickKids in Toronto, and he had a bunch of testing done. They were supposed to send the results to London. London didn't get them. So, then I have a tele, like, a video appointment with London and they said, well, we want him to get an MRI, and he had an MRI done. ‘We don't see an MRI’. So, then I have to call Toronto. It's, like, I'm manning all of it (Anna Kowalski).

As parents progressed and moved between the liminal space of crisis and the ordinary, confidence in managing their child’s care and needs grew. Sofia shared, “In the last 10 years, there's a little more space for people, like for advocacy generally. It felt like I had to get a little

more heated with people when she was a baby" (Sofia Garcia). Families also recalled the confusion during hospital discharge and the journey back home to Thunder Bay. Mei recalled, "They released us from Sick Kids, we were allowed to leave Sick Kids. We weren't allowed to leave Toronto… That was a weird transition—like, who's supposed to be coming? Where am I calling? Who's calling me now?" (Mei Chen). Another family had a similar experience: Shena explained how she needed to coordinate extended care in Toronto and advocate to ensure safety before being sent back to Thunder Bay.

> Friday afternoon is not the time to discharge us, not when we're flying back on an airplane. We're not going to North Bay. We're going to Thunder Bay… but we definitely did have to do some advocacy there to say like, look, this is not a safe discharge plan. We can't get appropriate follow up if need be. And we're not like, so then you're going to be discharging us to a hotel for a couple of days until we feel comfortable to then get on a plane? (Shena MacLeod).

Coordinating care across multiple sites, providers, and a large province caused significant distress for families. Parents were often left to stitch the pieces of their broken care together to ensure their child didn't fall through the cracks. Many parents talked about the need for a point person or as some said an anchor.

6.4.2.3 The Importance of an Anchor in a Sea of Chaos. As families shared their frustrations with the fragmented healthcare system, where they often felt adrift in a sea of chaos, many described the importance of having an *anchor* in the form of a constant and compassionate care provider. Although families experienced relational discontinuity with their specialized cardiac care teams, they also spoke about the grounding role of the local pediatricians. This provider could bring stability and reassurance amid the chaos. Having someone they could relate

to, who knew their child's history and whom they could trust, made a positive impact on how the families experienced their cardiac journey. Due to the transient nature of the London children's hospital clinics held twice a year in Thunder Bay, families found it difficult to build similar relationships with visiting specialists.

A central finding was families overwhelming appreciation for the paediatric team in Thunder Bay. They attributed their positive care experiences to having at least one strong therapeutic relationship with a local pediatrician, acknowledging their knowledge, compassion and commitment. One mother expressed: "Dr. (Name) was so good, and he was very knowledgeable, and as I said, when I called him about her blue hands and feet, I do feel - I would feel more comfortable calling him and asking him than calling London." (Melissa Gagnon). Another mother shared how helpful and supportive the health care team in Thunder Bay was, "I feel like Dr. (name) really saw me as not like the mom of this child, but like another person in the healthcare team that was going to sort of get her through to the other side" (Lina Nguyen). Lina further shared how meaningful that relationship became,

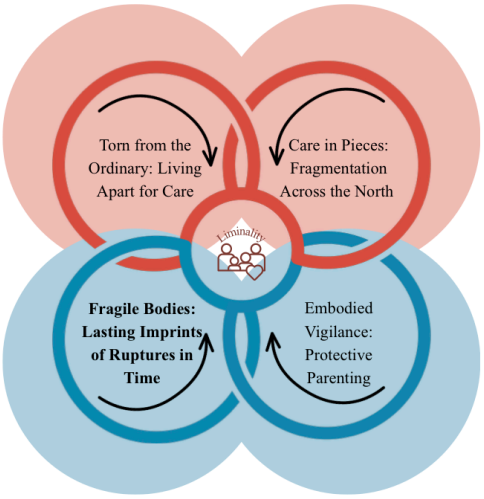
> There were times where I would lose my mind a little bit and she would be the person that I would just give a hug to and kind of - and then she would make me feel better. Right? Or she would have the same sense of relief as I would if we heard something different. And that's what makes her just such an incredible human being (Lina Nguyen).

For many families, a local pediatrician became their "*go to*" person, someone they trusted to ensure nothing was overlooked and that referrals for follow-ups at the larger children's cardiac centres were managed appropriately. One mother expressed, "I've been very fortunate to have Dr. (Name) in my corner. Who at the last appointment, knew I had major concerns. So he actually checked in with the cardiac cardiologist, twice during the appointment" (Jessica Brown).

Many parents shared similar experiences, emphasizing that building a relationship with at least one trusted care provider had a meaningful impact on their care journey.

A 'downside' to having developed such deep connections and therapeutic bonds over the years was that it made transition in care difficult. For some parents, letting go of their local pediatrician was their biggest stressor when their child transitioned to adult care, with one father lamenting, "Just not maybe having access to Dr. (Name) is the thing that bugs me" (Julian Tremblay). Despite the absence of specialized services locally, families felt genuinely connected to their care providers. Their frustrations were not directed towards the local team but rather the fragmented nature of the broader healthcare system and the barriers it has created.

Ultimately, families stressed the need for constant, compassionate relationships in their lives; these relationships were viewed as an at-home anchor. Within families underpinning experiences of liminality, where they often felt suspended between crisis and stability, home and hospital, the trusted pediatric providers from their 'home-hospital' were that human connection. They are the anchor that helped to restore a sense of steadiness in an otherwise unpredictable and unsteady care journey. Figure 2 bolds the next theme explored, fragile bodies: lasting imprints of ruptures in time.



6.4.3 Fragile Bodies: Lasting Imprints of Ruptures in Time

This third theme captured how families experienced their child's body as fragile and vulnerable across their cardiac journey, and how these experiences created enduring imprints on emotional, physical and relational well-being. Ruptures in time began at diagnosis and continued through hospitalization, surgery, acute cardiac crisis and the disruptions of early family life. Within the experiences shared, the vulnerabilities of both parents and children became closely intertwined; the child's fragile state heightened the fragility of the parent's mind and body. The following subthemes will discuss additional ruptures in time, such as (1) disruptions of early maternal-infant bonding, (2) acute ruptures in time: witnessing the child's fragile body, and, finally, (3) lasting imprints on parental well-being.

6.4.3.1 Disrupted Bodies: Lasting Imprints of Interrupted Beginnings. This sub-theme captures how the early and interrupted newborn period formed ruptures in time, triggering a cascade of lasting emotional, physical, and relational imprints. While these experiences unfolded in the immediate postpartum period, mothers' accounts suggested that their effects extended far beyond these early moments. Ultimately, this contributed to the shaping of ongoing perceptions of child vulnerability and embodied stress. This did not end once these ruptures in time had passed but instead continued to shape how parents experienced their child, their caregiving role and themselves over time.

Considering this, these early disruptions to maternal infant bonding, physical recovery for both mother and child, and caregiving did not allow for a rerun to 'normalcy'. Instead, it left parents in the prolonged liminal state, where they remained 'in between, navigating persistent uncertainty, suspended in the constant unsteady rhythms of time, never knowing what would come next, or how one would heal physically and emotionally.

The following two subthemes build on initial worry and vulnerability, contributing to the continued state of liminality. Illustrating how these initial ruptures were not isolated incidents yet starting points to a cumulative process that left lasting impacts on parents over time.

The newborn stage marks a particularly vulnerable time for all mothers; not only do they experience the potential challenges of physical healing, but they also experience an immense new mental load and responsibility. For the mothers in this study, these early beginnings were distinctly gendered, as mothers carried the physical, emotional and relational weight of both postpartum recovery and their infant's critical illness. These early beginnings were disrupted not only by being uprooted into unfamiliar environments but also by the physical challenges experienced by both mother and child. Mothers' challenges were magnified as they were left with little time to digest their new reality.

Many were forced to give birth over 1000km away from home, separated from friends, family and social support. Separation from their infant often happened immediately post birth, leaving the mother frequently alone, without answers, and having to make complex decisions before even holding their newborn. Jasmine discussed her experience before even holding her newborn,

> I had him at Mount Sinai, and they took him through the tunnel to Sick Kids…they ended up, like, having to do, like, surgery right away just to keep his blood flow. And I remember them calling me after I was in labour and asking for consent, and I had no idea what I was consenting to, but I'm like, yeah, go ahead… the next day I kind of got to see him because when I had him, I didn't get to hold him or anything… he was so swollen. He was connected to so many needles, so many IVs, like so many. And just, like, swollen

> and bruised and everything. And I was like I didn't even think it was my kid because I hadn't expected it, you know? (Jasmine Smith).

These accounts illustrated how mothers were positioned at the centre of early decision-making and caregiving despite being in a state of physical vulnerability themselves. Postpartum healing is a demanding period under normal conditions; however, witnessing their child's fragile body for the first time in an unknown, hospitalized environment intensified this vulnerability for mothers. Some mothers also reported post-birth complications such as severe swelling and pre-eclampsia. Sophie shared, "oh, my legs were so swelled up. It was horrible" (Sophie Tremblay). Another mother echoed, "I was still having times where I was almost passing out from the blood pressure normalizing" (Erin O'Connor). Mothers described this period as a "*blur*", as they attempted to navigate their own healing alongside the immediate and ongoing needs of their families. In addition to managing their physical recovery, many mothers were simultaneously caring for other children and trying to maintain their family's routine in the midst of a crisis. Lina shared, "you're trying to get over your postpartum. You know, hormones. And you have a two-year-old, and it's Christmas, and you have this baby that looks perfectly normal and they're telling you, yeah, she's probably going to get sick" (Lina Nguyen). These stories speak to the great strength and endurance these mothers had to withstand to ensure a healthy outcome for both. For this group of women, their fragile bodies became secondary; they had to battle through their own health needs to ensure their child's survival.

Mothers frequently discussed the moments where their baby was quickly taken away, surrounded by medical teams, cords and monitors. These precious early moments of an infant's life, when natural mother-infant bonding could occur, were disrupted by restricted access, requiring mothers to obtain permission or assistance to hold their baby. Sofia recalled, "they took

her away, she was on a table over there and there were six people around her and I couldn't tell what was going on, and that was the most like distressing part" (Sofia Garcia). Disruption to early beginnings also impacted newborn feeding. These mothers' infants required special diets or tube feedings, causing many emotions, including stress and a feeling of loss. Shena reflected on the stress of her child requiring a feeding tube, limiting her ability to feed her child, "the next most stressful thing because…it's the one thing you feel you can do as a mom and as much of a burden as it is…it's also a very lovely thing to be able to feed your child" (Shena MacLeod). Sofia shared her similar experience, "It was a lot of sitting beside an incubator, waiting for the next time I was allowed to touch her" (Sofia Garcia). Mothers described wanting to hold and nurture their babies, yet were often told it could be too much for their fragile bodies. Sofia continued to add,

> I think just how hard it has to be being a mom. I feel like you can't actually provide what your child needs most. Like the mother instincts want to hold and comfort your baby, but for a lot of the first while it was literally using too many of her precious calories to interact with her too much (Sofia Garcia).

The disruptions experienced by mother and infant bodies in the early beginnings caused ruptures in time that have left lasting imprints on maternal well-being. The following subtheme illustrated how these ruptures in time accumulated over the child's fragile period.

6.4.3.2 Acute Ruptures in Time: Witnessing the Child's Fragile Body. Families recounted other ruptures in time through the extremely stressful experiences of acute medical and surgical cardiac care, where they were forced into the role of waiting and worrying observers. Across these accounts, acute ruptures in time are marked by direct encounters with the child's fragile body during surgery, critical care, and emergency events.

Families described the intense worry and trauma surrounding their child's surgery; several parents recalled witnessing their child's fragile body cut open, memories no parent should ever have to endure. Sarah shared, "his chest is open. You could see his heart beating" (Sarah Anderson). Another family recalled a similar experience post-open-heart surgery. Jennifer shared that she almost "passed out" when she entered the room, "they had to leave his chest open for a week because his heart was so swollen from, like, being worked on and stitches" (Jennifer Wilson). The compounding traumatic experiences of watching their child go through procedures and undergoing testing were emotionally exhausting for parents.

Many families also recalled acute cardiac events where their child went unresponsive and turned blue, and emergency services and interventions were needed. One mother described an experience while at home caring for her other children, "She's thrown up. Now she's grey and she's limp and she's in my arms" (Mei Chen). Mei asked the oldest sibling to run and ask a neighbour to come while she left in the ambulance, leaving her other children behind. These traumatic experiences were shared across the parents within this study, as another mother recalled,

> I ran up there and she was fully blue and unresponsive. And I picked her up and I just kind of, like, said a short prayer and I was like, okay, help me. Because I knew somewhere in my brain, cognitively was the information to do resuscitation. I just - but it's your kid so and she's so limp. It was like Jello and so no tone. And I found the file somewhere in my head, and I gave her some back thrusts, and I flipped her over and checked her airway and then turned her over again because we did that. So, it took three attempts, but she coughed or whatever and took a breath. And I don't know how long she was down for. It felt like a long time (Erin O'Connor).

Erin's account emphasized how temporal moments of crisis can seem to take a very long time, yet, if measured, these felt ruptures in time may take only minutes. She relayed another event where her child needed resuscitation and its impact on her husband, Laim, "He was holding her and feeding her. So, he just kept saying, ' It's my fault. Did I kill our baby?" These traumatic events place an immense weight on families' shoulders, causing feelings of tremendous guilt and fear. Families often described these specific moments as deeply traumatic.

Although each event may have been brief, it left lasting, vivid, and intrusive imprints on parents' emotional, physical, and relational well-being, continuing to shape their everyday realities. The following final sub-theme captured the experiences of both parents caring for their child with CHD and its lasting imprints on their overall physical and mental well-being. This highlights that it is not a single rupture in time or critical event that left a lasting imprint; rather, it is cumulative, impacting parents over time.

6.4.3.3 The Lasting Imprints on Parental Wellbeing. The overarching theme and the preceding subthemes have illustrated how parents moved from early ruptures in the newborn period to acute, crisis-driven events. Together, these cumulative experiences have contributed to the lasting imprints parents now carry, impacting their daily lives. Understanding these shared experiences, and the reasons why they have progressively shaped parents' well-being over time, was essential for making sense of the lasting imprints explored in this final subtheme.

The fragile body of the child and the myriad ruptures in time left families with a heavy emotional and physical strain, ultimately impacting their overall wellbeing. Families often described more than one event that had impacted their well-being. This included trauma diagnoses such as PTSD and heightened anxiety. One mother talked about how it the significant impact it had on her stating: "I actually was diagnosed with PTSD from a psychologist because

of all this… just like dealing with me leaving my other kids and then dealing with this really sick kid" (Jasmine Smith). Even after the traumatic events and crisis periods had passed, some parents who reflected on their experiences said they often didn't know whether they were still in shock or dealing with emotional long-term impacts. Melissa recalled, "I suffered from like post-traumatic stress…So that's why when I started working with a therapist, like I just said to my husband, like, there's something not right with me. Like, I feel like I'm high anxiety all the time" (Melissa Gagnon). Another mother who reflected upon her experiences said she didn't realize she was in shock. Erin remembered resuscitating her child after finding her "blue in the crib", and recalled, "I didn't realize I was in shock. I was just holding the baby, watching every single breath" (Erin O'Connor).

Families also discussed the continued anxiousness and fear surrounding the child's illness and outcomes: "my fear was always that I was going to lose him, I didn't know his heart. I didn't understand if his heart was…going to fail when I took him home, that was one of my biggest fears" (Jessica Brown). Parents also discussed the challenges during COVID-19 and the impacts it had on exacerbating their anxiety. Jasmine described having "complete panic attacks" and keeping her son home from school for 6 to 8 months as he got repeatedly sick when he was younger. Jasmine said, "If he gets Covid, it made me think he was just going to get sick and die. And that's where my thoughts would go" (Jasmine Smith). Parents were continually faced with catastrophic thoughts that contributed to their heightened anxiety, fear and panic.

Families also recalled triggers. One mother shared, "Even just walking into SickKids, I feel anxiety walking" (Shena MacLeod). One Dad related fall time as evoking emotional distress, as this is when the twice-a-year cardiac clinic comes to TBRHSC, sharing, "It stresses me out, actually. Fall time sucks" (Julian Tremblay). The hospital space triggered unpleasant

emotional responses. Another father reflected on his emotional triggers, “when I would get a phone call from her at work” (David Chen). Mei jumped in to finish the story, sharing, “I’d be like, hey, do you want to pick up pizza on the way home from work? And he’d be like, are you kidding me? That's not what I thought you were gonna say” (Mei Chen). Mei nervously laughed and continued to say “Oh, right. Like I should pre-text you. We're fine – [I’m] calling about food” (Mei Chen). Another mother shared a similar emotional trigger of just a simple phone call,

> Even today when my phone went off and I - it was a London, Ontario phone number- I was like, why is London calling me? And I was like, oh God, what's happening? And so that instant feeling of like, oh God, what's happening? Why is London calling me? You know, that sets off an emotion, right? You know, and like, even just that every six-month appointment, just that lead up to it. You know… I'm sitting on edge (Jessica Brown).

These experiences shared by families emphasized how previous traumatic events have left parents with an underlying fear and anxiety that will never truly go away. Even small, ordinary moments, where families described a simple phone call, reignited overwhelming emotions days, months, or years after such events. Parents also shared how mental health supports or screenings were not routine throughout their experiences. One mother discussed how her partner was struggling emotionally due to the “*chaos*” and traumatic events surrounding the birth; they even shared having to pay out of pocket to see a therapist, yet discussed that the financial implications didn’t matter, even on maternity leave.

> In 24 hours, he watched me seize and go blind. The chaos of inducing the birth. And then he was holding her, so he was upset…remember it being like 200 and something dollars, but and at that time I was facing mat leave and all this stuff, and I just thought, whatever, it is what it is, and you need to pay, you need to talk to somebody. And I'm too

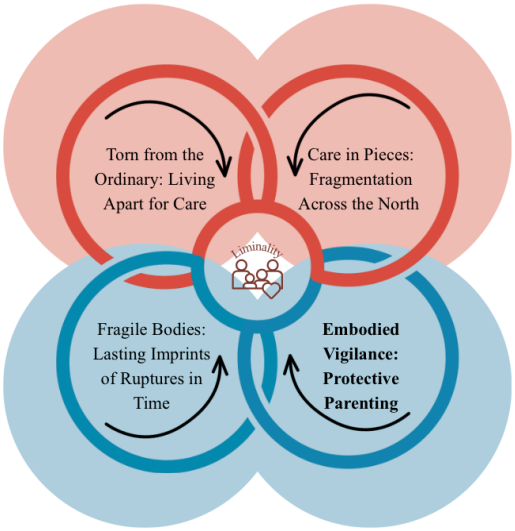
> overwhelmed to help you through this in that way right now. Go talk to somebody (Erin O'Connor).

The traumatic experiences that parents went through while caring for their sick child left emotional scars. Parents and families needed professional and additional support to guide them through these challenging times. All parental participants described how their own physical and emotional health was often overlooked as care was centred around their child. Parents were forced to put on a brave face for their family, often overlooking their own needs. A mother recalled,

> She was probably three. And like that is kind of when I started to like deteriorate because you can only do that for so long. And then it was like, you know, the fibromyalgia, the celiac disease, the like autoimmune junk. But again, she was more okay, but I do think that there was a fallout from there just not being more support. It was one of those because I handled it, it seemed fine. In hindsight, not optimal (Sofia Garcia).

Another mother who reported similar experiences also had suggestions about how to provide support to diminish this overload. She said: "I feel like what could have been a benefit in hindsight would have been a couple like wellness calls for mom… Just like, hey, are you doing, okay? Do you understand…do you have a question?" (Erin O'Connor).

Many of the experiences described by the parents reflected how their capacity to '*handle it'* often hid their unmet needs, allowing anxiety and distress to build up over time. The gaps in family-centred care, specifically addressing the unmet mental health needs of parents, across their child's care continuum, were highlighted as a significant concern across all families. Figure 2 bolds the next theme explored, embodied hypervigilance: protective parenting.



6.4.4 Embodied Hypervigilance: Protective Parenting

The final theme captures how parents' ongoing sense of uncertainty left families in a prolonged liminal state, which became embodied as hypervigilance, shaping their everyday parenting practices and relationships. Over time, parents described living in a continual state of readiness, no longer in the acute crisis of early diagnosis and surgery yet never returning to a sense of ordinary life. In this 'in-between' space, parents closely monitored their child's body behaviours and environments in an effort to prevent further harm. This embodied hypervigilance gave rise to protective parenting practices that were not simply expressions of anxiety but rather responses to living with the enduring possibility of sudden change or crisis.

In this study, hypervigilance referred to parents' embodied state of constant alertness and anticipatory threat, whereas protective parenting described the concrete actions they took to try to keep their child safe (Maag et al., 2021; O'Donovan, & Nixon, 2019). Hypervigilance and protective parenting were closely intertwined. Parents' heightened internal emotional state from years of cumulative events and living in an ongoing state of liminality often drove protective practices that structured daily life.

This theme is explored through its interconnected subthemes: (1) differing experiences: shielding children from the weight of illness, (2) protecting children within everyday and medical environments and (3) parental healing over time.

6.4.4.1 Differing Experiences: Shielding Children from the Weight of Illness. Parents often described working tirelessly to ensure their child was protected both medically and emotionally. Even while navigating significant challenges, including financial strain, employment disruption, changes to family life, and frequent travel for care, many parents spoke about their efforts to shield their child from the full weight of these burdens.

Children's accounts often differed from those of their parents, particularly in how they described travel and hospital experiences. While parents frequently described these periods as stressful and disruptive, many children in this study were indifferent and shared that they didn't mind going to the hospital, both at home and away. Many children stated they "felt comfortable" (e.g., "I don't know. It's just – it's a hospital"; *Sally* Brown) and recalled positive aspects to their experiences such as treats or special activities, which are described in more detail in the children's findings section.

As previously discussed, parents in this study experienced hospital visits and the need to travel differently. They did not share their child's positive recollections. Memories are an expression of time, and parents' perception of time was very different; their protective parenting shielded their children from potentially painful experiences and, thus, painful memories, turning events and periods that were anything but ordinary into something extraordinary for their children.

Most parents perceived their children to be experiencing stress and anxiety when they visited the hospital or travelled for their medical appointments. One mother shared, "If we're

going to go for a medical appointment, I got him basketball tickets. Like, we try to turn it into a fun location because it's such a stressful time for him" (Jasmine Smith). The protective layer of extraordinary, positive experiences orchestrated by parents shaped many children's memories. When one child was asked about travelling to Toronto for appointments, they immediately recalled the enjoyable parts about the trip: "I look forward to - I usually get to do something when I'm there, like have fun" (Charlie Smith). Charlies' mom quickly jumped in to share, "I'm in the background. I'm just going to say that he stresses about his appointments for weeks ahead of time and he does stress out for the actual appointments. but we usually do try to do something fun" (Jasmine Smith). It was only after this, and when gently prompted to describe what they liked about Toronto and the hospital visits that Charlie acknowledged disliking certain procedures and having some anticipatory anxiety. Yet they still emphasized their love for Toronto. Charlie responded, "I just love Toronto…until the doctor's appointment…I'm not the biggest fan of MRIs…it's a long process…it's a dye, yea, that's not fun" (Charlie Smith). This account, along with others, highlighted how parents' protective parenting appeared to positively influence their child's medical experiences. The majority of the children in this study reported positive, impartial, or fun memories of travelling and/or visiting the hospital.

These accounts contrast with many parents' descriptions of the same periods, often described as stressful and disruptive. This difference may reflect the ways parents worked to create a sense of safety and normalcy for their child despite ongoing liminality. It may also speak to the way children, depending on their developmental age and stage, understood and made meaning of these experiences. Together, these findings suggested that parents' hypervigilance and protective parenting may have played a role in shaping how children perceived these

periods. This includes what they may have noticed and remembered about hospital spaces, travel, and interactions with the health care team.

6.4.4.2 Protecting Children within Everyday and Medical Environments. Building on parents' embodied hypervigilance, this subtheme explores how ongoing perceptions of risk translated into concrete protective practices in both everyday and medical settings. Parents described creating protective environments for their children by heightening infection control, restricting activities, and carefully monitoring who cared for their child. These practices were woven into daily life, shaping their family routines, relationships, and parents' sense of responsibility for preventing further harm.

Several families spoke about keeping a protective bubble and safety net around their child. Parents shared their fear of contracting "respiratory illness" as many children already had "trouble breathing". These worries fuelled a state of hypervigilance in which parents were constantly scanning the environment for potential threats, even in seemingly ordinary events. In response, protective practices, such as strict infection control, activity limits, and careful control of social contact, became embodied routines, etched into daily life. Ali spoke about these practices with notable intensity in her voice, saying, "I am always watching to see if he's breathing, if his breathing has changed, if he's looking more pale… anything that the doctor has told me to watch out for… I know that I am not gonna overlook those things" (Ali Samson).

The protective parenting for some families included homeschooling, isolation and/or no outside supports, such as daycare, to try and limit outside infections. Lina shared, "I remember my hands were just raw. They were like bleeding" (Lina Nguyen) due to constant handwashing to minimize infection risk. Another mother recalled an experience while at the hospital where she felt responsible for maintaining a protective boundary and space around her child. Melissa

described asking health care workers hygiene questions, such as, “Have you cleaned your stethoscope? Have you washed your hands? All of those types. Like I was the gatekeeper for her” (Melissa Gagnon). One father expressed, “You have to kind of be always a little bit kind of restrictive at times, and maybe, or more overly concerned” (Julian Tremblay). This was due to the lack of a local specialist. When their child became sick or when Julian had questions about developmental milestones, he felt there was no one to discuss these concerns with, which led him to increase his parental vigilance and in turn, his protective behaviours.

Parents also spoke about the need to maintain physical activity limitations, so that the child didn’t overexert or cause any additional issues in relation to their CHD. Sophie shared,

> Well, I did go into the soccer field when he was playing indoor…I'm watching and I'm like, okay, he's slowing down, but they're still yelling at him, go, go, go. So I go out there halftime, like, "Yo, look, this is (Name). You know he's been around for how many years? No more." Yeah. I don't think he ever forgave me (laughs) (Sophie Tremblay).

Another mother echoed her restrictions with sports and looming catastrophic thoughts around activity and the child’s heart condition, sharing, “We probably kept him from playing sports for so long” (Jasmine Smith).

Parents also expressed deep hesitation about leaving their child with others, including friends, families and external supports such as daycares. One mother shared that although grandparents could watch over their child, it was not the same as her attentive parenting. Many parents described feeling they were the only people who could safely care for their child due to concerns about their child's fragility and often complex care needs, especially in the early years. Several families shared similar experiences, Sofia reflected,

> If I'm honest, like probably up until she was even like five or six, I wasn't comfortable leaving her with anyone that hadn't like been around enough to understand what it looks like specifically if she's choking, or like what her normal mannerisms are… I couldn't just like have a teenager babysit. You know what I mean? (Sofia Garcia).

These shared experiences illustrated how parents' hypervigilant awareness of their child's fragility translated into highly protective caregiving practices. This included reluctance to leave their child with others and a belief that no one could safely manage their child's needs.

A common theme throughout parent interviews was their experiences of hypervigilance toward their child, even in times of calm or ordinary situations, and their shared feeling of being misunderstood by others because of it. Parents relayed that friends and family sometimes viewed their protective parenting as overreactions. Ali shared, "It's just the heart is always something to worry about for (Name). I don't think people really understand it…I think they think [their family] we are very overprotective" (Ali Samson). Others felt that their family did not understand what they had truly "really lived through" (Melissa Gagnon). This feeling of being misunderstood, of others not understanding the lived reality of caring for a sick child, intensified parents' hypervigilance and protective parenting and reinforced their need to control the environments and relationships their child was exposed to. Several families sought out support systems where their vigilance was shared and understood. Parents discussed finding this support through online groups with other parents of children with CHD or chronic illnesses. Erin expressed,

> We found our people. But that was honestly, like, really important to us because you don't - you hear - you hear other parents talking about their new babies and all these things, and you're just hoping to not find them dead in the crib. That's your biggest goal.

> And the other moms are like, well, this milestone and this milestone and blah, blah, blah. And they're not mom bragging, per se or maybe they are, but your priorities are different when your kid's sick (Erin O'Connor).

Although some parents spoke about these supports, many wished for hospital-based support groups or someone coordinating opportunities for connections with other families that had lived or are living through similar situations. One mother shared, "I would say we failed there. We have totally 100%. Like I - there's nothing really out there like other than building a relationship with your pediatrician who obviously is there to support you...like there's nobody" (Jessica Brown). The absence of family support groups left parents carrying a tremendous emotional weight, often alone. Having additional support systems in place for families could help reduce parents' hypervigilance by offering emotional support and shared understanding.

6.4.4.3 Parental Healing Over Time. Within this study, parents embodied hypervigilance and protective parenting behaviours lessened over time. Time allowed parents to heal from the initial and ongoing trauma in the early years, as they were able to watch their child's positive developmental progression over the years.

Parental healing was tied to their child meeting developmental milestones and engaging with friends and activities. One mother shared, "seeing him play basketball…He's more confident…[I] definitely am more comfortable…I [can]definitely say it's improved where I don't coddle him…I can't just, like, bubble wrap him because, he, like looking at him you would think he's like any other kid…except for height" (Jasmine Smith). Another mother similarly felt her worries decreasing over time, saying "she's a brainiac…she is in every sport. I did worry. I'll admit when she was little… but not now. She's fine. She's like, she tries everything, every sport" **(**Melissa Gagnon).

Families described that over time, after the acute period and the accompanying feelings of worry and anxiety, these feelings lessened. One father shared, “All of a sudden, I just sat one day, looked at him and [was] going, like, the kid's huge, like, and he's doing okay” (Julian Tremblay). Some families described their child doing well in school and thriving with friends, which helped them ‘*let go’* and trust their child’s growing independence. A mother shared, “I feel like, just like the last two years, he's really changed…become more independent... And I think that's helped me to learn to let go” (Jasmine Smith).

Confidence was also reinforced with continued monitoring and reassurance from medical professionals. Regular appointments and test results provided parents with physical confirmation of the knowledge they had gained through experience that their child was doing well. This reinforcement of parental experience played a central role in the healing process. The new, trusted knowledge about their child’s condition and trajectory was a powerful driver of a decrease in parents’ hypervigilance and protective parenting behaviours. Reinforced confidence from their health care providers gave comfort to parents*,* “I knew they knew what they were doing… I felt a sense of relief, you know, after all, every appointment every year. So that's what makes me feel better about him…I know he can play hockey and everything like that” (Jennifer Wilson).

The underlying uncertainty caused by the complex nature of their child’s CHD left all the parents in a continuous, embodied hypervigilant state. The protective parenting behaviours of always being on guard, watching, and protecting their child within their ever-changing environment became ingrained in parents’ bodies. It affected how they interacted with others across different spaces, often shaping whom they trusted and how they managed social situations. The concept of time, specifically witnessing their child heal, grow and demonstrate

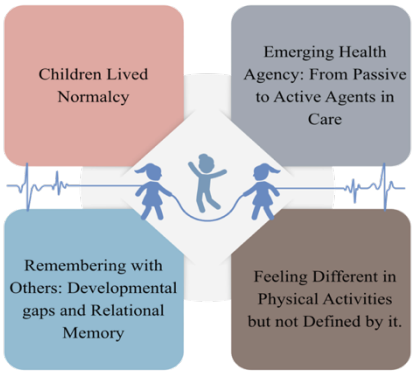
strength over time, gradually allowed parents to heal. As their child's acuity decreased and the parents' sense of stability and normalcy increased, many parents experienced greater ease related to their child's condition. This ultimately allowed them to soften their hypervigilant and overprotective state and helped them reclaim aspects of 'ordinary' reality. Still, there will always be embodied and lasting imprints of their child's cardiac journey and crisis on the minds and bodies of the parents. The findings suggest that this will forever impact the way they move through their world, which has been shaped and underpinned by an ongoing state of liminality.

6.5 Child Findings

As described above 10 children participated in the study, ranging in age from 8 to 16 years, and represented a variety of CHD diagnoses. Four core themes emerged, including 1) children living in normalcy, 2) feeling different in physical activities, but not defined by it, 3) emerging health agency: from passive to active agents in care, and 4) remembering with others: development gaps and relational memory. Figure 3 portrays the children's findings. The cardiac rhythm running throughout reflects the uniqueness of each child's 'special' heart, as well as the fact that, over time, with each heartbeat, the child grows and develops. Time and how it shapes the child's sense of self and relationships with others in their varying environments is critical when understanding and interpreting these four interconnected themes.

Figure 3

Child Themes



6.5.1 Children lived Normalcy: "I just feel normal"

While parents described living with a constant fear and uncertainty surrounding their child's fragile bodies, children experienced their bodies in notably different ways. They viewed their bodies not as medicalized or sick, but rather as capable, and no different than their peers.

Children living with CHD often described themselves as "normal", with one child declaring, "I feel like I wake up, have the same day as really any other kid" (Charlie Smith). Children did not organize their identity around their illness or diagnosis. For the children, CHD was something they were born with; it did not define them, while it was a part of their life story, it was something they rarely thought about. One child affirmed, "I don't really talk about it that much because… its not really that important" (Leo Tremblay). Rather than shaping their identity around their illness, many children didn't even consider it a defining factor; they spoke about their normal routines with school and friends. When asked whether their condition had affected various areas of their life, including family, school routines, day-to-day activities, or friendships, most children responded, "No" or "I feel the same." One child shared, "My friends know about my heart things. They're nice about it. Like they're supportive, I'd say. Same with the teachers"

(Charlie Smith). Supportive environments from friends and teachers appeared to foster a sense of normalcy among peers.

Many reported that their medical appointments had little impact on missing school, as they were infrequent and resulted in only a few days of missed school. As they grew and got older, and their CHD became less acute, daily life, including school, became less disrupted. When asked if they felt different from peers, many children again underscored, “No, I just feel normal” (Fran Harrison).

Children also described hospital visits in ways that emphasized familiarity and, at times, enjoyment rather than fear. during hospital visits and when travelling to Sick Kids. Children spoke about seeing therapy clowns and getting rewards; one child shared, , . Most children also found the experience of travelling to Toronto “exciting” with several sharing that they “liked travelling” (Harrison Kowalski), which often included exciting outings like going “up the CN tower for a Christmas present” (Renna Chen). These accounts suggested that for many within the study, hospital visits and associated travel had been incorporated into their lives as ordinary or even fun experiences rather than primarily distressing. This links back to the parents’ final theme of embodied hypervigilance: protective parenting.

A few children reported anticipatory feelings, predominantly anxiety, when approaching medical appointments, and just under half of the children reported a dislike of certain procedures, such as blood work. Yet the majority reported feeling indifferent or having positive experiences about going to the hospital or having procedures done. When asked what they enjoyed at the hospital, one child quickly responded, “Basically, a lot of things. Like all of them… I really like when I go on the treadmill to test my heart…its really fun!” (Fran Harrison). Their idea of going to the hospital for appointments or checkups was also normalized; to them, this was integrated

into their life, and they knew no difference. What might be viewed as abnormal for other children was an ordinary part of their world. For some, it was even viewed as an inconvenience: "I don't want to get behind on school or something just to go to the doctor" (Renna Chen). Others viewed it as a break from school, Mason shared, "It's boring there [hospital], but its better than school so I'll take it" (Mason Wilson). The common theme in the children's lived experiences, that everything is *normal* in all facets of life, highlighted that they don't perceive their bodies as fragile or different; they felt a sense of normalcy. Their illness did not define who they were, how they interacted with others, or how they moved through their daily routines.

Even when children were asked whether they were bothered by their bodily scars from their cardiac journey, they all responded positively. One child referred to their cardiac scar on her chest as her "zipper" (Renna Chen), another saying "I think it's really cool" (Mason Wilson). Even though they know their bodies may look different than their peers, the children expressed that they were proud of their scars; having them did not make them feel different overall; it was just part of who they were. A child shared their experience of showing a friend their scars, "I have like a scar from the feeding tube…she was like, is that your belly button?...I was like, no, it's a scar…then we were like laughing at the fact that she thought it was my belly button" (Lucia Garcia). Lucia continued, "I'm not worried about my scars at all… it's just kind of like part of my body" (Lucia Garcia). The children did not feel their scars disrupted their sense of normalcy; the scars did not make them feel fragile or embarrassed; rather, they were part of their embodied identity. Children did not feel they had to hide their scars or shy away from others seeing them; they lived openly and were comfortable sharing their scars without any shame.

Together, these shared experiences suggested that children living with CHD within this study largely constructed identities that were not centred on their illness or perceived fragility.

Instead, they framed their bodies as normal and capable, much like those of others around them. They incorporated their scars into a positive or neutral sense of their embodied identity rather than viewing their body as a source of stigma or difference. In contrast to their parents' ongoing fears and hypervigilance, children's narratives emphasized everyday normalcy in continuity and how they moved throughout their worlds.

6.5.2 Feeling Different in Physical Activities but Not Defined by It

Although children in this study described feelings of normalcy in their sense of self, relationships with others, and engagement in school life, they noted differences in sports and physical endurance. During interviews, children were asked if they felt different from their friends. One child shared, "I have decently bad endurance, but I don't think that's like related [CHD condition] in any big way" (Lucia Garcia). Another child shared that, along with bodily scars, "stamina's a pretty big thing, I feel." This child continued "oh and my height…I'm, like, under five foot. They're almost - one of them is six foot, and a couple of them are almost six foot" (Charlie Smith). When asked if this bothered him, Charlie responded, "The height thing a little bit" (Charlie Smith). When asked follow-up questions about his heart and whether it affected him in any other ways, Charlie responded "I don't really think so. I feel like I wake up, have the same day as really any other kid" (Charlie Smith). These differences didn't change their sense of self or their sense of identity, though they recognized differences in bodily exertion, fatigue, and physical restriction compared to others when involved in sports and activities

As they aged, children became more comfortable with their bodies and limits when engaging in sports. Although some children simply reported "no" when asked if engaging in sports was impacted due to their CHD. Many children recognized their limitations and symptoms, such as chest pain, shortness of breath, and/or generalized fatigue. They would report

that once they felt these symptoms, they would listen to their body and slow down, take a break or stop completely. One child shared that “intense” exercise like “running” may trigger their heart, “might start to feel, I guess, almost pain in my chest from how, I guess, how fast my heart is beating and then it's overwhelming. I think just kind of like slowing down to a walking pace” (Leo Tremblay). Even with their notable differences, children knew their bodily limits to ensure their own safety. Another child shared, “I don’t go full force. I just go kind of like normalish” (Fran Harrison). Some children spoke to the impacts it had on group sports. One child shared that their “stamina” is affected when playing basketball, sharing, “if I'm constantly running for five minutes straight just because I play basketball. So if I'm like - every three minutes, just like a substitution, so I'm pretty tired after that” (Charlie Smith). Another shared, “I know with team sports it's harder to do team sports when I feel like I am a bit more of a burden. So I can't keep up with everyone else, even if I am more skilled or whatever” (Leo Tremblay). Through their bodily awareness, the children have learned to navigate their CHD in their own environment, minimizing its impact on live their lives and the way they want to live.

While children recognized some bodily differences when engaging in sports or physical activity, these experiences did not appear to significantly alter their sense of self or their relations with others. This finding aligns with the previous theme of perceived normalcy, in which most children described feeling no different from their peers and did not express distress or concern about their condition in their everyday lives. Moments when the child experienced symptoms such as chest pain or fatigue were often described in ways that suggest these experiences are just ‘normal’ and part of their everyday life, rather than something that disrupted their sense of self or impacted relationships around them. Overall, the findings suggest that many children demonstrate embodied attentiveness to their physical limits and stay within them. Children

described listening to their bodies and responding appropriately to ensure their own comfort and safety without being prompted by parents or others.

6.5.3 Emerging Health Agency: From Passive to Active Agents in Care

The third theme that emerged from the children's experiences centred on their growing confidence in their care and developing desire to understand their health needs. Several children in the study shared how health education and teaching were predominantly directed towards parents, often making them passive agents in their own care and bodies. When asked about health-related teaching, several children shared the desire for more direct inclusion, “I mean, a little bit, yeah…Maybe just about my heart and what is it because I didn't realize, actually, until I got the letter and read it, I didn't realize that it was actually called congenital heart disease.” (Riley Gagnon). Another child shared, “they [health care team] could include me more” (Fran Harrison).

Children's experiences further revealed how medical language shaped their ability to engage. Several shared that they had difficulty understanding their providers' information. Lucia shared, “In terms of actual hospital, I don't really know all the words and like what everything means” (Lucia Garcia). Renna shared that she liked the information about her health being shared with her parents. When asked why, she shared, “then they can tell me in a way I can understand” (Renna Chen). Another child echoed a similar experience; their mother jumped in to scaffold the recent memory and shared, “I think that's the piece…she doesn't understand the doctors, what they're saying to her… Using big terms, right? Right. Using big terms, like big words” (Jessica Brown). The child added, “And they're using their hands and making shapes” (Sally Brown). This reinforced the idea that memories and understanding were often co-created

and shaped with parents, but also highlighting the need for greater engagement and clarity between healthcare providers and children.

As children aged, their developmental capacity grew, allowing them to develop a deeper understanding of their illness and shaping how they engaged with their care over time. Several children described a gradual deepening of understanding, with one child sharing, “I pretty much always knew I had like a heart problem at some point, and then I like gradually learned more fun facts about how crazy I am as I grew older” (Lucia Garcia). Changes in emotional experiences often accompanied this growing knowledge; Lucia continued to express being “much calmer” over time. Another child shared their comfort over time, particularly when getting medical procedures or going to the hospital.

> When I was little, I didn't like it. I didn't know why I would have to get ultrasounds and stuff. I guess I might have been maybe a little bit nervous, but now I don't really - it doesn't matter to me as much anymore (Riley Gagnon).

These shared accounts highlight how, over time, children become more active agents in understanding their disease and its impact on their bodies. Leo shared when asked if they feel confident in managing their own care, “I’ve had it – I’ve been told this my whole life, so I’m – I know what to look for” (Leo Tremblay). Leo continued to share,

> Talking to the doctor, I do learn quite a bit from them. Also, what I found is throughout the years, I didn't actually understand my condition very well. Like it was more I’d go to the doctor, I get checked out, and that's it. I knew something was wrong with me, I just didn't actually know what was wrong for a while (Leo Tremblay).

Another child shared experiences of their growth in confidence, including managing their own care over the years. “I feel like, as of my last three years, probably since I was like ten,

they've [health care team] given me lots of information too. But before then, it was a lot like, used pretty much all of it to my parents" (Charlie Smith). When asked about going home and feeling comfortable managing and monitoring their own health, Charlie further shared, "Yeah, I feel like I know what's happening… Like I know like what's, I guess you say wrong or like what the results are kind of like. And if I have any questions, I usually just ask my mom." (Charlie Smith). Despite the shifts to greater independence and agency within their own care, children's interactions and understanding remained deeply relational and dependent on their parents. Having their parent to fall back on for different explanations or support was a common finding among the children. This illustrates that children's growth and development in becoming active agents in their own care does not occur in isolation, yet within supportive relational environments. Children's comments about wanting to be included more and struggling with terminology used suggest a need for healthcare providers to adapt their teaching and communication to engage more directly with their paediatric clients.

This theme suggests that as children grow older, many move from being largely passive recipients of care to more active participants in understanding and monitoring their health condition. Children within this study increasingly sought information, recognized symptoms, and described knowing what to look for. For many, they still continually relied on their parents to interpret medical language and provide support. Children's requests for greater inclusion in discussions about their health care underscored both their emerging health agency while also reflecting the continued relational nature of their engagement with parents and health care team.

6.5.4 Remembering with Others: Developmental Gaps and Relational Memory

Children's memories of their health care experience and overall cardiac journey were shaped by both their developmental stage and the relational memories co-created and shared with

their parents. For many children, early medical experiences occurred before they had the cognitive capacity for reflective awareness, resulting in limited, fractured or absent memory of critical events. When asked about these early periods, many children answered similarly that they ‘don’t remember’. Leo reflected, “I don’t remember getting like really sick…I was obviously way too young to remember any of that” (Leo Tremblay). Another child who currently lives in Thunder Bay, yet in the first few years lived in another city, shared similar feelings,

> That's mainly because of how little I remember from all the like surgeries and stuff. I definitely do remember more of like what was like going on with my medical things here [Thunder Bay] just because I was older, but I don't really remember any noticeable differences because I don't remember the hospital experience from like even [previous home city] really at all (Lucia Garcia)

These memory gaps were not experienced by the children as distressing or problematic yet reflected typical developmental timing. Hospitalizations, procedures, and travel during periods of acute illness were often described as events that happened rather than as experiences, they could recall directly. Leo shared, “When I was born, I was immediately shipped off to Toronto…So I know that was stressful for everybody else. Not for me, because I didn’t know what was happening” (Leo Tremblay). Children were not concerned about these memory gaps; instead, they spoke comfortably about what they do remember. These experiences highlighted how early illness, although it may have occurred before a child developed the capacity to recall such evets, remained a significant part of the family’s overall journey and narrative. The child’s inability to recall these early memories did not diminish their experience; it simply reflected the developmental context in which the events occurred.

Children in this study have been admitted and attended regular appointments, both in and out of the hospital, since birth. As children grew and their developmental abilities advanced, their understanding of their disease changed, and they gained confidence in managing their health care experiences. Lucia, now 13, shared how comfortable they felt while waiting for their appointment, stating the "experience isn't scary…even when I was…in the waiting room, I felt more confident than I did leading up to the appointment. I was like, "Yeah, I've been here before. I know how this goes." I know all things" (Lucia Garcia). The older the child, the better their recall of procedures, interactions with the health care team, and hospital visits went. This enabled them to express their preferences clearly and independently. It reflected their age-related awareness and growing ability to understand their bodies and interactions with others across different environments. Leo, now 16, shared their feelings about hospital preferences and travelling for care: "I guess I feel comfortable going to both…Going to Toronto Sick Kids was very different because you had to fly out there and fly back the same day, so it's more stressful" (Leo Tremblay). As children's awareness deepened with age, their experiences of care became deeply situated in their bodies. Rather than something that happened to them, medical experiences became events that children could anticipate, interpret, and understand.

Even as children's developmental abilities grew and they recalled memories more independently, parents still intervened during interviews to scaffold the child's memories. Throughout these interviews, parental suggestions and memory scaffolding helped trigger partial memories, allowing children to recall fragments of past experiences. For some children, partial recall was necessary to access full memories. After parents offered a reminder, children often recalled the experience and added details, confirming what their parents had said. Frequently, parents recalled specific nurses, hospital visitors, or how the child felt before appointments. For

example, one mother remembered the name of a healthcare worker who became close to the family. This prompted the child to share her memories: “Oh, yeah. That person I loved (Name)... I forgot her name, but I loved her. She was great… Like we would play games, and she would read me books occasionally” (Lucia Garcia). Sometimes, children remained silent, allowing parents to fully recall their perception of the past medical experience, without distress about their parents speaking for them or about their inability to remember. For instance, when asked about resources within the community, a mother responded first: “So you're not seeing anybody right now, but she's talking about like, remember when (Name) used to come and do your occupational therapy or when you were really little? remember you had that nurse? Do you remember those times?” (Mei Chen). The child shyly answered, “I kind of remember” (Renna Chen). Mei continued to try to evoke her child’s memory: “You always thought it was pretty fun when they would come because they were, like, special for you and coordinated your outfit.” Renna paused, smiled, looked away, and had nothing more to add. Another mother-daughter pair reflected on past memories, this centred around the child’s CHD diagnosis, which was later than most, happening in the early childhood years. Sally stated after her mother Jessica had given her multiple prompts, “I don’t remember being told, it was too long ago” (Sally Brown). Jessica continued to try to scaffold Sally's memory, asking, “Do you remember what you did though? There was something that you did in your class. Do you remember that?” (Jessica Brown). Sally quickly responded, which led to a back-and-forth dialogue between the two as they scaffolded earlier memories. This was common throughout the child interviews. This highlights the importance of supportive and caring environments for a child living with CHD, as heavy reliance on past memory recall lies with their parents and the collaboration between them. It may also reflect methodological implications. Interviewing children and parents together, even when

children are the primary focus, may facilitate access to shared, co constructed memories that would not emerge in individual interview.

The relational scaffolding and collaboration in shaping memories shaped how children move through their worlds, as much of their medical history was remembered and sometimes narrated by others. As noted in the parent findings, ‘protective parenting’ and shared recall appeared to foster a strong sense of normalcy for the children, as often painful or stressful memories were blanketed by positive ones. In doing so, potentially distressing memories were softened, and children seemed to recall more positive, parent-framed experiences.

7.0 Chapter Seven: Discussion

7.1 Discussion Overview

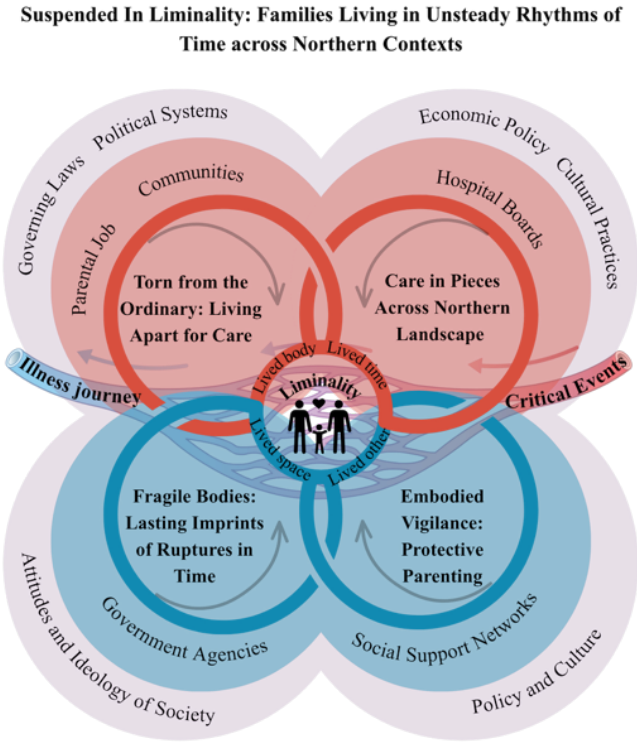
The chapter interprets the study's findings. The aim is to develop a deeper meaning from the findings to enrich our understanding of what the experiences of children with CHD and their families in Northwestern Ontario reveal about time, place, body, and relations. Drawing on van Manen's four existentials and Bronfenbrenner's Bioecological theory guided by the Process-Person-Context-Time (PPCT) model. The discussion situates these experiences within the broader structural, societal, and political context. These frameworks are not only used to interpret what families experienced but to examine the various intersecting factors that shape those experiences. They will also help in considering what changes are needed to better support families living with CHD in the north. The conceptual model of families' experience is presented in Figure 4, which builds on earlier figures in the analysis.

In this figure, the family living in liminality is placed at the heart of the model, surrounded by the four themes and by the ecological systems that shape everyday life in the north. Lived body, lived space, lived time, and lived relations are intertwined within each theme. They illustrate how parents and children experience CHD in the north through their bodies, homes, hospital, spaces, and shifting relationships. These aspects within the core themes are consistently disrupted by temporal rhythms arising from ruptures in time, such as critical events. The artery running through the figure represents the core finding of liminality, which reflects van Manen's lived time and Bronfenbrenner's external chronosystem. Disruption in time includes the child's CHD diagnosis, the unfolding illness journey and the ongoing possibility of crisis that places families in an enduring state of liminality. Around the family centre are the microsystem, mesosystem, exosystem, macrosystem and chronoystem. They are depicted as overlapping

structures that are dynamically interconnected rather than separate layers. Together, the life-world existentials and ecological systems shape how families live apart for care and wait in uncertainty while living in the north. The continuous fear of disrupting ordinary life and being catapulted back into crises leaves families suspended in unsteady rhythms of time and in an ongoing liminal state. Through families' experiences and integration of the literature, the discussion will highlight how much of the findings are produced by systemic structural and policy arrangements rather than the individual or illness itself.

Figure 4

Conceptual Model of Families' Experiences



The discussion begins with the overarching finding that parents' experiences are suspended in liminality, followed by the four interconnected themes: Torn from the Ordinary: living apart for care; care in pieces across the north; fragile bodies: lasting imprints of ruptures in time; and embodied vigilance: protective parenting. The chapter then turns to the children's findings with particular attention to the under-representation of children's voices in the CHD literature. This chapter aims to enhance understanding of the profound complexities faced by children and families living with CHD in a northern context. Complexities are not just medical but are a complex web of interrelated geographical, relational, structural, and political challenges.

Throughout the discussion, each theme is first presented with a narrative story drawn from the families' and child experiences. Following each narrative, the discussion synthesizes findings from the existing literature to compare, extend, and, at times, challenge what is already known.

This research addresses a significant gap. While the literature on CHD and family experiences has grown substantially, almost no studies have examined the specific experience of children and families living with CHD in rural, remote or northern regions. Further, the vast majority of existing literature relies on quantitative designs and parent proxies, leaving children's own voices and perspectives largely absent. This study's dual focus on both parental and child experiences, grounded in van Manen's phenomenological approach, represents a meaningful methodological and substantive contribution to the field.

7.2 Suspended in liminality: Families Living in Unsteady Rhythms of Time

7.2.1 Family Narrative Overview

For families within this study, there is no single moment when uncertainty ends. The diagnosis marks the initial rupture in time, the moment when ordinary time shatters, and a life once known disappears. In its place, an unfamiliar and unsteady rhythm begins. The underlying fear of being torn from their ordinary worlds and catapulted back into crisis leaves families living in a constant state of anticipation, suspended between two realities. This includes a life they are trying to rebuild and knowing that at any moment it could be uprooted again and taken from them. This fear never leaves; parents describe it as a 'bouncy ball'. Fear that can be pushed away yet quickly bounces back to the forefront of your thoughts. This distress is not linear or time-limited; instead, it persists in cycles. These efforts to maintain stability only provide temporary relief, as families continue to live in a liminal space, pulled between times of crisis and the regaining of stability. The impact is not only on the child with CHD and their parents, but also siblings.

Within this liminal state, families wait. They wait for their next appointment, the next result, the next phone call that could change everything. Plans are made and unmade. Stability is reached, only to be repeatedly interrupted. The possibility of crisis is never fully absent; it lives quietly in the background of ordinary moments and can surface at any moment in time. The future, once assumed and planned for, becomes difficult to hold on to, clouded by uncertainty about what their child's health will allow.

In Northwestern Ontario, geography deepens this liminality in ways that families elsewhere may not experience. When a child's condition shifts, families must leave home suddenly. There is often no return date, and they travel over 1500 kilometres away from their partners, and their

other children. Living with CHD in the north is not a series of isolated crises; it is an ongoing, unsteady rhythm of time leading to an enduring liminality that reshapes every area of a family's life.

7.2.2 Literature and Implications

Within the CHD literature, liminality has begun to emerge as a useful lens for understanding how families navigate key transitions (Gaskin et al., 2024; Harris et al., 2020). Gaskin et al. (2024) used liminality to conceptualize parents' transition from perceived safety of the hospital to the responsibility of managing complex care at home. Highlighting the 'betwixt and between' nature of this discharge period. Similarly, a qualitative study conducted in the United States, including 27 participants from 17 families who received a prenatal diagnosis of CHD, found that this diagnosis left families with persistent and unresolved uncertainty between the moment of diagnosis and birth of their child (Harris et al., 2020). Even though the explicit use of liminality remains relatively sparse in the CHD literature, these studies together suggest that prenatal diagnosis and early post-discharge represent liminal phases in families' CHD trajectories. These phases are often marked by persistent uncertainty. This study adds to the emerging body of CHD research by illustrating that liminality is not confined to discrete clinical transitions yet extends and is interwoven across everyday family life.

Beyond CHD, a Canadian narrative study by Bruce et al. (2014a) deepens this understanding by describing "pervasive liminality" among adults living with life-threatening illnesses such as cancer, chronic kidney disease, and HIV/AIDS. Findings showed overlapping, contradictory narratives, such as fear and fearlessness, and being alive but not living, which can persist over time (Bruce et al., 2014a). Gibbons et al. (2014) further extended the concept of liminality by framing family caregiving more broadly as a sociocultural rite of passage. The

integrative review of 26 studies describes caregiving as unfolding through pre-liminal, liminal, and post-liminal phases marked by role ambiguity, social disruption, and persistent uncertainty, as they make efforts to establish a "new normal" (Gibbons et al., 2014). Building on these insights, this study demonstrates that, in a northern context, liminality is additionally shaped by geography. The vast physical distances separating families from specialized care adds a layer of spatial and temporal uncertainty that has not been previously documented in the CHD literature.

A recent Canadian contribution by Nemes et al. (2024) employed a timeline-mapping methodology with parents of children with CHD to explore the temporal dimensions of the parenting experience, revealing the nonlinear, cyclical nature of parental distress. Although Nemes et al. (2024) acknowledge challenges with geographical access, this was not explicitly theorized. Importantly, the authors noted that a significant limitation was the exclusion of parents from northern health regions, a gap that this dissertation's findings directly address.

Consistent with prior literature, parents described ongoing fear and uncertainty about their child's future and development (Bruce et al., 2014b; Catapano et al., 2024; Dandy et al., 2024; David Vainberg et al., 2019; Kankaya et al., 2025; Leo et al., 2023). Across the qualitative studies, two were conducted in Europe and one in the United States, which described this ongoing fear and uncertainty as living in a prolonged emotional space (Bruce et al., 2014b; Catapano et al., 2024; Kankaya et al., 2025). Parents described that to manage these emotional challenges, some families intentionally avoid thoughts about the future. This was a protective cognitive strategy, consistent with Lumsden et al.'s (2019) systematic review, which found that families attempt to restore normality by moving forward rather than dwelling on the unknowns. Parents described their fears as a bouncy ball, temporarily constrained but never fully resolved, capable of bouncing back at any moment. This image powerfully captures the cyclical nature of

parental distress and aligns with Bruce et al.'s (2014a) notion of liminal narratives that endure over time.

Other research has also found that emotional experiences of liminality were frequently intensified by sudden, urgent travel demands of unknown duration and repeated attempts to rebuild stability. This underscore that the whole family's routines are destabilized due to the complex nature of CHD (Cruz et al., 2022; Dalir et al., 2021; David Vainberg et al., 2019; Mombach Barreto et al., 2016; Sood et al., 2019), also disrupting siblings' lives not just parents or the child living with CHD (Bichard et al., 2022; Cruz et al., 2022; Schamong et al., 2021; Watkins et al., 2022; Vasilescu et al., 2024), and with studies

Liminality is also structurally produced. In Canada, the centralization of specialized pediatric cardiac care in a small number of urban tertiary centers means that families living in rural, remote and northern regions must often travel long distances to access life-sustaining care (Anish et al., 2025; Olugbuyi et al., 2022; Van Buuren et al., 2026). When a health care system requires families to travel more than 1500 kilometres for essential cardiac care, families are physically and mentally pulled between home and hospital. This forces the family into an ongoing structurally imposed liminal space, where everyday life, relationships, and additional responsibilities remain 'back home'. Paediatric and cardiac care is also not prioritized in the same way as adult cardiac care is. Recent provincial investments in Northwestern Ontario illustrate this dynamic. Ontario is expanding access to cardiovascular surgery in Thunder Bay, promising advancements in adult cardiac care and bringing services closer to home, yet there is no mention of this for child's cardiac services (TBRHSC, 2025). Children's Healthcare Canada (2025) has stressed that essential care wait times are longer for many children than for adults within Canada. They call on federal party leaders to introduce a Canadian-wide children's health

and wellbeing strategy, create separate funding dedicated to children's health, and support families through economic uncertainty (Children's Healthcare Canada, 2025). These institutional and political designs, shaped by the regionalization of services and the fragmentation of pediatric care in northern and remote regions, further marginalize families living in under-resourced areas (CIHR, 2021; Van Buuen et al., 2026).

The World Heart Federation's (2026) World Heart Report on CHD documented that in lower and middle-income countries, over 90% of children reside in 'pediatric heart health deserts. Meaning timely and appropriate CHD care for these children in inaccessible areas (World Heart Federation, 2026). Even within high-income countries, disparity is noted as death rates are eight times more likely in lower-income areas compared to higher-income areas (World Heart Federation, 2026). While Northwestern Ontario is not a low or middle-income region, the structural inaccessibility of pediatric cardiac care for families in this region shares common features of the 'pediatric heart health desert'.

The findings of this theme collectively suggest the need for a layered response. At a clinical level, psychosocial family screening must be timed to coincide with key ruptures in the child's illness trajectory and sustained throughout the child's cardiac journey (Golfenshtein et al., 2021; Jaschinski et al., 2022; Lisanti et al., 2021; McClung et al., 2018), recognizing liminality as ongoing rather than a state (Bruce et al., 2014a). At a policy level, northern geography and structural travel burdens must be considered in health system planning and funding. The spatial fragmentation of care experienced by families must be taken into account to improve care coordination, enhance collaboration between sites, strengthen regional services, and inform innovative models of pediatric care (Sansone et al., 2024). By attending to clinical and structural dimensions and considering families' experiences in Northwestern Ontario, it may be possible to

reduce the ambiguity surrounding families' ongoing liminal state. Offering clearer pathways and more practical, family-centred care supports could aid this.

7.3 Torn from the Ordinary: Living Apart for Care

7.3.1 Family Narrative Overview

Living apart for care emerges as a central way in which families in Northern Ontario are pulled out of ordinary life and held in an ongoing state of liminality. Rather than a single time-bound disruption, these separations became frequent and recurring, especially during the early years. Essential care requirements require that families live apart, reorganizing families' routines, relationships, caregiving roles, and financial security. Living apart for care is not only about physical distance, but fundamentally alters how families live together and apart, creating a fragile ‘new normal’ that can be ruptured at any moment by another crisis. Siblings' expectations of parental presence are repeatedly disrupted. Living apart for care turns ordinary mornings and errands into moments filled with fear that parents might suddenly disappear. Family life is reorganized around the child with CHD, sometimes at the expense of time and attention to siblings. Living apart for care also reshapes caregiving and work in gendered ways. Most mothers reduced work hours or leave employment entirely to become primary caregivers, while fathers maintain employment to secure family income from afar. These arrangements, negotiated in a liminal state, where families are continually suspended between home and hospital, crisis and ordinary life, affect mothers' careers, the family's finances, and the emotional labour of parents. Long distances to specialized paediatric cardiac care produce hidden expenses including flights, accommodations, food, childcare and time of work. Families are essentially living in two places at once, accumulating hidden expenses while away, while honouring existing obligations at home. Even with partial support, such as travel grants, families carry the debt and delays in

being remunerated for these services, often relying on others, including family members, to help cover travel and care expenses.

7.3.2 Literature and Implications

Findings about living apart for care, from care for families in Northwestern Ontario, and the disruptions that families, including siblings, face, echo what has been described in the existing literature. As caregiving demands intensify, everyday family rhythms are disrupted, often resulting in unintentional consequences for the siblings (Cruz et al., 2022; Dalir et al., 2021; Schamong et al., 2021; Sprong et al., 2024; Watkins et al., 2022; Vasilescu et al., 2024). This study builds on existing research by demonstrating that impacts are intensified in northern contexts, with parents travelling long distances, often with no clear timeline for return**,** and family life reorganized around the child with CHD, often at the expense of the other sibling's time and attention (Cruz et al., 2022; Dalir et al., 2021). Growing attention within the CHD literature highlights how repeated hospitalizations, ongoing uncertainty, and parental absence negatively influence siblings' emotional well-being and QOL (Schamong et al., 2021).

Consistent with existing literature, these caregiving demands also contribute to significant employment disruptions (Cruz et al., 2022; Dalir et al., 2021; Delaney et al., 2024; Kankaya et al., 2025; McClung et al., 2018; Moorman et al., 2025; Pickles & Keller, 2025). In this study, this was particularly evident among mothers. Previous reports also highlighted that mothers reduced their working hours or left their jobs to assume the primary caregiving role (Cruz et al., 2022; Kankaya et al., 2025; Sood et al., 2018). This is not an isolated phenomenon. The broader literature consistently identifies a gendered gap in caregiving responsibility where serious childhood illness tends to return families towards traditional gender roles, with mothers absorbing the greatest share of direct care (Mark et al., 2025; Werner, 2023).

Fathers in this study also reported significant emotional distress, particularly related to geographic separation from their families and the pressure to maintain employment. However, the evidence does not always support a conclusion that the overall emotional demands are similar or equal between parents (Werner, 2023). Father's experiences, though meaningful, remain less visible in this study and in the broader literature. This may reflect the ongoing influence of social gender roles and expectations (Dandy et al., 2024; Lin et al., 2021). Still, the unequal distribution of caregiving responsibilities should not just be viewed as a product of individual choice; it is largely shaped by structural and policy conditions (Werner, 2023).

Comparison between Canada and countries such as Denmark illustrates how policy frameworks can either mitigate or exacerbate these inequities. Denmark offers substantially more parental leave, as mothers employed in the public sector are entitled to full salary for up to 26 weeks of parental leave following birth, and if both parents are employed by the state, they are entitled to full pay for 24 weeks of leave each (IDA, 2026a). Parents not employed by the state are also entitled to 52 weeks of paid leave, which includes before and after the birth, and can be shared, with a weekly top-up earning substantially higher than Canadian benefits (Nordic Council of Ministers, 2025). Additionally, if parents have to take a leave from work due to their sick child, they are entitled to wage replacement benefits (IDA, 2026b). In contrast, Canada's employment insurance system only replaces 55% of insurable earnings, with capped benefits, in cases of critical childhood illness (Government of Canada, 2026b; Government of Canada, 2026c).

Families in the study face substantial financial and travel costs for care, which are compounded by policies that are not designed with their circumstances in mind. Policy differences in parental leave between countries like Denmark and Canada highlight significant

gaps in financial support for families. Families living in rural, remote, or northern regions of Northwestern Ontario, like the families participating in this study, are at an even greater disadvantage, as they must repeatedly travel for care and bear the financial consequences of the illness. The significant financial and caregiver challenges connected to geography that families face are not caused by lack of strength or perseverance, but rather political decisions and policy gaps. If anything, the families in this study demonstrated immense strength in enduring and overcoming the structural, geographical, and political roadblocks.

Although Canada's publicly funded health care system alleviates the burden of direct medical costs, this study highlights a substantial, often hidden, and overlooked financial strain associated with accessing care at a distance. Families endure recurrent expenditure on travel, accommodation, meals, and taxis, none of which is fully covered by available assistance programs. The Northern Health Travel Grant (NHTG) (2024) is a key resource for offsetting travel costs for families living in northern Ontario. As of 2024, several positive changes were made to the NHTG to improve access to medical care and reduce financial challenges for families living in the North (Ontario Ministry of Health, 2026). The NHTG reimburses travel at $0.41 per kilometre, calculated on the round-trip distance, and provides an accommodation allowance of $175, up to a maximum of $1,150, for eligible northern Ontario residents (Ontario Ministry of Health, 2026). Even with the recent 2024 amendments, the NHTG still excludes meals and taxi services, requires upfront payments, and restricts reimbursement to a single caregiver (Ontario Ministry of Health, 2026). The inadequacy of the NHTG is not a new finding. The office of the Auditor General of Ontario (2025) found that the ministry had long used outdated mileage rates and, unlike comparable jurisdictions, did not cover meal expenses. For parents in this study, covering only one caregiver automatically means you are separating a

family, as only one parent would qualify as the caregiver eligible for reimbursement. The study highlighted that partial reimbursements were insufficient and failed to offset the true hidden costs of repeated travel. This aligns with the Auditor General's findings, which underscored systemic concerns about the adequacy and evaluation of the NHTG at the systemic level (Office of the Auditor General of Ontario, 2025).

These findings align with the broader literature documenting the significant financial hardships families undergo related to their childs CHD care (Choi et al., 2021; Cruz et al., 2022; Kankaya et al., 2025; Kolt et al., 2020; Ludomirsky et al., 2021; McClung et al., 2018; Mombach Barreto et al., 2016; Moorman et al., 2025; Peterson et al., 2022; Pickles & Keller, 2025; Scearbo et al., 2025; Sood et al., 2019). A recent cross-sectional study conducted in the United States highlighted the substantial lifetime costs associated with complex CHD. Findings estimating expenses of around 2.1 million, with 43-63% of the costs paid by families, noted that the early years were the most financially challenging, accounting for one-third of lifetime costs (Pickles & Keller, 2025). Although much of the literature is conducted across varying healthcare systems, including the United States, this study's findings highlight that financial strain remains a significant concern even in a publicly funded system (Belza et al., 2024; Massel et al., 2023). Considering the broader literature on families caring for children with complex medical needs. A recent cross-sectional study conducted in Ontario highlighted the financial strain and out-of-pocket expenses these families endure (Belza et al., 2024). Factors contributing to this included travel for care, employment disruptions, and system gaps, leaving many families covering a large portion of care-related expenses themselves (Belza et al., 2024). Findings from this study reflect these patterns, with families describing the significant financial pressures of travelling for care. This was particularly financially challenging in the early and highly unstable years, as families

often had to travel frequently with little notice. Beyond medical expenses, families were required to cover the cost of meals, hotels, flights, and taxis, all while having limited income due to employment impacts (Belza et al., 2024; Delaney et al., 2024; Zhang et al., 2023). Findings add to the existing literature around the hidden costs of care, especially at a distance, where families living in the north appear to face heightened challenges due to structural, political and geographic inequities.

7.4 Care in Pieces: Fragmentation Across the North

7.4.1 Family Narrative Overview

Across families' accounts of raising a child with CHD in northern Ontario, a clear picture emerges of care being fragmented across the north. This leaves parents to assume the work of putting the pieces together to ensure the child's cardiac care needs are met. Their experiences are shaped by several factors, including fragmentation of care, communication, geography, and relationships. This deepens the ongoing liminal state between stability and crisis, between knowing and not knowing, between connection and frequent disconnection between healthcare sites.

Rather than moving through a coordinated system, families are required to actively manage their child's health across dispersed providers, institutions and timelines. In doing so, they assume responsibility not only for caregiving but also for serving as a health care coordinator. Parents actively manage varying information, help coordinate services, and safeguard continuity of care by making frequent and ongoing attempts to follow up with health care providers. Families do this so their children's care doesn't fall through the cracks or get lost in the dispersed, fragmented system. This work is intensified by structural conditions beyond families' control, including geographic isolation and limited access to specialists. Environmental

uncertainty becomes heightened for families in the north, contributing to heighted challenges as it intersects in profound ways.

Amid the fragmentation, families seek and highly value relational continuity. The presence of a trusted local provider, most often the local pediatrician, becomes an anchor amid the sea of chaos. They serve as a critical stabilizing force, offering reassurance, advocacy, and a sense of being understood. These core relationships help bridge some systemic gaps, but do not resolve them. Families are not only managing illness, but also navigating an unstable and complex system, compounding their ongoing state of liminality.

7.4.2 Literature and Implications

As highlighted in the family narratives, distance, weather, and travel are catalysts that actively disrupt timely access, continuity and care pathways for families of children with CHD in Northwestern Ontario. Building on this, current findings show that fragmentation extends beyond juggling logistics, producing persistent uncertainty and fear which was more evident during periods of clinical instability and crisis.

The CHD literature consistently emphasizes the importance of clear and ongoing communication with health care providers (Cruz et al., 2022; Catapano et al., 2024; Dandy et al., 2024; Franklin et al., 2021). However, this study suggests that communication is not only an interpersonal concern but is structurally and geographically constrained. Access to specialized cardiac care required interactions with multiple geographically distant providers and intermittent outreach clinics. Therefore, limiting opportunities to build sustained therapeutic relationships, particularly for families in the north. As a result, limited CHD-specific expertise and inconsistent recommendations left families uncertain about care, reducing their trust in providers, something previously highlighted by Cruz et al. (2022). Rather than reinforcing reassurance and support

among families, as continuity has been shown to do (Catapano et al., 2024; Chong et al., 2018; Cruz et al., 2022), the system provided families with conflicting narratives of care, often leaving them to navigate on their own.

Similar to findings by Kerber et al. (2019) and Vestal et al. (2024), breakdowns in communication, missing information, unclear documentation, and poor coordination across sites are not isolated incidents. These patterns were also major aspects of the care experiences of the families participating in this study, highlighting major gaps in the current health care system. These gaps reflect the broader literature on structural issues in regionalized models of pediatric subspecialty care. In these models, expertise is concentrated in southern centres and outreach to northern regions is intermittent, leaving families with limited support and no choice but to travel for care (Simmons et al., 2026; Vestal et al., 2024). Although outreach clinics have been reported to facilitate bridging gaps in care (Vestal et al., 2024), the outreach clinic local to this study faces challenges as reported by families and local health care workers, including inconsistent staffing, weather-related challenges, and resource constraints (A. Halverson, personal communication, April 30th, 2026). While adding another outreach cardiac clinic may improve access (A. Halverson, personal communication, April 30th, 2026), it does not address concerns about continuity, information sharing across institutional sites, or the relational work required to support families over time. Study findings and family suggestions point to the need for more continuous local pediatric cardiac care delivered through multiple modes, for example, in-person outreach and telehealth. Telehealth-supported paediatric subspecialty care, including virtual consultations and remote review of investigations, has been used in other rural and remote contexts within Canada and internationally to reduce travel and increase the timeliness of specialized input (Ellis & Russell, 2019; Marcin et al., 2016; Vestal et al., 2024). Similar

approaches could help families in Northwestern Ontario bypass weather-related barriers and receive more regular follow-up.

Adding health care support locally with specialization in pediatric cardiology, such as a Nurse Practitioner, may also address continuity and provide additional support for families. Similarly, a study conducted in the United States of models developed for children with medical complexities found that such roles can enhance communication, streamline care across settings and provide a consistent point of contact for families (Pordes et al., 2018).

These study findings also highlight the need for a cardiac clinic family support and advocacy group where families can come together to provide mutual support but also make suggestions for improvement for the care teams, thereby providing a voice to families. National work on pediatric patient and family advisory councils shows that structured councils can provide a sustained way for family engagement, bringing caregivers and staff together to improve care experiences and services (Richard et al., 2020). Broader child health advocacy, and family engagement with models are being used at Children's Hospital of Eastern Ontario (CHEO) (2025), which has developed a Complex Care Family Advisory Council for parents. This council engages with parents to support hospital programs and deliveries (CHEO, 2025). Complex Care for Kids Ontario (CCKO) (2026) is another family-centred care program by Health Services North in Sudbury that aims to improve care coordination for children with complex medical systems and their families.

Findings also stress the critical need for a cardiac care coordinator to serve as a liaison among the various moving parts of the northern and southern healthcare teams. This liaison would also work alongside the health care teams and families in order to create an environment

where gaps in services are addressed through listening and understanding the various perspectives that shape the healthcare landscape in the north.

Parents' care coordination roles within this fragmented system are not voluntary; they are forced to assume these new roles to ensure their child's care is managed and maintained. Relational discontinuity and system gaps meant that coordination became part of everyday caregiving as families tracked referrals, monitored follow-up appointments, and facilitated communication across care sites. While similar coordination burdens have also been noted in the literature (Bruce et al., 2014b; Cruz et al., 2022), this study's findings suggest that in northern contexts, this burden is intensified by geography and structural inequalities. Although families want to participate in their child's care, they are already challenged with a significant load of responsibilities and external pressures. Phenomenological work conducted in Sweden found that, while parents wish to be involved in their child's care, boundaries are necessary due to limited time, knowledge, and emotional resources (Bruce et al., 2014b). Parents "do not want to take full responsibility for the quality and constant vigilance of their children's medical care" further stating "Support means to be relieved from what they feel are their healthcare responsibilities so that their role as a mother can play a dominant part in their relationship with the child" (Bruce et al., 2014b, p. 62). In this study, however, many families describe routinely planning and organizing most aspects of their child's care and, over time, normalizing these responsibilities. Fragmentation within the healthcare system effectively shifted organizational responsibilities, such as navigation, coordination, and follow-up, from formal structures onto families.

Coordination frequently shifted into advocacy, particularly around discharge. The CHD literature around parental discharge is recognized as a period of mixed emotions, including excitement, anxiety, and fear (Gaskin et al., 2024), with parents having to manage complex care

at home without the perceived safety net of the hospital (Simeone et al., 2018). The northern location of the families in this study amplified these challenges because families are physically and structurally distant from the services they depend on. This meant that missed appointments or follow-ups could carry serious consequences contributing to an ongoing sense of liminality in which they could never fully relax or step back from their care roles. These factors can also lead to increased hypervigilance and protective parenting practices and psychological impacts among parents (Demianczyk et al., 2022).

This CHD literature, links consistent, compassionate communication with better coping and reduced uncertainty (Dandy et al., 2024). Family-centred care, individualized to the family and child, is central to positive care experiences; families need to feel seen as partners in care, not just as patients (Dandy et al., 2024; Sprong et al., 2024). Building on this, the present study underscores the importance of relational ‘anchors’ in fragmented northern systems. For many families the local pediatrician team functioned as this ‘anchor’ providing long term relationships that offered continuity and advocacy which was largely missing from the specialized cardiac pathway.

Transition to adult care further highlights families’ reliance on these relational anchors. Anticipating the loss of the local pediatric team generated a sense of grief and heightened stress as families feared being left to navigate complex, discontinuous systems alone. Transition literature emphasizes the importance of ongoing communication, supportive relationships and for individuals to become active members in their care (Bratt et al., 2018; Ruban et al., 2026). The study's findings suggest that in fragmented systems within the northern context, these relational anchors serve an even greater role. Families’ frustrations were directed not at individual providers but at the structures and organization of the health care system.

7.5 Fragile Bodies: Lasting Imprints of Ruptures in Time

7.5.1 Family Narrative Overview

The parents' heightened sense of vulnerability left lasting marks on their emotional, physical, and relational lives, which continued to shift over time. Early beginnings were often marked by abrupt ruptures in time; mothers gave birth hundreds of kilometres from home, separated from their newborns, and sometimes had to consent to urgent procedures before they had even held their baby. Mothers were faced with all of this while trying to recover from their own complications post-birth. They also had to witness their newborn swollen and bruised, often surrounded by medical tubes and monitors. In this context, their own bodies and needs became secondary. Usual pathways of bonding and feeding were disrupted and medicalized. Ruptures in time continued through surgery, intensive care, critical cardiac events at home, requiring emergency services and intervention, and parents witnessing their child's open chest. While these episodes only lasted minutes, they became vivid, intrusive memories that left lasting imprints on parents' emotional well-being. Over time, the accumulation of these events left many parents living with PTSD or high anxiety. Ordinary triggers such as walking into hospital buildings, particular seasons of the year, or a simple phone call could instantly cause parents' emotional distress. Across parents' accounts, it was emphasized that their own emotional and physical needs were rarely assessed in their child's cardiac care. Mental health supports were not routine, and their apparent ability to 'handle it' often hid significant unmet needs. Rather than a single event, it was a layering of interrupted beginnings, repeated crises, and a lack of systemic support that left lasting imprints on parental well-being and kept families living in a state of ongoing liminality and hyper vigilance.

7.5.2 Literature and Implications

Profound disruption of early parent-infant interactions in the context of CHD and intensive care has been widely described in the literature (Catapano et al., 2024; David Vainberg et al., 2019; Kankaya et al., 2025; Moorman et al., 2025). Qualitative studies of parents of infants and children with CHD report that hospitalization, intensive care admission, and the demands of cardiac surgery often interrupt anticipated early caregiving experiences (Catapano et al., 2024; Moorman et al., 2025). This interruption includes lost or delayed opportunities to hold, feed, and care for their baby in ways they associate with 'normal' early parenting (Catapano et al., 2024; Moorman et al., 2025). Across several international qualitative studies, separation from the hospitalized child, restrictions on physical closeness, and limited involvement in everyday care are described by parents as a major source of intense stress, grief, and feelings of helplessness (Catapano et al., 2024; David Vainberg et al., 2019; Kankaya et al., 2025; Moorman et al., 2025). Literature on parents' experiences of a hospitalized child with CHD reports that the separation due to the child's health status caused perceived disruptions in the early bonding and attachment period (de Man et al., 2021; Catapano et al., 2024; David Vainberg et al., 2019; Kankaya et al., 2025; Moorman et al., 2025). These reports are consistent with the experiences of mothers in this study, who similarly emphasize the impact of early separation and constrained caregiving on their ability to bond with and care for their newborn.

The postpartum period is recognized as a challenging and vulnerable time for new mothers generally. This vulnerability is suggested to be heightened among mothers of infants with CHD who experience difficulty adapting to the diagnosis and additional psychological distress (Davey et al., 2024; Tecar et al., 2025). Existing literature, in line with this study, also describe mothers of children with CHD having to navigate profound fear and uncertainty as they

witness their infant's fragile bodies (Catapano et al., 2024; David Vainberg et al., 2019), faced the possibility of loss (Bruce et al., 2014b; Kankaya et al., 2025) and unknowns about their child's future (Bruce et al., 2014b; Catapano et al., 2024; Dandy et al., 2024; David Vainberg et al., 2019; Kankaya et al., 2025; Leo et al., 2023). Neither for mothers in this study nor for mothers in comparable research was early motherhood remembered as a period of bonding and recovery, but as entering into and being in a liminal space defined by constant instability and uncertainty.

While the psychological burden on parents of children with other severe illnesses, such as cancer, is well documented (Caruso et al., 2017; Ozdemir Koyu, & Tas Arslan, 2021), there appear to be fewer studies conducted on how pediatric CHD shapes the mental health and well-being of parents (Biber et al., 2019; Thomas et al., 2023). Existing CHD studies, nevertheless, indicate high rates of trauma-related outcomes, including PTSD diagnoses among parents (Jones et al., 2024; Tecar et al., 2025; Woolf-King et al., 2017) and heightened anxiety (Biber et al., 2019; Bruce et al., 2014b; Catapano et al., 2024; Dandy et al., 2024; Davey et al., 2023; Kankaya et al., 2025; Lopez et al., 2016; Mombach Barreto et al., 2016). Findings add to the existing body of knowledge that the emotional impacts of caring for a child with CHD do not end when the medical crisis or ruptures in time have passed; it is felt long after (Jackson et al., 2015; Mombach Barreto et al., 2016; Nemes et al., 2025; Watkins et al., 2022). These findings underscore that family resources and supports should account for the critical component of time. As parents live in a constant state of liminality, with ever-changing needs due to their child's cardiac trajectory, their emotions fluctuate over time, intensifying around key ruptures in time (Cruz et al., 2022; Elliott et al., 2021; Pridham et al., 2018; Sprong et al., 2024; Zhang et al., 2023).

While research consistently reports significant psychological distress among parents of children with CHD, there is a gap in understanding how parents interpret their needs and care experience over time (Wei et al., 2015). This emphasizes the importance and need for increased longitudinal research, including qualitative research, to better understand families' experiences and how they unfold (Wei et al., 2015). Parents in this study and in the work of Nemes et al. (2025) reported feeling unsupported during times of crisis, noting they wanted follow-up care, or a wellness call to check in and address their needs. Families of children with CHD who have fewer supports and psychological resources are reported to be at greater risk of lower overall wellbeing and persistent psychological distress over time (Jackson et al, 2015; Thomas et al., 2023). This is significant for families in northern areas, where geographic and structural barriers limit access to supports, leaving them to navigate care within constrained contexts and intensifying their ongoing emotional and relational challenges.

Family-centred care is a pillar for many health care organizations, and the findings from this study, as well as those of Nemes et al. (2025) and Thomas et al. (2023), confirm a critical need for increased family mental health screening, assessment, and support to be appropriately implemented. This should not be a one-size-fits-all approach, as each family's experiences are unique and needs vary (Franklin et al., 2021). Due to the many fractured and critical periods in time that have shown to have lasting imprints on families, supportive care and psychosocial needs should be assessed proactively and repeatedly rather than at one single point in time (Thomas et al., 2023). Particularly before and after major traumatic events, to address the evolving emotional needs of parents in their fragile state throughout their child’s cardiac journey. Evidence supports findings, indicating that timely psychological follow-up can reduce acute

stress and lower the risk of PTSD, ultimately reducing health care costs associated with untreated parental distress (Rössler et al., 2026).

7.6 Embodied Vigilance: Protective Parenting

7.6.1 Family Narrative Overview

Families live in a space that never fully returns to normal after their child's diagnosis; although the urgency of early surgeries and hospitalizations may pass, a lingering sense of uncertainty remains. This shapes how families move through their everyday life over time. It becomes embodied as a constant state of watchfulness; parents spoke of always scanning and anticipating. They remain aware that their child's condition can shift without warning. In response, families adapted their daily lives to create a sense of safety. Parents structure routines around protection, limit exposure to illness, carefully choose who can provide care, and modify activities to prevent overexertion. Parents often feel solely responsible for maintaining this protective environment, believing others didn't fully grasp the true weight of what they had been through. Parents intentionally work hard to enhance their child's care experience. They try to make it less challenging than their own, and to absorb as much of the fear, stress, and logistical burden as possible, creating moments of normalcy and enjoyment for their child. A gradual shift happens as the children grow and meet developmental milestones. Ongoing reassurance from medical follow-up and growing confidence in care over the years allow some of these protective practices to soften with parents slowly and often cautiously letting go little by little as the child shows positive growth. With this growth, parents allow their child to gain greater independence and participate in everyday childhood activities. Despite all of this, families still emphasize that the imprint of their experiences remains, the vigilance never entirely disappearing, rather becoming integrated in how they understand their child and their roles as caregivers. Parenting

continues to be shaped by an enduring awareness of fragility and the possibility that stability can be shaken, again suspending families in an ongoing liminal state.

7.6.2 Literature and Implications

In line with existing CHD literature, hypervigilance becomes embodied and normal for parents within this study. In existing work focusing on children with CHD, parents are, due to perceived vulnerability of their child, reported to live in a continual state of heightened vigilance, often demonstrating overprotective parenting behaviours (Dahlawi et al., 2024; Demianczyk et al., 2022; Leo et al., 2023; Nayeri et al., 2021; Sprong et al., 2024). Parents in other studies are described as closely watching their child's physical symptoms for signs of deterioration (Dalir et al., 2021; Lumsden et al., 2019; Nayeri et al., 2021) and frequently scanning their environment for potential threats, trying to enforce physical limitations to ensure their child's safety (Dahlawi et al., 2024; Dalir et al., 2021; Demianczyk et al., 2022; Nayeri et al., 2021; Sprong et al., 2024). Echoing the findings from Sprong et al. (2024), this included limiting daycare, avoiding outside supports, and homeschooling. Dahlawi et al. (2024) & Rempel et al. (2007) discuss parents' monitoring for external infections through enforced handwashing or disinfecting practices. Consistent with previous research, many parents reported that, due to the child's acute and fragile needs, they hesitated to trust babysitters, daycares, or even other family and friends, especially during the younger, more acute years (Sprong et al., 2024).

Consistent with Wangmo et al. (2017), parents actively worked to protect their children from the emotional burden of illness; however, an understanding of how these parental efforts shape children with CHD's emotional and experiential worlds has not been previously explored. The findings add to the literature on parental hypervigilance and protective parenting, suggesting that their active involvement may help preserve a sense of normalcy and safety for children. This

may influence how children remember these periods throughout their lives, as further discussed in the section on child findings.

Parents in the study often felt that people around them did not fully grasp the reasons for their ongoing watchfulness and protective routines. They felt their behaviours were interpreted as overprotectiveness rather than others truly understanding their experiences while caring for their ill child. This echoes Moorman et al. (2025) finding that parents' non-death losses are not always acknowledged by others, leaving them feeling that their experiences are invisible or misunderstood. The existing literature widely cites increased caregiving challenges as associated with feelings of isolation among parents of children with CHD (David Vainberg et al., 2019; Jackson et al., 2018; Kankaya et al., 2025; Mombach Barreto et al., 2016; Nayeri et al., 2021). In response, many families sought to connect in online groups with other parents of children with CHD or chronic illness for support (Bruce et al., 2016; Bruce et al., 2014b; Dandy et al., 2024; David Vainberg et al., 2019; Franklin et al., 2021; Lumsden et al., 2019; Mombach Barreto et al., 2016; Sood et al., 2019). However, families in this study reported limited awareness of such groups and a desire for more accessible, regionally relevant supports. The Circle of Hearts Family Support Network, based in Winnipeg and serving families from Manitoba, parts of Northwestern Ontario, and eastern Saskatchewan, could be an excellent resource to help address these gaps. However, it remains one of the few cardiac support groups for families living in Northwestern Ontario and only covers some areas, potentially limiting access for some families.

As children grow stronger, everyday activities such as participating in sports and engaging with school and friends become an important source of healing. While their bodies may still carry the imprint of past trauma, these new experiences support recovery and a return to a new normal. Ongoing monitoring and positive feedback from healthcare further strengthen

families' confidence (Sprong et al., 2024). Broader literature from a recent qualitative study of 15 parents in the United States examined parents' experiences navigating their child's chronic illness. Findings described how, over time, the child's diagnosis becomes woven into everyday family life (Thompson & Smith, 2025). Although parents still had underlying uncertainties, they gained a new sense of normalcy and experienced more moments of joy, gratitude, and emotional ease (Thompson & Smith, 2025). Healing for these families required navigating a new normal and watching their child successfully live within the constraints of their CHD diagnosis. Over time, positive health experiences help restore a sense of safety, allowing parents to gradually reclaim a feeling of normal time-space relationships, even as some level of vigilance remains. This hypervigilance isn't just reported during times of crisis or when the child was unwell; it is ingrained in day-to-day parental behaviour. The lasting imprints of trauma on parents' bodies leave them in a constant state of embodied vigilance, enacting protective orienting behaviours.

7.7 Child Findings Discussion

This section discusses the child-focused findings and situates them within existing literature on children growing up with CHD and other chronic conditions. Drawing on Van Manen's phenomenological approach and Bronfenbrenner's Bioecological model, children's own accounts highlight how they negotiate normalcy, difference, and agency in the context of everyday life and medical care. In the child findings, four core themes emerged. Within this section, they will be discussed in the following sequence, 1) Children Lived Normalcy: "I just feel normal", 2) Feeling Different in Physical Activities, But Not Defined by It, 3) Emerging Health Agency: From Passive to Active Agents in Care, and 4) Remembering with Others: Developmental Gaps and Relational Memory.

7.8 Children Lived Normalcy: “I just feel normal”

7.8.1 Child Narrative Overview

While parents in this study live in a state of ongoing liminality marked by uncertainty and hypervigilance, children experience their bodies and lives differently. Children understand their lives as normal. Often in direct contrast to parents’ beliefs about their child’s body as fragile, children do not view themselves as medicalized or living with a complex disease. They view their bodies as capable and do not perceive themselves as different from their peers. For many, CHD is not something they thought about often; it is simply part of their life.

7.8.2 Literature and Implications

Several studies have discussed how children living with CHD are often aware of differences, strive to fit in with peers, and may experience social difficulties (Knowles et al., 2016; Savaş et al., 2024). The findings in this study challenge these illness narratives. In this study, many children described friendships with limited interruptions. Social relationships were experienced as stable and typical, suggesting that CHD did not significantly shape how they engaged with peers or understood themselves in social spaces.

Considering self- and proxy-reported QOL, discrepancies have previously been found between parents' and children's perceptions of social well-being, with children rating this domain higher than their parents (Koster et al., 2025). This suggests that children may experience an internal sense of social normalcy that is not fully shared by or visible to their families (Koster et al., 2025; Pillay et al., 2020). In a South African mixed-method study, Pillay et al. (2020) report that children with CHD describe resilient social functioning in peer activities despite their medical history. Whereas parents focus more on the child's vulnerability and past health crises. Similarly, two cross-sectional studies, one from Tanzania by Koster et al. (2025), and one from

Germany by Jaschinski et al. (2022), show that parents' perceptions of their child's social well-being and overall HRQoL are often tied to past memories surrounding their child's illness severity and ongoing worry. Considering this literature and findings from the present study, it is suggested that childhood illness does not always translate into social disruption from the child's perspective. These differences between child and parent reports could be due to various contextual factors, including the child's age, CHD severity, mood that day, and comfort in the interview environment.

A similar pattern emerged within the school. Literature suggests that children with CHD often face multiple school-related challenges, which are not attributed to one single case but arise from a complex interplay of factors. These include cognitive (Millen et al., 2025; Spillman et al., 2021), functional, attendance (Farr et al., 2018; Flemming et al., 2024; Pfitzer et al., 2019; Savaş et al., 2024) and health-related factors that shape their ability to engage in classroom activities, complete academic tasks, and overall achievement (Farr et al., 2018; Flemming et al., 2024; Millen et al., 2025). Although this study did not directly measure these abilities, children were asked to reflect on their school experiences. The findings were again in contrast to the current literature. The majority of children reported minimal disruption to school attendance, activities, or daily routines.

Knowles et al. (2016) found that children felt their hospital stays, visits, appointments, and surgeries were reminders that they were different and played a significant role in shaping their identity. Within this study, children's CHD diagnosis did not appear to shape their identity; it was something they never dwelled on; it was just part of who they are. Children appeared to have incorporated their condition into their everyday lives. Hospital visits, checkups or procedures were familiar and expected; they were part of what their lives had always been. What

might be considered medically ‘abnormal’ for most children, for those living with CHD, is part of their everyday lifeworld.

Dahlawi et al. (2024) conducted a qualitative study in Saudi Arabia and interviewed 10 children with CHD and their parents to explore their experiences with hospitalization and its impact on behavioural and emotional issues. The study found that children were often scared before invasive procedures, yet many within the study said they were excited about going back to the hospital even after procedures were done. Similarly, Knowles et al. (2016) found that children felt their hospital stays, visits, appointments, and surgeries were reminders that they were different and played a significant role in shaping their identity. Within this study, only a small number of children reported situational anxiety related to appointments or specific procedures such as blood work, and just under half reported their dislike for medical procedures (Knowles et al., 2016; Savaş et al., 2024). In contrast, the majority of children within this study did not live with anticipatory procedural anxiety or fear; in fact they expressed positive experiences or felt indifferent about these events. Like this study, Silva et al. (2013) contrasted dominant narratives about children with CHD, noting that children appeared to adapt to their condition over time. Their sense of normalcy was grounded in the reality that their condition had always been present, supported by positive family environments and adaptive coping strategies over time (da Silva et al., 2013).

In opposition to most other studies, this study highlights that many children do not feel defined by their diagnosis; although it has fundamentally shaped their life course, it has done so in a way often unknown to them, as it has been woven into their lived experience since early years. Parental influence is central to these findings. The findings suggest that protective parenting practices described within this study, such as reframing stressful experiences,

maintaining routines, and shielding children from emotional burden, play a role in shaping how children make sense of their condition. Children's sense of normality is not only individually constructed but also deeply relational within the family and environmental contexts.

Children's experiences surrounding their positive reflections on their bodily scars also reflect the above narrative. Rather than being a source of distress and social vulnerability as reported by other authors (Dahlawi et al., 2024; Knowles et al., 2016; Savaş et al., 2024), their scars were often viewed as ‘cool’, part of their bodies, with some even having fun nicknames. Children recognized that their bodies looked different from their peers’, but most were proud. Scars were part of their embodied identity; they did not feel ashamed or embarrassed, which allowed them to feel a sense of normalcy with minimal disruption to their sense of self and to others.

The findings in this study and within the broader CHD literature capture a disconnect between clinical and parental constructs of illness and children’s lived experiences. These findings add to the literature and challenge some assumptions around CHD and its disruption to children’s sense of normalcy. However, much of the literature on children living with CHD is quantitative in design and collected via proxy reports from parents (Farr et al., 2018; Lee et al., 2021; O’Connor et al., 2023; Pfitzer et al., 2019). Given the limited body of research, particularly in qualitative methodologies that include children’s voices, and the divergent findings from existing research, further research in this area is warranted. Qualitative interviews with children, particularly including those living in underserved rural, remote and northern communities, will aid in a deeper understanding of the complex experiences of children living with CHD across ages, while considering different contexts.

These findings also stress the importance of family-centred care approaches that support parents' own mental health and caregiving capacity (Woolf-King et al., 2017). Supporting families in remaining at their child's bedside and travelling for care without financial impacts or job loss is critical to providing this layer of protection for the child (Liu et al., 2025; Walker, 2021). If the parent is suffering socioeconomically or mentally, with limited support, it can affect parenting and caregiving practices, ultimately impacting the child's health (Walker, 2021). Considering children's sense of normality from a larger lens using Bronfenbrenner's Bioecological model, the outer systems, including health care systems and policies, have a direct impact on the microsystem of the family (Liu et al., 2025).

7.9 Feeling Different in Physical Activities, But Not Defined by It

7.9.1 Child Narrative Overview

Children recognize bodily differences, particularly in relation to physical endurance and participation in sports and or activities. They describe noticing limits in stamina, fatigue, and, in one case, differences in physical development. Bodily differences do not appear to disrupt their sense of self or belonging among peers. Over time, as children develop, they gain greater confidence in managing and understanding their bodies and the limits they need when engaging in sports or physical activity. Children demonstrate a strong embodied awareness, recognizing symptoms such as chest pain or shortness of breath and act accordingly by slowing down or modifying effort. Children are not only independently managing their condition, but they are also competent and attuned, caring for their bodies, regardless of their limitations and through their bodily awareness. Children successfully learn to navigate living with CHD, often with minimal impact on how they want to live, engage in sports, and interact with peers. Feelings of normalcy are dominant despite differences with physical limitations in sports and activities.

7.9.2 Literature and Implications

These findings are consistent with existing child CHD literature documenting challenges related to physical endurance (Farr et al., 2018; Millen et al., 2025), fatigue (Blais et al., 2020; Dahlawi et al., 2024; Knowles et al., 2016), and physical restriction during sports and activities compared to their peers (Hsiao et al., 2024; Leo et al., 2023; Savaş et al., 2024; Venna et al., 2025).

For these children, bodily differences did not appear to disrupt their sense of self or belonging among peers. As children developed over time, they gained increasing confidence in managing and understanding their bodies and the limits needed when engaging in sports or physical activity (Knowles et al., 2016; Nematollahi et al., 2020). Children demonstrated a strong embodied awareness, recognizing symptoms such as chest pain or shortness of breath and acted accordingly by slowing down or modifying effort (Knowles et al, 2016; Lavenant et al., 2023; Nematollahi et al., 2020). Findings underscore that children are not only independently managing their condition but are also competent and attuned, caring for their bodies. Regardless of their limitations and through their bodily awareness, children have learned to navigate living with CHD. This was often done with minimal impact on how they wanted to live their lives, engage in sports, and interact with peers. Normalcy remains dominant despite differences with physical limitations in sports and activities. Consistent with prior literature, the findings suggest that positive interactions among peers, family, and the child's health may contribute to the child's continued involvement in sports and activities, regardless of their CHD (Bennett et al., 2021; Blais et al., 2020).

The findings also suggest that children do not view themselves as vulnerable bodies, but rather as attuned, adapted, and capable (Skivenes & Strandbu, 2006). Rather than focusing on

limitations or deficits, these findings suggest a need to reframe how children's bodies and physical capabilities are perceived, recognizing their capacity to adapt and become active agents in their own care (Skivenes & Strandbu, 2006). This study challenged the dominant literature, as children can experience bodily difference without it affecting their sense of self or their sense of being different from those around them (Knowles et al., 2016; Savaş et al., 2024). It is important to emphasize from these findings that children appear to adapt early on while living with CHD, and it appears to become ingrained and part of who they are. Findings further suggest that as children develop over time, their confidence in monitoring and responding to their bodies also increases. Aligning with past literature, the findings suggest that positive interactions among peers, family, and the child's health may contribute to the child's continued involvement in sports and activities regardless of their CHD. What is notable within the findings is not the awareness of these differences, but how the children understood and integrated them into their everyday lives.

7.10 Emerging Health Agency: From Passive to Active Agents in Care

7.10.1 Child Narrative Overview

Children's roles in their healthcare shift over time, moving from more passive involvement toward a growing desire to be active agents in their own bodies and care. Early in their care, children are often positioned on the periphery, with decision-making about information directed primarily towards the parents. Even as children age, this pattern remains true for many. With age comes deeper developmental capacities, heightened awareness, an ability to express a clear understanding of their illness, what to monitor, and how their bodies respond. This growing awareness leads to increased confidence, particularly in recognizing symptoms and responding to them. Children feel more confident and less anxious about

procedures and hospital visits over time, with some linking this shift to a growing understanding of their condition and rationales for interventions. While many children enjoy their parents as collaborators in their healthcare and often use them as ‘backup’, many children want more personal engagement with their healthcare team. A key barrier to this is a lack of involvement and information sharing between the child and health care providers. Children describe difficulty understanding the terminology and language used by their health care provider, limiting their ability to participate meaningfully. This often pushes them into passive roles in their care, leaving them to rely on their parents to interpret and translate information.

7.10.2 Literature and Implications

In line with the literature, while many children still enjoyed their parents as collaborators in their healthcare and often used them as ‘backup’ when seeking a different understanding, many children in this study still wanted more engagement with their healthcare team (Wangmo et al., 2017). This highlights the importance of individualized, family-centred care to ensure the health care provider can engage the child, with the support of their parents, in a meaningful way (Wangmo et al., 2017).

With age came deeper developmental capacities, heightened awareness, and a desire to be involved in their own care. Children were able to express a clear understanding of their illness, what to monitor, and how their bodies responded. This growing awareness of their own bodies and their role in care also led to increased confidence, particularly in recognizing symptoms and responding to them. Children also described feeling more confident and less anxious about procedures and hospital visits over time. Some linked this shift to a growing understanding of their condition and the reasons behind such interventions. This suggests that familiarity and knowledge helped reduce their uncertainty.

A key barrier identified in these findings was the lack of involvement and information sharing between the child and health care providers (Savaş et al., 2024). Many children described difficulty understanding the terminology and language used by their health care providers, which limited their ability to participate meaningfully. This often pushed children into passive roles in their care, leaving them to rely on their parents to interpret and translate information in ways they could understand. Although the parents' involvement is important, there needs to be space for the child to learn on their own.

Within research and health care contexts, children's perspectives are often overlooked or excluded from the decision-making processes (James, 2007; Runeson et al., 2001; Wangmo et al., 2017). Findings from this study indicate that children not only want to be active participants in their care but also have the capacity to understand when information is communicated in developmentally appropriate ways. Limited involvement is not solely a reflection of children's abilities but rather of how communication is structured within clinical encounters (Bell & Condren, 2016). When information is not relayed in ways that align with a child's age and developmental stage, it can reinforce reliance on caregivers and restrict opportunities for children to develop independent health agency (Bell & Condren, 2016).

Addressing these concerns requires health care providers to engage children through varying, age-appropriate, and meaningful ways (Lavenant et al., 2023; Savaş et al., 2024; van Driessche et al., 2025), including creative methods such as an arts-based approach (Dahlawi et al., 2024). Beyond the healthcare provider, structural factors, specifically, time constraints, are considered a key factor in enabling children within the decision-making process (Hietanen et al., 2025; Runeson et al., 2001). Healthcare organizations and practices must adopt flexible, child-specific approaches to enhance meaningful involvement (Runeson et al., 2001).

As this work and the work by Runeson et al. (2001) demonstrate, parents play a critical role in supporting children's understanding, yet this responsibility should not rest solely with them. Children's ability to become active agents in their own care appears to develop within supportive environments where both parents and healthcare providers contribute to their engagement (Runeson et al., 2001; Wangmo et al., 2017). These findings align with the literature, which suggests that children's participation in care is shaped not only by their right to be involved but also by relational supports and opportunities to make sense of their experiences (Ehrich et al., 2015; Runeson et al., 2001; Wangmo et al., 2017). There is a critical need to engage children in research to enhance understanding of their experiences, as their participation in care can only be enhanced when their voices are heard and understood (James, 2007; Skivenes et al., 2006; Wangmo et al., 2017). It is also important to consider the larger societal and social influences on how children view their lives (James, 2007; Voss et al., 2024). Evident within this study, and within the wider childhood show that these areas shape childhood space and ultimately have influence over how they experience their day-to-day realities (James, 2007; Voss et al., 2024).

Children’s maturity, developmental capacity, and family characteristics need to be considered when deciding whether to include children in their care (Runeson et al., 2001). Limited tools to assess children’s capacity have been cited in the literature as a barrier to including children in their care (Wangmo et al., 2017). Together, these findings suggest that children's capacity cannot be captured solely or easily by a standardized tool (Olsen, 2025; van Driessche et al., 2025). It is, instead, shaped by developmental stage, environments (van Driessche et al., 2025), prior hospitalizations, the nature of child-adult collaboration, and the contexts in which children participate (Olsen, 2025). Within this study, Piaget’s CDT supported

and underpinned the research interview guide and children's research assent scripts. This not only enhanced methodological rigour within the study but also ensured that engagement was tailored to each child's level of understanding, thereby improving communication.

7.11 Remembering with Others: Developmental Gaps and Relational Memory

7.11.1 Child Narrative Overview

Children’s understanding of their cardiac journey does not begin with clear memories of early illness but instead develops over time. Many children do not remember the early and frequently acute days of diagnosis, surgeries, and crises. However, they do not experience memory gaps as distressing; rather, they acknowledge that they reflect the typical timing of development and often describe the events as events that happened to them rather than as lived memories. The shared and relational accounts of their medical experiences may serve as a layer of protection for the children, with parents holding most of their early and past experiences, sharing them only when necessary.

7.11.2 Literature and Implications

Aligning with Jean Piaget's stages of cognitive development, children develop their capacity to understand illness over time (Koopman et al., 2004). Illness often occurred before children had developed the cognitive capacity for reflective awareness, resulting in experiences that often existed outside of their conscious memory (Bick and Nelson, 2016). Many children do not remember the early and frequently acute days of diagnosis, surgeries, and crises. Children do not experience memory gaps as distressing; rather, they acknowledge that they reflect the typical timing of development and often describe the events as events that happened to them rather than as lived memories.

A scoping review of 24 studies on child development in the context of serious illness found that children's age and advancing developmental abilities shape how they conceptualize illness and death (van Driessche et al., 2025). As children grow, this understanding becomes more complex, particularly when supported by past medical experiences and open communication with adults (van Driessche et al., 2025). This review suggests that understanding children's developmental stage can aid more active, developmentally appropriate engagement (van Driessche et al., 2025). In our study, children had improved memory recall of medical procedures, hospital visits and their interactions with the healthcare team. They were able to discuss medical events as lived experiences rather than as events that happened to them. These findings highlight how children move towards agency and ownership within their care.

Even with child development and greater independent recall, children's memories were not formed in isolation; they were co-constructed through ongoing parental scaffolding (Mermelshtine, 2017; Oppenheim, 2006). Storytelling about shared past events highlights its collaborative process. When individuals recount shared personal experiences, they must work together not only to tell the story but also to shape and interpret the events and meanings (Hyden et al., 2011). This aligns with the literature demonstrating that children's understanding of their experiences develops relationally through parent-child reminiscing, in which parents scaffold memories and help structure narratives (Salmon & Reese, 2016). Memory scaffolding from parents often served as a memory trigger, allowing children to recall fragments of their past medical history, adding more detail, and confirming what the parent had shared. At times, children appeared silent and deferred to their parents' accounts, with parents assuming a more prominent role in narrating past experiences. Children often showed no distress when parents narrated for them, or that they were unable to recall the memory. These findings could also have

been linked to the child withholding their experience due to anxiety or stress about the event shared. Although the relational scaffolding between the parent and child is important, further research is needed to find ways to better engage with the child, to better understand their lived experiences.

In contrast to previous literature that highlighted anxiety among adolescents with CHD when recalling past medical experiences (Savaş et al., 2024), this was not a strong finding within this study. Only a few children mentioned feeling nervous when thinking about past medical events, and most said they felt more comfortable now that they were older. Findings suggest that these experiences may be felt differently over time, are not always highly distressing due to positive adaptations, and are context-specific.

Existing literature highlights that co-construction of narratives between caregivers and children plays an important role in how children understand and cope with stressful events; the benefits of these discussions may depend on the context of the experience (Fivush & Sales, 2006; Oppenheim, 2006). This further emphasizes that children's comprehension of their illness is not based solely on independent memories; it is gradually co-constructed through interactions with their parents. Overall, the findings highlight that a child's early absence of memory does not diminish their experience. It underscores the importance of developmental timing and relational contexts in shaping how a child's experiences are understood as they grow.

Chapter 8.0: Contributions to Health Sciences and Northern Contexts

This study provides rich insight into a focus area that has received limited attention in the literature: pediatric cardiac care, particularly in northern settings, including the voice of the child as a person with lived experience. While research on parents of children with CHD is well established, much of the work is centred on urban and/or southern contexts, often overlooking how place and geography influence illness and health care experiences in and of themselves while also impacting other spheres and systems of influence. Similarly, focus on the experiences of the child living with CHD from the child's perspective has largely been omitted from the research record. In this chapter, I pull together the study's findings to outline their key contributions to health sciences and to care in northern contexts. Particular attention will be made to the theoretical, methodological and systemic implications of this work. The following section will first discuss this study's unique theoretical and methodological contributions to the field of research. This will be followed by an examination of the interconnected systems that shape care for families in Northwestern Ontario, the implications for practice and care delivery, future research needs, knowledge translation, and, finally, the strengths and limitations of the study.

8.1 Theoretical and Methodological Contributions

Methodologically, these findings resonate with recent phenomenological work conducted in Norway on parents of children with complex care needs, which also used van Manen's approach (Nygård et al., 2025). The findings reveal lived body, time, space, and relations in the context of parents' experiences of long-term childhood illness (Nygård et al., 2025). Building on this insight, a recent study by Du et al. (2025) in China combined Bronfenbrenner's theory and descriptive phenomenology to explore family caregiving challenges for children with cataracts.

This study advances Health Sciences knowledge, particularly for the north, by explicitly integrating van Manen's lifeworld existentials with Bronfenbrenner's ecological systems in the context of pediatric and family CHD. This theoretical alignment provides a new understanding of how lived experience unfolds across interconnected layers of diverse systems. It also demonstrates how van Manen's phenomenological approach can be applied in the structurally complex, geographically diverse context of northern pediatric and family cardiac care. The use of both van Manen and Bronfenbrenner together offers an in-depth understanding of the complex worlds in which children and families live and the systems they must navigate in order to receive care. Drawing on both frameworks also illustrates that both the theoretical and methodological approaches complement one another. They provide a deeper view of the interconnected systems that produce and sustain families' ongoing liminality, uncertainty, and disruption, rather than placing responsibilities solely on individual family coping.

Families' experiences are continually produced and reshaped through interactions with the health care system, policy, geography, and sociocultural expectations. By situating van Manen's lived time, space, body, and relation within Bronfenbrenner's micro, meso, exo, macro, and chrono systems, these findings illustrates that liminality is not a simple individual psychological state. Liminality is structurally produced, contributing to the ongoing and unsteady rhythms of life for these families in the north. To our knowledge, few studies on parents of children with CHD or other chronic conditions have explicitly amalgamated these two theoretical and methodological traditions. In doing so, this work offers a modest yet distinct contribution, situating parents' lived liminal experiences within Bronfenbrenner's model and opening new areas for intervention within the healthcare system. This goes beyond individual family coping towards more context-responsive care for families in the north. The conceptual model therefore

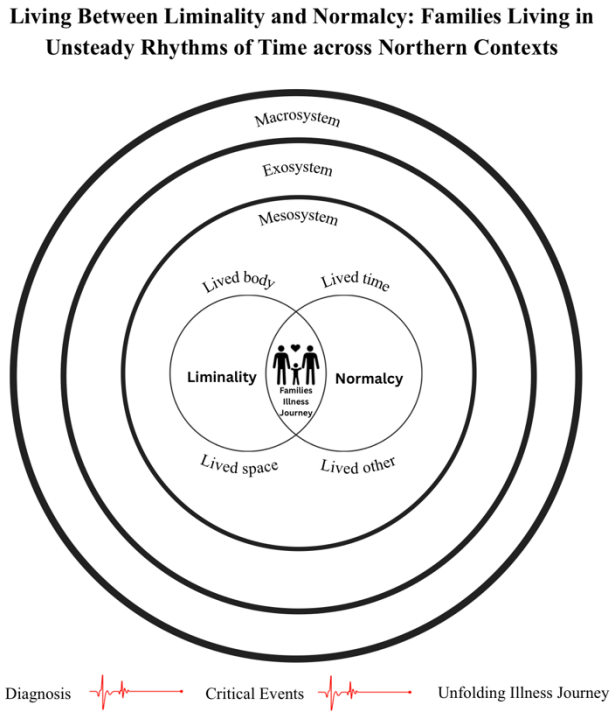
contributes theoretically by illustrating how lifeworld existentials, coupled with ecological systems, provide a clear illustration of how structural geographical and political conditions are recognized as active agents in producing ongoing liminality for families.

This study also contributes conceptually through its articulation of time. Liminality reflects van Manen's component of time, and the Chronosystem within Bronfenbrenner's ecological theory. It transcends and is interwoven within the nested ecological systems. Metaphorically, families are continuously suspended in a prolonged state of liminality, like an unsteady heartbeat. This was characterized by families as continued uncertainty and frequent disruption.

Figure 5 illustrates the conceptual framing of children and parents' experiences of living between liminality and normalcy. While parents remain suspended in this liminal state and in the unsteady rhythms of time, children predominantly live in the present, with a general sense of 'normalcy' in their everyday lives. The coexistence of both liminality and normalcy within the same family unit highlights the complexity of living and caring for a child with CHD. It also underscores the critical need for care approaches that are responsive to both parents' perspectives. The concept of temporal disagreement offers a new way to understand how illnesses unfold differently across family members and along the child's developmental trajectory. This theoretical insight highlights that time is not only disrupted but also perceived differently within the same family unit. Family-centred care needs to recognize and respond to these differing experiences of time and not treat the family as though everyone feels the same way.

Figure 5

Conceptual Model of Children and Families' Experiences



Methodologically, the study reinforces the importance of child-centred and creative approaches in health research. The inclusion of children's voices challenges the prevailing reliance on parent proxy and demonstrates that children are capable of articulating meaningful insights into their care experience. Further underscoring the need to provide a methodological space for children to share their experiences through child-centred interviews and creative methods (Bryan et al., 2019). In clinical practice, this supports the need for dual assessments that attend to both the child's needs and the parent's psychological well-being, recognizing the family is an interconnected system (Speyer et al., 2022).

More broadly, this study's theoretical and methodological approaches contribute to health science research in many diverse ways. Combining van Manen's phenomenology of practice with child-inclusive methods and an ecological approach can yield a multi-level understanding of pediatric and family illness and care in northern contexts. It can also provide a methodological template for future research seeking to understand the lived experiences of both child and family perspectives and their implications within broader systems and diverse geographical landscapes.

8.2 Interconnected Systems Shaping Northern Care

Findings from the study demonstrated that the families' experiences must be understood within broader intersecting systems that shape care in the north. These include geography, policy, healthcare distribution, culture and gender roles, all of which interact in complex and often fragmented ways.

8.2.1 Geography

Geography plays a central role in shaping healthcare trajectories. Families are required to travel long distances to access cardiac care, often resulting in prolonged separation, financial strain, and disruptions to family life. These experiences extend beyond logistical challenges and fundamentally alter parents' sense of place, identity, and relationships, reinforcing a sustained state of liminality. While travel for care has been documented in other illness contexts, e.g., cancer care; its specific impact on families of children with CHD in the context of geography has remained absent and underexplored (Auld et al., 2023; Fluchel et al., 2014)

8.2.2 Policy and Legislation

Policy and legislation further compounded these challenges. Families in the study describe significant financial burdens related to travel for care and hidden costs associated with this. This included issues such as delayed reimbursement and limited coverage. Current policies,

largely designed for southern populations, failed to account for the realities of northern living. For example, funding structures that support only one caregiver to travel with a child disrupt the family system, intensifying emotional distress and forcing family separation. The findings highlight critical gaps in policy and call for reforms that align with equity and the principles of the Canada Health Act (Government of Canada, 2023). These policy reforms need to be explicitly responsive to key social and ecological determinants of health (World Health Organization, 2025).

8.2.3 Health Care Distribution

Disparities in healthcare distribution also emerged as a significant concern. Despite national commitments to equitable access (Government of Canada, 2023), families in northern regions experience fragmented care and limited access to specialized services. Infrequent visiting clinics and weather-related challenges cause major gaps in communication between tertiary and local providers, contributing to a system that is difficult to navigate.

8.2.4 Culture and Gender Roles

Cultural and gender dynamics further shaped caregiving experiences (Mark et al., 2025; Werner, 2023). Consistent with broader societal patterns, mothers often assume primary caregiving roles frequently at the expense of their employment and financial stability (Cruz et al., 2022; Kankaya et al., 2025; Sood et al., 2018). Canada has established gender equity legislation, including the Pay Equity Act (Government of Canada, 2023b), Employment Equity Act (Government of Canada, 2022) as well as employment insurance caregiving benefits such as the Family Caregiver Benefit for children(Government of Canada, 2026c). Despite these measures, families in this study described supports as difficult to access and do not reflect the true costs and needs of families caring for a child with chronic disease in rural, remote and northern areas. As

such, these acts do not appear to translate to equitable support within the context of pediatric chronic illness. Fathers are less likely to access or be supported in taking caregiving leave, which again reinforces gender divisions, amplifying the weight of caregiving onto mothers (Yang et al., 2022).

8.3 Implications for Practice and Care Delivery

These findings have several implications for healthcare practice in northern settings. Health care providers in southern or urban centers not only need competence in the care they provide but also should have contextual knowledge of the geographical, cultural, and other limitations of the children and families they serve in the north. This should include a basic understanding of the health care systems and policies currently in place, which significantly impact the family's quality of life.

Families in this study spoke to the challenges around continuity of care. Particularly, regarding their relationships with infrequent cardiac clinics and the lack of understanding from health care teams when being discharged home from tertiary centers. There is a need to move towards more integrated models of care that prioritize continuity, shared communication across teams, and discharge processes that are tailored to the northern context. Changes must be made with consideration for the unique lived experiences of children and families residing in these regions. The results of this study provide detailed accounts of families' experiences and desires for change.

Parents within this study took on additional roles as health care coordinators and advocates due to the fragmented care across systems. The study highlights the gaps between northern and southern services. These factors also highlighted the additional strain and responsibility placed on parents. The shift of responsibility from the system to parents to

navigate their children's care across a vast geographical landscape raises significant concerns about equity and the need for more coordinated, supportive systems of care.

Children in this study expressed a clear desire to become more engaged and active participants in their cardiac care. Yet, communication was often directed at their parents, and the language was not developmentally appropriate. This suggests a need for more inclusive, developmentally appropriate, and child-centred approaches to care to encourage engagement among this group. In northern contexts where interactions with health care providers can be infrequent or constrained by system factors and distance, moments of communication become increasingly more important. Ensuring children are meaningfully included and encouraged to become involved in their own care through appropriate health teaching may, over time, support greater understanding, confidence, and a sense of agency.

Mental health support for families remains an urgent priority. Parents described ongoing psychological distress that often went unaddressed due to the sustained nature of their experiences. Routine mental health check-ins integrated across the child's cardiac trajectory are needed to support both parents and children. The findings from this study align with current literature and highlight an urgent need to screen the whole family for mental health needs (Golfenshtein et al., 2021; Jaschinski et al., 2021; Lisanti et al., 2021; McClung et al., 2018) as well as tailoring interventions to meet the evolving needs of families (Llewelyn-Williams et al., 2022) over the child’s cardiac trajectory.

8.4 Moving Forward towards Enhanced Equitable Care in the North

The findings of the study point to the need for systemic changes that better reflect the lived experiences and realities for northern families. The current model of infrequent, travelling cardiac clinics could be restructured to address the gaps in services, rather than functioning as

isolated points of care. Recently, with the addition of a cardiac clinic, three are now run within the year. Although for many families, this still does not accommodate their needs. Many families are still unable to access these clinics due to weather challenges. Given the geographical challenges families face in the north, considering different modes of delivery, e.g., telehealth services that could be more frequent, would help address their concerns of lack of continuity and access to specialty supports. Additionally, considering a cardiac NP that works locally with the pediatric team and tertiary teams could also address the current gaps in care and address families concerns.

There is an opportunity to strengthen collaboration between visiting specialist teams, the local hospital and families. Families expressed their desire for more structure and built-in supports within the care. This could include developing a family-informed support or navigation model, where families are no longer left to piece together and coordinate their child's care on their own. They would be supported by other individuals or groups who understand their experiences and work alongside the healthcare teams. The local hospital could also take a stronger role by supporting or facilitating a family cardiac care support group for families in the north. Several families spoke to the value of connecting with others who understand what they are going through, not just for emotional support, but for sharing knowledge and navigating the system. More inclusive and family-centred approaches tailored to the unique family needs of the north will not only improve families' access to care but also help organize services in a way that is responsive, coordinated, and manageable within the realities of northern life.

Although there are many challenges for children and families living with CHD in the north, the study also challenges deficit-based assumptions often associated with the northern context. Many families demonstrated resilience and adaptability while living in an uncertain time

and an ongoing state of liminality. Although families in this study live with a lasting impact from their caring journey in the north, they all demonstrated a strong and supportive family unit despite the unimaginable challenges they had to overcome and still endure. These strengths should be recognized and built upon in the design of healthcare services and supports.

8.5 Future Research

Future research is needed to build on the findings of this study and explore the experiences of children and families living with CHD in northern contexts. While this study provides meaningful insight into Northwestern Ontario, northern communities are not homogeneous. Therefore, further work must expand to include diverse geographical regions. This is particularly important within rural, remote, and northern communities, where families are often more marginalized and less connected to healthcare services.

The literature around children and families living with CHD is predominantly quantitative in design, limiting a deeper understanding of their lived experiences. Findings highlight the critical need for further qualitative approaches in research to include not only parents' perceptions but also the child's voice. Importantly, they also underscored the impacts of CHD on the entire family unit, highlighting the need to explore the perspectives and experiences of siblings.

A critical area for subsequent work should explore ways to meaningfully include and engage with children, especially younger participants. Children's voices remain limited throughout the literature. We know from these studies' findings that children want to be active agents in their care and have much to say about their preferences and experiences, not only in healthcare but also in their day-to-day lives. Although this study captured children's lived experiences, future studies are needed to explore various child-centred and developmentally

appropriate methods that support sustained engagement. Flexible, creative, and child-focused methodologies are needed to ensure children's voices are heard and given meaning, enhancing their overall experiences within care.

Longitudinal research is another key area to explore. This study captured the experiences of parents and children at a specific time within their cardiac journey. Findings emphasized how children and families' knowledge and ways of navigating care shifted significantly from earlier acute years to the present and will likely evolve again. Following families over time may capture important understandings into how early parent-child experiences unfold within their environment.

Given the differences between parental and child experiences of liminality and normalcy, future research should examine the family as a whole and how these experiences are understood within the home. This also emphasizes the need for future research to consider broader structural, environmental, social, and political factors that shape families' experiences over time. This should consider travel requirements, financial support, community care, and social support across diverse regions. Developing a deeper understanding of children and families experiencing living with CHD in northern communities can help inform enhanced and responsive approaches to care, underpinned by equitable family-centred principles.

Overall, these findings highlight many gaps in care for both children and families living in northern contexts. Future research should build on this work and advocate for marginalized families living in underserved communities, such as northern, rural, and remote areas. Future studies must continue to advocate for the inclusion of children within research, challenging the dominant narrative that their experiences are secondary and unreliable. This study emphasized

that children are both capable and willing to engage in discussion about their care when approached in developmentally appropriate ways.

8.6 Knowledge Translation

Knowledge translation is an important final step in completing this research project. Findings will be shared with participating children and families, as well as any families with a child who lives with CHD who is interested, healthcare providers and broader key stakeholders within the healthcare and academic setting. Findings will be shared through peer-reviewed publications and conferences. Lunch-and-learns with nurses and physicians at the local hospital will also be held to inform and engage the healthcare team. Presentations on key findings to key stakeholders at the local hospital and to tertiary care Pediatric cardiology teams will be essential for practice reform and, hopefully, lead to positive changes for families within the cardiac program in the north.

8.7 Strengths and Limitations

8.7.1 Strengths

This study has several key strengths. First, it intentionally included children as participants, ensuring their perspectives were central in the findings. Given that children are often underrepresented in research and health care, their inclusion adds important depth and understanding to the literature.

Secondly, the findings add to a limited body of research focused on the northern contexts, particularly within Canada. Considering the findings within the context of the northern setting provides insight and highlights gaps and challenges with access to care and regional systems. Ultimately, it sheds light on these families' experiences and how they may differ from those of other urban-based researchers.

A further strength was the theoretical and methodological frameworks that underpinned this study. Considering both Bronfenbrenner and van Manen throughout the research process allowed for a deeper exploration and understanding of children's and families' experiences, and the root causes behind them.

Finally, the interview guides and research assent scripts were developed using Piaget's Theory of Cognitive Development. Both the interview guides and assent scripts were developed with age-appropriate language and questions underpinned by Piaget's theory to ensure children's cognitive abilities and level were considered. This helped ensure participant engagement and inclusivity within this study.

8.7.2 Limitations

While this study provides in-depth insight into families and children within a specific northern and CHD context, the findings should be understood as contextually situated. They may not be broadly generalizable to other areas. The experiences captured in this study reflect families who were able to access services and participate in English-language interviews. The majority of families also live in Thunder Bay, with only a few living in rural communities surrounding it. As a result, the findings may underrepresent diverse families, those that are more geographically isolated, or those that are less connected within healthcare systems.

Although this study captured children's voices, some interviews were shorter than others, resulting in less depth within their accounts. Unfortunately, the draw-and-tell method was only successful with one participant. Among the ten child participants, although there was equal representation across genders, the majority of ages captured in this study were 7 and above, limiting perspectives from the younger population. This may suggest that an alternative, child-

centred approach is needed when using the proposed draw-and-tell method to engage children and fully capture their perspectives, particularly among younger participants, in research.

As parents self-selected into the study, the findings may be shaped by selection bias, as those with more resources or a stronger desire to share their story may participate (Hiratsuka, 2025). Parents' experiences shared within the study often reflected past interpretations of emotionally intense periods. This may shape how experiences were remembered and interpreted over time. This is also a key factor within the children's shared experiences, as they were influenced by their developmental stage and evolving capacity to understand. Their memories are often also co-constructed with their caregivers and, therefore, could influence their recall and understanding of certain memories. This highlights that the memories shared may represent interpretations that have evolved rather than fixed-in-the-moment accounts of these lived experiences.

Finally, I recognize that I am still developing expertise in qualitative research and child-centred interviewing approaches; therefore, this may have limited the depth of the findings. Despite these limitations, this study offers important insight into the true lived experiences of children and families living with CHD in a northern context. While this study may not capture the full diversity of experiences across northern settings or the depth of children's perspectives, it does provide meaningful and rich insight into how families navigate care and everyday life within this context. These limitations highlight the need for future research that uses diverse, child-centred methodologies to engage a broader range of families to support further and extend this work.

8.8 Conclusion

Overall, this study contributes to Health Sciences and broader research by offering a comprehensive, theoretically grounded understanding of pediatric cardiac care and northern contexts. By integrating child and parent perspectives in situating them within the broader ecological systems, it underscores how geography, time, and systemic structures shape families' experiences. These insights provide a foundation for enhanced family-centred approaches that are more equitable and responsive to the care for families in northern regions.

References

Aalhus, M., Oke, B., & Fumerton, R. (2018). *The social determinants of health impacts of resource extraction and development in rural and northern communities: A summary of impacts and promising practices for assessment and monitoring.* Northern Health and the Provincial Health Services Authority. impacts-promising-practices-assessment-monitoring.pdf (northernhealth.ca)

Abda, A., Bolduc, M.-E., Tsimicalis, A., Rennick, J., Vatcher, D., & Brossard-Racine, M. (2019). Psychosocial outcomes of children and adolescents with severe congenital heart defect: a systematic review and meta-analysis. *Journal of Pediatric Psychology*, *44*(4), 463–477. https://doi.org/10.1093/jpepsy/jsy085

Abell, B., Donovan, T., Eagleson, K. J., Justo, R., Auld, B., Riley, S., & McPhail, S. M. (2025). Family and health profession perspectives of the CHD LIFE cardiac developmental long-term care pathway: a qualitative evaluation. *Paediatric Research*. https://doi.org/10.1038/s41390-025-04380-8

Agrawal, S. K., & Zoe, C. (2024). Housing and homelessness in Indigenous communities of Canada's north. *Housing Policy Debate, 34*(1), 39–69. https://doi.org/10.1080/10511482.2021.1881986

Alase, A. (2017). The interpretative phenomenological analysis (IPA): a guide to a good qualitative research approach. *International Journal of Education and Literacy Studies, 5*(2), 9–. https://doi.org/10.7575/aiac.ijels.v.5n.2p.9

Allam, L. E., Nabih, M. A.-E., & El-Missiry, M. A. (2018). The psychological impact of permanent cardiac pacemakers on pediatric patients and their parents: A case- control study. *Indian Heart Journal, 70*(6), 872–878. https://doi.org/10.1016/j.ihj.2018.02.007

Almesned, S., Al-Akhfash, A., & Al Mesned, A. (2013). Social impact on families of children with complex congenital heart disease. *ANNALS OF SAUDI MEDICINE*, *33*(2), 140–143. https://doi.org/10.5144/0256-4947.2013.140

Almomani, J., N. (2020). Congenital heart diseases: a phenomenological study of parents' lived experience in Jordan. *American Research Journal of Nursing, 6*(1), 1-9.

Amram, O., Schuurman, N., Pike, I., Friger, M., & Yanchar, N. (2016). Assessing access to paediatric trauma centres in Canada, and the impact of the golden hour on length of stay at the hospital: an observational study. *BMJ Open, 6*(1), e010274–e010274. https://doi.org/10.1136/bmjopen-2015-010274

Angell, C., Alexander, J., & Hunt, J. A. (2015). 'Draw, write and tell': A literature review and methodological development on the 'draw and write' research method. *Journal of Early Childhood Research : ECR, 13*(1), 17–28. https://doi.org/10.1177/1476718X14538592

Anish, N., Minnabarriet, H., Hawe, N., Martini S., & Jaworsky, D. (2025). Navigating the odyssey: the challenges of medical travel for people living in rural and remote communities in Canada a narrative review. *Canadian Journal of General Internal Medicine, 20*(3), 162-185. https://utppublishing.com/doi/full/10.3138/cjgim.2025.0003

Anishnawbe Mushkiki Community Health and Wellness. (2020). Our health counts Thunder Bay an inclusive community-driven health survey for Indigenous Peoples in Thunder Bay. http://www.welllivinghouse.com/wp-content/uploads/2020/11/Final_OHC-TB-Factsheet-Demographics.pdf

Animasahun, A., Kehinde, O., Falase, O., Odusanya, O., & Njokanma, F. (2015). Caregivers of Children with Congenital Heart Disease: Does Socioeconomic Class Have Any Effect on

Their Perceptions? *CONGENITAL HEART DISEASE*, *10*(3), 248–253. https://doi.org/10.1111/chd.12210

Azhar, A., AlShammasi, Z., & Higgi, R. (2016). The impact of congenital heart diseases on the quality of life of patients and their families in Saudi Arabia. *SAUDI MEDICAL JOURNAL*, *37*(4), 392–402. https://doi.org/10.15537/smj.2016.4.13626

Auld, B. C., Abell, B., Venugopal, P. S., & McPhail, S. (2023). Geographical challenges and inequity of healthcare access for high-risk paediatric heart disease. *International journal for equity in health*, *22*(1), 229. https://doi.org/10.1186/s12939-023-02040-z

Belza, C., Cohen, E., Orkin, J., Fayed, N., Major, N., Quartarone, S., & Moretti, M. (2024). Out-of-pocket expenses reported by families of children with medical complexity. *Paediatrics & Child Health, 29*(4), 216–223. https://doi.org/10.1093/pch/pxad040

Bell, J., & Condren, M. (2016). Communication strategies for empowering and protecting children. *The Journal of Pediatric Pharmacology and Therapeutics, 21*(2), 176–184. https://doi.org/10.5863/1551-6776-21.2.176

Bennett, E. V., Voss, C., Faulkner, G., & Harris, K. C. (2021). From “it makes me feel free” to “they won’t let me play”: the body and physical activity-related perceptions and experiences of children with congenital heart disease and their parents. *Qualitative Research in Sport, Exercise and Health, 13*(2), 325–341. https://doi.org/10.1080/2159676X.2019.1710858

Besley, B., Davies, S. J., & Donnelly, J. (2025). Effects of hospital treatment for congenital heart defects on mother-infant bonding, maternal stress, and parenting. *Journal of PaediatricNursing, 80*, 83–90. https://doi.org/10.1016/j.pedn.2024.11.012

Biber, S., Andonian, C., Beckmann, J., Ewert, P., Freilinger, S., Nagdyman, N., Kaemmerer, H., Oberhoffer, R., Pieper, L., & Neidenbach, R. (2019). Current research status on the

psychological situation of parents of children with congenital heart disease. *CARDIOVASCULAR DIAGNOSIS AND THERAPY*, *9*, S369–S376. https://doi.org/10.21037/cdt.2019.07.07

Bsesa, S. S., Srour, S., & Dashash, M. (2023). Oral health-related quality of life and oral manifestations of Syrian children with congenital heart disease: a case-control study. *BMC Oral Health, 23*(1), Article 316. https://doi.org/10.1186/s12903-023-03017-8

Bichard, E., McKeever, S., Bench, S., & Wray, J. (2022). Experiences of siblings of children with congenital heart disease during Coronavirus disease 2019; A qualitative interview study. *Journal of Paediatric Nursing*, *63*, 96–101. https://doi.org/10.1016/j.pedn.2021.12.019

Bick, J., & Nelson, C. A. (2016). Early adverse experiences and the developing brain. *Neuropsychopharmacology (New York, N.Y.), 41*(1), 177–196. https://doi.org/10.1038/npp.2015.252

Billotte, M., Deken, V., Joriot, S., Vaksmann, G., Richard, A., Bouzguenda, I., Godart, F., Baudelet, J.-B., Rakza, T., Nguyen The Tich, S., & Guillaume, M.-P. (2021). Screening for neurodevelopmental disorders in children with congenital heart disease. *European Journal of Pediatrics*, *180*(4), 1157–1167. https://doi.org/10.1007/s00431-020-03850-x

Blais, A., Lougheed, J., Yaraskavitch, J., Adamo, K., & Longmuir, P. (2020). “I really like playing games together”: Understanding what influences children with congenital heart disease to participate in physical activity. *CHILD CARE HEALTH AND DEVELOPMENT*, *46*(4), 457–467. https://doi.org/10.1111/cch.12754

Bourgeault, I. L., Labonte, R., Packer, C., & Runnels, V. (2017). *Population Health in Canada: Issues, research, and action*. Canadian Scholars.

Bowen, S. and Graham, I.D., 2013. Integrated Knowledge Translation. In: S. Straus, I. Graham, J. Tetroe (Eds.). *Knowledge Translation in Health Care: Moving from Evidence to Practice*, pp.14-23.

Bratt, E. L., Burström, Å., Hanseus, K., Rydberg, A., & Berghammer, M. (2018). Do not forget the parents—Parents' concerns during transition to adult care for adolescents with congenital heart disease. *Child : Care, Health & Development, 44*(2), 278–284. https://doi.org/10.1111/cch.12529

Braveman, P. A., Cubbin, C., Egerter, S., Chideya, S., Marchi, K. S., Metzler, M., & Posner, S. (2005). Socioeconomic Status in Health Research: One Size Does Not Fit All. *JAMA : the Journal of the American Medical Association, 294*(22), 2879–2888. https://doi.org/10.1001/jama.294.22.2879

Bronfenbrenner, U. (1977). Toward an experimental ecology of human development. *The American Psychologist, 32*(7), 513–531. https://doi.org/10.1037/0003-066X.32.7.513

Bronfenbrenner, U. (1979). *The ecology of human development: experiments by nature and design*. Harvard University Press.

Bronfenbrenner, U. (2001). The bioecological theory of human development. In U. Bronfenbrenner (Ed.), *Making human beings human bioecological perspectives on human development* (pp 3-15). SAGE. ISBN 0-7619-2712-3 (pbk.).

Bronfenbrenner, U., & Ceci, S. J. (1994). Nature-nurture reconceptualized in developmental perspective: A bioecological model. *Psychological Review, 101*(4), 568–586. https://doi.org/10.1037/0033-295X.101.4.568

Bronfenbrenner, U., & Morris, P. A. (2006). The Bioecological Model of Human Development. In R. M. Lerner & W. Damon (Eds.), *Handbook of child psychology: Theoretical models of human development* (pp. 793–828). John Wiley & Sons, Inc

Bruce, A., Sheilds, L., Molzahn, A., Beuthin, R., Schick-Makaroff, K., & Shermak, S. (2014a). Stories of liminality: living with life threatening illness. *Journal of Holistic nursing, 32*(10), 35-43. https://doi.org/10.1177/0898010113498823

Bruce, E., Lilja, C., & Sundin, K. (2014b). Mothers' lived experiences of support when living with young children with congenital heart defects. *Journal for Specialists in Paediatric Nursing*, *19*(1), 54–67. https://doi.org/10.1111/jspn.12049

Bryan, G., Bluebond-Langner, M., Kelly, D., Kumpunen, S., Oulton, K., & Gibson, F. (2019). Studying children's experiences in interactions with clinicians: identifying methods fit for purpose. *Qualitative Health Research, 29*(3), 393–403. https://doi.org/10.1177/1049732318801358

Bruce, E., Lindh, V., & Sundin, K. (2016). Support for Fathers of Children With Heart Defects. *Clinical Nursing Research*, *25*(3), 254–272. https://doi.org/10.1177/1054773815586351

Bsesa, S. S., Srour, S., & Dashash, M. (2023). Oral health-related quality of life and oral manifestations of Syrian children with congenital heart disease: a case-control study. *BMC Oral Health, 23*(1), Article 316. https://doi.org/10.1186/s12903-023-03017-8

Bucholz, E. M., Sleeper, L. A., & Newburger, J. W. (2018). Neighborhood socioeconomic status and uutcomes following the norwood procedure: an analysis of the Paediatric heart network single ventricle reconstruction trial public data set. *Journal of the American Heart Association, 7*(3). https://doi.org/10.1161/JAHA.117.007065

Buck-McFadyen, E. (2022). Rural homelessness: how the structural and social context of small-town living influences the experience of homelessness. *Canadian Journal of Public Health, 113*(3), 407–416. https://doi.org/10.17269/s41997-022-00625-9

Bulbul Oztoprak, M., Bilici, M., Dogac, T., Akin, A., Ture, M., Balik, H., Yilmaz, K., Satıcı, O., & Emir, B. (2024). Assessment of quality of life and psychosocial problems in children with congenital heart disease. *Cardiology in the Young, 34*(11), 2316–2322. https://doi.org/10.1017/S1047951124026155

Campbell, K. A., MacKinnon, K., Dobbins, M., Van Borek, N., & Jack, S. M. (2019). Weathering the rural reality: delivery of the Nurse-Family Partnership home visitation program in rural British Columbia, Canada. *BMC nursing, 18*, 17. https://doi.org/10.1186/s12912-019-0341-3

Canadian Cardiovascular Society. (2023). *Find a center*. https://ccs.ca/find-a-centre/

Canadian Congenital Heart Alliance. (2026). *CHD facts and issues*. https://cchaforlife.org/learn-about-chd/facts-issues/

Canadian Institute for Health Information. (2006). *How healthy are rural Canadians? an assessment of their health status and health determinants*. https://secure.cihi.ca/free_products/rural_canadians_2006_report_e.pdf

Canadian Institute for Health Information. (2021). Rural health service decision guide. https://www.cihi.ca/sites/default/files/document/rural-health-service-decision-guide-manual-en.pdf

Canadian Institute for Health Information. (2026). *What is travel burden and how dies it vary throughout Canada?*. *https://www.cihi.ca/en/what-is-travel-burden-and-how-does-it-vary-throughout-canada*

Caruso, R., Nanni, M. G., Riba, M. B., Sabato, S., & Grassi, L. (2017). The burden of psychosocial morbidity related to cancer: patient and family issues. *International Review of Psychiatry (Abingdon, England), 29*(5), 389–402. https://doi.org/10.1080/09540261.2017.1288090

Capra, M. E., Pederiva, C., Viggiano, C., De Santis, R., Banderali, G., & Biasucci, G. (2021). Nutritional Approach to Prevention and Treatment of Cardiovascular Disease in Childhood. *Nutrients, 13*(7), 2359–. https://doi.org/10.3390/nu13072359

Carter, N., Bryant-Lukosius, D., DiCenso, A., Blythe, J., & Neville, A. J. (2014). The use of triangulation in qualitative research. *Oncology Nursing Forum, 41*(5), 545–547. https://doi.org/10.1188/14.ONF.545-547

Carter, B. S. (2017). Liminality in pediatric palliative care. *American Journal of Hospice & Palliative Medicine, 34*(4), 297–300. https://doi.org/10.1177/1049909116629758

Castleberry, A., & Nolen, A. (2018). Thematic analysis of qualitative research data: Is it as easy as it sounds? *Currents in Pharmacy Teaching and Learning, 10*(6), 807–815. https://doi.org/10.1016/j.cptl.2018.03.019

Cassidy, A. R., Newburger, J. W., & Bellinger, D. C. (2017). Learning and memory in adolescents with critical biventricular congenital heart disease. *Journal of the International Neuropsychological Society, 23*(8), 627–639. https://doi.org/10.1017/S1355617717000443

Catapano, F., Steinwurtzel, R., Parravicini, E., & Wool, C. (2024). A qualitative analysis of parents' experiences while their neonates with congenital heart disease require intensive care. *Frontiers in Pediatrics, 12*,1425320. https://doi.org/10.3389/fped.2024.1425320

Cepuch, G., Kruszecka-Krówka, A., Lalik, A., & Micek, A. (2023). Toxic stress as a potential factor inducing negative emotions in parents of newborns and infants with cyanotic congenital heart disease. *Children (Basel), 10*(12), 1893. https://doi.org/10.3390/children10121893

Cherestal, B., Hudson, Z., & Lopez, K. N. (2022). Applying interventions to address the social determinants of health and reduce health disparities in congenital heart disease patients. *Current Cardiovascular Risk Reports, 16*(12), 241–248. https://doi.org/10.1007/s12170-022-00710-1

Children's Healthcare Canada. (2025). *Prioritizing kids health today to build a stronger Canada tomorrow.* https://www.childrenshealthcarecanada.ca/en/news/posts/prioritizing-kids-health-today-to-build-a-stronger-canada-tomorrow/

Choi, S., Park, J., Shin, H., Heo, J., & Kim, W.-H. (2020). How Do Caregivers of Children with Congenital Heart Disease Navigate the Health Care System in Ethiopia? *Health Services Research*, *55*(S1), 65–65. https://doi.org/10.1111/1475-6773.13418

Chong, L. S. H., Fitzgerald, D. A., Craig, J. C., Manera, K. E., Hanson, C. S., Celermajer, D., Ayer, J., Kasparian, N. A., & Tong, A. (2018). Children's experiences of congenital heart disease: a systematic review of qualitative studies. *European Journal of Pediatrics, 177*(3), 319–336. https://doi.org/10.1007/s00431-017-3081-y

Children's Hospital of Eastern Ontario. (2025). *Complex care family advisory council.* https://www.cheo.on.ca/en/clinics-services-programs/complex-care-family-advisory-council.aspx

Clark, A., & Statham, J. (2005). Listening to young children experts in their own lives. *Adoption & Fostering, 29*(1), 45–56. https://doi.org/10.1177/030857590502900106

Clarke, S. L., Menzies, J. C., Shkurka, E., & Drury, N. E. (2025). Exploring parental perspectives of physiotherapy in children with congenital heart disease: a qualitative study. *BMJ Paediatrics Open, 9*(1), e003705. https://doi.org/10.1136/bmjpo-2025-003705

Clarke, S. L., Milburn, N. C., Menzies, J. C., & Drury, N. E. (2024). The provision and impact of rehabilitation provided by physiotherapists in children and young people with congenital heart disease following cardiac surgery: a scoping review. *Physiotherapy, 122*, 47–56. https://doi.org/10.1016/j.physio.2023.09.001

Coates, K., Holroyd, C., & Leader, J. (2014). Managing the Forgotten North: governance structures and administrative operations of Canada's Provincial Norths. *Northern Review (Whitehorse)*, 38, 6–.

Cole, L., Ridings, L., & Phillips, S. M. (2024). Stress and coping factors affecting health-related quality of life in parents of children with congenital heart disease: an integrative review. *PaediatricCardiology, 45*(3), 457–470. https://doi.org/10.1007/s00246-023-03227-5

College of Nurses Ontario. (2023). *Code of Conduct*. https://www.cno.org/globalassets/docs/prac/49040_code-of-conduct.pdf

Conway, J., Mackie, A. S., Smith, C., Dover, D. C., Kaul, P., & Hornberger, L. K. (2024). Impact of remoteness of residence and socioeconomic status on outcomes among children with heart disease in alberta. *JACC. Advances (Online), 3*(11), Article 101351. https://doi.org/10.1016/j.jacadv.2024.101351

Cousino, M. K., Pasquali, S. K., Romano, J. C., Norris, M. D., Yu, S., Reichle, G., Lowery, R., Viers, S., & Schumacher, K. R. (2021). Impact of the COVID-19 pandemic on CHD care and emotional wellbeing. *Cardiology in the Young, 31*(5), 822–828. https://doi.org/10.1017/S1047951120004758

Creswell, J.W., & Poth, C.N. (2018). *Qualitative inquiry and research design: Choosing among five approaches.* Sage Publishing.

Cruz, A. C., Aranha, G. A., Silva, C. M. C., & Pedreira, M. L. G. (2022). The complexity of having a child with a congenital heart defect in a developing country: A qualitative study of parental needs. *Journal of PaediatricNursing*, *64*, e159–e165. https://doi.org/10.1016/j.pedn.2021.11.026

da Silva, M., Schoen-Ferreira, T., Diogenes, M., & Carvalho, A. (2013). Behaviour problems in adolescents with cardiac disease: An exploratory study in a paediatric cardiology outpatient clinic. *CARDIOLOGY IN THE YOUNG*, *23*(3), 368–376. https://doi.org/10.1017/S1047951112001242

Dahlawi, N., Milnes, L., & Swallow, V. (2020). Behaviour and emotions of children and young people with congenital heart disease: A literature review. *JOURNAL OF CHILD HEALTH CARE*, *24*(2), 317–332. https://doi.org/10.1177/1367493519878550

Dahlawi, N., Milnes, L., & Swallow, V. (2024). Children's behavioural and emotional reactions towards living with congenital heart disease in Saudi Arabia: a grounded theory study. *Health Expectations : An International Journal of Public Participation in Health Care and Health Policy, 27*(2), e13959-n/a. https://doi.org/10.1111/hex.13959

Dalir, Z., Manzari, Z., Kareshki, H., & Heydari, A. (2021). Caregiving strategies in families of children with congenital heart disease: A qualitative study. *IRANIAN JOURNAL OF NURSING AND MIDWIFERY RESEARCH*, *26*(1), 60–67. https://doi.org/10.4103/ijnmr.IJNMR_19_20

Dallaire, F., Battista, M.-C., Greenway, S. C., Harris, K., Jean-St-Michel, E., & Mackie, A. S. (2021). The Canadian Paediatric cardiology research network: a model national data-sharing organization to facilitate the study of Paediatric heart diseases. *CJC Open (Online), 3*(4), 510–515. https://doi.org/10.1016/j.cjco.2020.11.014

Dandy, S., Wittkowski, A., & Murray, C. D. (2024). Parents' experiences of receiving their child's diagnosis of congenital heart disease: A systematic review and meta-synthesis of the qualitative literature. *British Journal of Health Psychology, 29*(2), 351–378. https://doi.org/10.1111/bjhp.12703

Darbyshire, P., MacDougall, C., & Schiller, W. (2005). Multiple methods in qualitative research with children: more insight or just more? *Qualitative Research: QR, 5*(4), 417–436. https://doi.org/10.1177/1468794105056921

Dardas, L. A., Pan, W., Hamdan, A. I., Abu Jabeh, R. A. H., Eid Ashakhanba, A., Sami Abdelhai, O., Naim Abid, M., Ahmad Mohammad, H., & Al-Ammouri, I. (2024). Quality of life in Arab children with congenital heart disease. *PloS One, 19*(1), e0290306. https://doi.org/10.1371/journal.pone.0290306

Davey, B. T., Lee, J. H., Manchester, A., Gunnlaugsson, S., Ohannessian, C. M., Rodrigues, R., & Popp, J. (2023). Maternal reaction and psychological coping after diagnosis of congenital heart disease. *Maternal and Child Health Journal, 27*(4), 671–679. https://doi.org/10.1007/s10995-023-03599-3

David Vainberg, L., Vardi, A., & Jacoby, R. (2019). The experiences of parents of children undergoing surgery for congenital heart defects: a holistic model of care. *Frontiers in Psychology, 10,* 2666. https://doi.org/10.3389/fpsyg.2019.02666

Davidson, A. (2019). *Social determinants of health: A Comparative Approach*.2nd Ed. Oxford University Press

de Morais Almeida, S. L., de Carvalho, L. I. A., Araujo Júnior, E., Byk, J., & da Rocha Amorim, L. A. (2024). The role of spirituality in the well-being of families with children with congenital

heart disease: scoping review. *Translational Pediatrics, 13*(8), 1457–1468. https://doi.org/10.21037/tp-24-134

de Man, M. A. C. P., Segers, E. W., Schappin, R., van der Leeden, K., Wösten-van Asperen, R. M., Breur, H., de Weerth, C., & van den Hoogen, A. (2021). Parental experiences of their infant's hospital admission undergoing cardiac surgery: A systematic review. *Acta paediatrica (Oslo, Norway : 1992)*, *110*(6), 1730–1740. https://doi.org/10.1111/apa.15694

De Stasio, S., Boldrini, F., Ragni, B., Bevilacqua, F., Bucci, S., Giampaolo, R., Messina, V., & Gentile, S. (2019). Sleep Quality, Emotion Regulation and Parenting Stress in Children with Congenital Heart Disease. *MEDITERRANEAN JOURNAL OF CLINICAL PSYCHOLOGY*, *7*(3). https://doi.org/10.6092/2282-1619/2019.7.2250

Delaney, A. E., Fu, M. R., Conway, C., Marshall, A. C., Lindberg, J., Thiagarajan, R. R., & Glazer, S. (2024). Financial stressors for parents of children and emerging adults with congenital heart disease: a qualitative study. *Journal of Pediatric Health Care, 38*(4), 574–585. https://doi.org/10.1016/j.pedhc.2024.04.001

Dellborg, M., Giang, K. W., Eriksson, P., Liden, H., Fedchenko, M., Ahnfelt, A., Rosengren, A., & Mandalenakis, Z. (2023). Adults with congenital heart disease: trends in event-free survival past middle age. *Circulation*, *147*(12), 930–938. https://doi.org/10.1161/CIRCULATIONAHA.122.060834

Desai, P. P., Sutton, L. J., Staley, M. D., & Hannon, D. W. (2014). A qualitative study exploring the psychosocial value of weekend camping experiences for children and adolescents with complex heart defects. *Child: Care, Health and Development, 40*(4), 553–561. https://doi.org/10.1111/cch.12056

Destination Ontario. 2026. *Northwest Ontario*. https://www.destinationontario.com/en-ca/regions/northwest-ontario

Demianczyk, A. C., Bechtel Driscoll, C. F., Karpyn, A., Shillingford, A., Kazak, A. E., & Sood, E. (2022). Coping strategies used by mothers and fathers following diagnosis of congenital heart disease. *Child : Care, Health & Development, 48*(1), 129–138. https://doi.org/10.1111/cch.12913

Dibley, L., Dickerson, S., Duffy, M., & Vandermause, R. (2020). *Doing hermeneutic phenomenological research a practical guide*. SAGE. ISBN 978-1-5264-8573-1.

Donovan, D. J., Theoharakis, M., Rose, A., Epstein, R., Butensky, A. M., Fremed, M. A., Chrisomalis-Dring, S., & Ferris, A. (2023). Parental perceptions of the effect of the COVID-19 pandemic on outpatient services for patients with single ventricle congenital heart disease. *Progress in PaediatricCardiology, 70*, Article 101665. https://doi.org/10.1016/j.ppedcard.2023.101665

Dowling. (2007). From Husserl to van Manen. A review of different phenomenological approaches. *International Journal of Nursing Studies, 44*(1), 131–142. https://doi.org/10.1016/j.ijnurstu.2005.11.026

Driessnack, M. (2006). Draw-and-tell conversations with children about fear. *Qualitative Health Research, 16*(10), 1414–1435. https://doi.org/10.1177/1049732306294127

Drazenovich, G. (2025). Discrimination in Health Care: A Scoping Review of the Ontario Experience. *Health and Human Rights, 27*(1), 27–42.

Du Plessis, V., Beshiri, R., Bollman, R. D., & Clemenson, H. (2001). *Rural and small-town Canada analysis bulletin*. Statistics Canada. https://www150.statcan.gc.ca/n1/en/pub/21-006-x/21-006-x2001003-eng.pdf?st=MUNy9j-A

Du, Q., Li, X., Wang, Z., Chen, S., Zhang, X., Liang, J., Guo, H., Chen, N., Yu, H., Zhu, X., Zhou, X., & Sun, K. (2024). Effects of 6-month customized home-based exercise on motor development, bone strength, and parental stress in children with simple congenital heart disease: a single-blinded randomized clinical trial. *BMC Medicine, 22*(1), Article 27. https://doi.org/10.1186/s12916-023-03242-6

Du, Y., Wang, A., Wang, C., Chen, Y., & Lin, Y. (2025). A qualitative study of the family caregiver burden for caregivers of children with congenital cataracts from a social ecosystem theory perspective. *BMC nursing*, *24*(1), 833. https://doi.org/10.1186/s12912-025-03495-x

Eagleson, K. J., McCombs, D., Gerlich, T. M., Justo, R. N., Kasparian, N. A., & Bora, S. (2023). Systematic review of instruments assessing psychosocial adaptation and outcomes among families of children with congenital heart disease. *Journal of PaediatricPsychology, 48*(6), 537–552. https://doi.org/10.1093/jpepsy/jsad015

Egale Canada. (2021). *Systems of oppression and privilege*. https://egale.ca/wp-content/uploads/2021/11/Systems-of-Oppression-and-Privilege-Definitions.pdf

Elliott, M., Erickson, L., Russell, C. L., Chrisman, M., Gross Toalson, J., & Emerson, A. (2021). Defining a new normal: A qualitative exploration of the parent experience during the single ventricle congenital heart disease interstage period. *Journal of Advanced Nursing*, *77*(5), 2437–2446. https://doi.org/10.1111/jan.14785

Ellis, M. J., & Russell, K. (2019). The potential of telemedicine to improve pediatric concussion care in rural and remote communities in Canada. *Frontiers in Neurology, 10*, 840. https://doi.org/10.3389/fneur.2019.00840

Errasti-Ibarrondo, B., Jordán, J. A., Díez-Del-Corral, M. P., & Arantzamendi, M. (2019). van Manen's phenomenology of practice: How can it contribute to nursing? *Nursing Inquiry, 26*(1), e12259–n/a. https://doi.org/10.1111/nin.12259

Ehrich, J., Pettoello-Mantovani, M., Lenton, S., Damm, L., & Goldhagen, J. (2015). Participation of children and young people in their health care: understanding the potential and limitations. *The Journal of Pediatrics, 167*(3), 783–784. https://doi.org/10.1016/j.jpeds.2015.05.001

Farr, S., Downing, K., Riehle-Colarusso, T., & Abarbanell, G. (2018). Functional limitations and educational needs among children and adolescents with heart disease. *CONGENITAL HEART DISEASE*, *13*(4), 633–639. https://doi.org/10.1111/chd.12621

Falvo, N. (2019). *The use of homeless shelters by Indigenous peoples in Canada.* https://homelesshub.ca/blog/2019/use-homeless-shelters-indigenous-peoples-canada/

Fehr, K. K., Leraas, B. C., & Littles, M. M. D. (2020). Behavioral health needs, barriers, and parent preferences in rural pediatric primary care. *Journal of Pediatric Psychology*, *45*(8), 910–920. https://doi.org/10.1093/jpepsy/jsaa057

Ferdinand, A. S., Paradies, Y., Perry, R., & Kelaher, M. (2014). Aboriginal health promotion through addressing employment discrimination. *Australian Journal of Primary Health, 20*(4), 384–388. https://doi.org/10.1071/PY14035

Fivush, R., & Sales, J. M. (2006). Coping, attachment, and mother-child narratives of stressful events. *MERRILL-PALMER QUARTERLY-JOURNAL OF DEVELOPMENTAL PSYCHOLOGY, 52*(1), 125–150. https://doi.org/10.1353/mpq.2006.0003

Fleming, M., Athanasopoulos, P., Mackay, D. F., & Pell, J. P. (2024). Educational outcomes among children with congenital heart disease compared to peers: a Scotland-wide record-linkage

study of 715,850 schoolchildren. *BMC Pediatrics, 24*(1), Article 405. https://doi.org/10.1186/s12887-024-04848-2

Fleming, V., Gaidys, U., & Robb, Y. (2003). Hermeneutic research in nursing: developing a Gadamerian-based research method. *Nursing Inquiry, 10*(2), 113–120. https://doi.org/10.1046/j.1440-1800.2003.00163.x

Fluchel, M. N., Kirchhoff, A. C., Bodson, J., Sweeney, C., Edwards, S. L., Ding, Q., Stoddard, G. J., & Kinney, A. Y. (2014). Geography and the burden of care in pediatric cancers. *Pediatric Blood & Cancer, 61*(11), 1918–1924. https://doi.org/10.1002/pbc.25170

Franklin, M. K., Karpyn, A., Christofferson, J., McWhorter, L. G., C Demianczyk, A., L Brosig, C., A Jackson, E., Lihn, S., C Zyblewski, S., E Kazak, A., & Sood, E. (2023). Barriers and facilitators to discussing parent mental health within child health care: perspectives of parents raising a child with congenital heart disease. *Journal of Child Health Care, 27*(3), 360–373. https://doi.org/10.1177/13674935211058010

Franklin, M., Karpyn, A., Christofferson, J., McWhorter, L., Demianczyk, A., Brosig, C., Jackson, E., Lihn, S., Zyblewski, S., Kazak, A., & Sood, E. (2021). Barriers and facilitators to discussing parent mental health within child health care: Perspectives of parents raising a child with congenital heart disease. *JOURNAL OF CHILD HEALTH CARE*. https://doi.org/10.1177/13674935211058010

Fregonas, A., & Kugamoorthy, P. (2024). Congenital heart disease in Canada: the need for comprehensive and accessible care. *Open Cardiology Research, 2*(1). https://www.researchgate.net/publication/399059541_Congenital_Heart_Disease_in_Canada_The_Need_for_Comprehensive_and_Accessible_Care

Gaskin, K. L., Barron, D., & Wray, J. (2024). Parents' journeys of mastery and knowledge construction after their infant's first stage of surgery for complex congenital heart disease. *Comprehensive Child and Adolescent Nursing, 47*(1), 68–81. https://doi.org/10.1080/24694193.2023.2293993

Geskey, J. M., & Cyran, S. E. (2012). Managing the Morbidity Associated with Respiratory Viral Infections in Children with Congenital Heart Disease. *International Journal of Pediatrics*, 646780–646788. https://doi.org/10.1155/2012/646780

Giacomini, M. (2010). Theory matters in qualitative health research. In: I. Bourgeault, R. Dingewall, & R. de Vries (Eds.), *The sage handbook of qualitative methods in health research* (pp. 125-156). Sage Publications.

Gibbons, S. W., Ross, A., & Bevans, M. (2014). Liminality as a conceptual frame for understanding the family cregiving rite of passage: an integrative review. *Research in Nursing & Health, 37*(5), 423–436. https://doi.org/10.1002/nur.21622

Gillespie, J. (2023). Health disparities for Canada's remote and northern residents: can COVID-19 help level the field? *Journal of Bioethical Inquiry, 20*(2), 207–213. https://doi.org/10.1007/s11673-023-10245-8

Goodwin, J., Savage, E., & O'Donovan, A. (2023). Using the draw and tell method with adolescents as part of an interpretive descriptive study. *Qualitative Research Journal, 23*(3), 273–286. https://doi.org/10.1108/QRJ-08-2022-0105

Golfenshtein, N., Hanlon, A. L., Lozano, A. J., Srulovici, E., Lisanti, A. J., Cui, N., & Medoff-Cooper, B. (2021). Parental Post-traumatic Stress and Healthcare Use in Infants with Complex Cardiac Defects. *Journal of Pediatrics*, *238*, 241–248. https://doi.org/10.1016/j.jpeds.2021.06.073

Goodley, D. (2013). Dis/entangling critical disability studies. *Disability & Society, 28*(5), 631–644. https://doi.org/10.1080/09687599.2012.717884

Government of Canada. (2019). Rural opportunity, national prosperity an economic development strategy for rural Canada. https://ised-isde.canada.ca/site/rural/sites/default/files/documents/2022-03/rural-strat-eng.pdf

Government of Canada. (2022a). *Tri-council policy statement: Ethical conduct for research involving humans – TCPS 2 (2022)*. Retrieved from https://ethics.gc.ca/eng/documents/tcps2-2022-en.pdf

Goverement of Canad. (2022b). *Overview of policy issues and background employment equity act review*. https://www.canada.ca/en/employment-social-development/corporate/portfolio/labour/programs/employment-equity/reports/act-review-overview-backgrounder-policy-issues.html

Government of Canada. (2023). *Canada health act*. https://laws-lois.justice.gc.ca/eng/acts/c-6/page-1.html

Goverment of Canada. (2023b). *Overview of the pay equity act*. https://www.canada.ca/en/services/jobs/workplace/human-rights/overview-pay-equity-act.html

Government of Canada. (2025). *Insights on Canadian society far from home: high school completion for First Nations people, Métis, and Inuit in remote communities, 2016 to 2021*. https://www150.statcan.gc.ca/n1/pub/75-006-x/2025002/article/00002-eng.htm

Government of Canada. (2026a). *2024-2025 highlight report: urban Indigenous*. https://www.rcaanc-cirnac.gc.ca/eng/1746796120178/1746815978032

Government of Canada. (2026b). *EI Maternity and parental benefits.* https://www.canada.ca/en/services/benefits/ei/ei-maternity-parental.html

Government of Canada. (2026c). *Family and caregiver benefits*. https://www.canada.ca/en/services/benefits/family.html

Grimaldi Capitello, T., Correale, C., Amodeo, G., Balsamo, M., Carlucci, L., & Fiorilli, C. (2025). Childhood heart disease and parental emotional wellbeing: a predictive model to explain the perception of quality of life in children and adolescents. *Health and Quality of Life Outcomes, 23*(1), Article 1. https://doi.org/10.1186/s12955-024-02328-w

Harris, K. W., Brelsford, K. M., Kavanaugh-McHugh, A., & Clayton, E. W. (2020). Uncertainty of prenatally diagnosed congenital heart disease: A qualitative study. *JAMA Network Open, 3*(5), e204082. https://doi.org/10.1001/jamanetworkopen.2020.4082

Health Quality Ontario. (2017). *Health in the north a report on geography and the health of people in Ontario's two northern regions*. https://healthinthenorth.hqontario.ca/

Health Quality Ontario. (2018). *Northern Ontario health equity strategy a plan for achieving health equity in the north, by the north, for the north*. https://www.hqontario.ca/Portals/0/documents/health-quality/health-equity-strategy-report-en.pdf

Health Sciences North. (2026). *Complex care for kids Ontario (CCKO).* https://hsnsudbury.ca/en/Services-and-Specialties/NEO-Kids-Family-and-Womens-Program/Pediatric-Services/Pediatric-ACU/CCKOhttps://hsnsudbury.ca/en/Services-and-Specialties/NEO-Kids-Family-and-Womens-Program/Pediatric-Services/Pediatric-ACU/CCKO

Heinonen, K. (2015). van Manen's method and reduction in a phenomenological hermeneutic study. *Nurse Researcher, 22*(4), 35–41. https://doi.org/10.7748/nr.22.4.35.e1326

Hejl, J. L., Hulgaard, D. R., Rasmussen, A. S. D., Larsen, L. E. N., & Rask, C. U. (2026). Linking heart and mind - lived experiences of parents to children with congenital heart disease and mental health issues. *Clinical Child Psychology and Psychiatry, 31*(1), 232–246. https://doi.org/10.1177/13591045241267129

Hidestrand, P., Svensson, B., Simpson, P., Liuba, P., & Weismann, C. G. (2025). Impact of underweight, overweight, and obesity on health-related quality of life in children with tetralogy of fallot variants. *PaediatricCardiology, 46*(2), 355–361. https://doi.org/10.1007/s00246-024-03416-w

Hietanen, M., Nahlén Bose, C., Stålberg, A., Raghothama, J., & Meijer, S. (2025). A systematic review on children's participation in healthcare from a child's perspective. *SCANDINAVIAN JOURNAL OF CARING SCIENCES, 39*(4), e70157-n/a. https://doi.org/10.1111/scs.70157

Hill, G. D., Block, J. R., Tanem, J. B., & Frommelt, M. A. (2015). Disparities in the prenatal detection of critical congenital heart disease. *Prenatal Diagnosis, 35*(9), 859–863. https://doi.org/10.1002/pd.4622

Hsiao, Y.-H., Chung, H.-T., Wang, J.-K., Mu, P.-F., Chen, S.-W., Shu, Y.-M., & Chen, C.-W. (2024). Subjective experience of parent–child relationship in adolescents with congenital heart disease: a qualitative study. *Journal of PaediatricNursing, 77*, 204–211. https://doi.org/10.1016/j.pedn.2024.03.028

Hiratsuka, T. (2025). The volunteer participation paradox: Ethical tensions between self-selection and targeted sampling. *Research Methods in Applied Linguistics, 4*(2), Article 100206. https://doi.org/10.1016/j.rmal.2025.100206

Huot, S., Ho, H., Ko, A., Lam, S., Tactay, P., MacLachlan, J., & Raanaas, R. (2019). Identifying barriers to healthcare delivery and access in the Circumpolar North: important insights for health professionals. *International Journal of Circumpolar Health, 78*(1), 1571385–1571385. https://doi.org/10.1080/22423982.2019.1571385

Hydén, L.-C. (2011). Narrative collaboration and scaffolding in dementia. *Journal of Aging Studies, 25*(4), 339–347. https://doi.org/10.1016/j.jaging.2011.04.002

IDA. (2026a). *Parental leave for salaried employees in Denmark*. https://ida.dk/en/career-and-legal-advice/children-and-parental-leave/parental-leave-for-salaried-employees

IDA. (2026b). *Rules concerning illness of a child*. https://ida.dk/en/career-and-legal-advice/children-and-parental-leave/parental-leave-for-salaried-employees

Ibrahim, E., & Edgley, A. (2015). Embedding researcher's reflexive accounts within the analysis of a semi-structured qualitative interview. *Qualitative Report, 20*(10), 1671–1681.

Im, Y.-M., Yun, T.-J., & Lee, S. (2018). Health condition and familial factors associated with health-related quality of life in adolescents with congenital heart disease: A cross sectional study. *Health & Quality of Life Outcomes*, *16*, 1-N.PAG. https://doi.org/10.1186/s12955-018-0841-y

Im, Y., Lee, S., Yun, T., & Choi, J. (2017). School-related adjustment in children and adolescents with CHD. *CARDIOLOGY IN THE YOUNG*, *27*(7), 1349–1355. https://doi.org/10.1017/S1047951117000324

Jackson, A. C., Frydenberg, E., Liang, R. P.-T., Higgins, R. O., & Murphy, B. M. (2015). Familial impact and coping with child heart disease: A systematic review. *PaediatricCardiology, 36*(4), 695–712. https://doi.org/10.1007/s00246-015-1121-9

Jackson, A., Higgins, R., Frydenberg, E., Liang, R., & Murphy, B. (2018). Parent's Perspectives on How They Cope With the Impact on Their Family of a Child With Heart Disease. *JOURNAL*

OF PAEDIATRICNURSING-NURSING CARE OF CHILDREN & FAMILIES, *40*, E9–E17. https://doi.org/10.1016/j.pedn.2018.01.020

James, A. (2007). Giving voice to children's voices: practices and problems, pitfalls and potentials. *American Anthropologist, 109*(2), 261–272. https://doi.org/10.1525/aa.2007.109.2.261

Janusz, B., & Walkiewicz, M. (2023). Parental experiences of the liminal period of a child's fatal illness. *Health (London, England : 1997), 27*(4), 439–457. https://doi.org/10.1177/13634593211046850

Jaschinski, C., Knetsch, V., Parzer, P., Meyr, J., Schroeder, B., Fonseca, E., Karck, M., Kaess, M., & Loukanov, T. (2022). Psychosocial Impact of Congenital Heart Diseases on Patients and Their Families: A Parent's Perspective. *World Journal for Paediatric& Congenital Heart Surgery*, *13*(1), 9–15. https://doi.org/10.1177/21501351211044127

Jones, M. B., Cameron, V. K., Lee, S., & McNelis, A. M. (2024). Traumatic stress in parents of children with congenital heart disease: a scoping review. *Cardiology in the Young, 34*(8), 1622–1635. https://doi.org/10.1017/S1047951124025332

Kankaya, E. A., Özer Özlü, N. G., & Müezzinler Evsine, N. (2025). A qualitative study on the experiences of caregivers of children undergoing surgery for congenital heart diseases. *Journal of PaediatricNursing, 80*, 137–146. https://doi.org/10.1016/j.pedn.2024.11.016

Karikoski, E., Junttila, K., Järvinen, M., Sarkola, T., & Blomqvist, M. (2022). Parental perceptions and experiences of an oral health care promotion intervention for children with congenital heart defects. *International Journal of Qualitative Studies on Health and Well-Being*, *17*(1), 2070968. https://doi.org/10.1080/17482631.2022.2070968

Kassam, A. (2021). Mental health and addictions care: A path towards mental health care with northern Indigenous people. In R. Schiff & H. Møller (Eds.), *Health and health care in northern Canada*. (214-230). University of Toronto Press. ISBN 978-1-4875-2179-0

Kauppi, C., Faries, E., Montgomery, P., Mossey, S., & Pallard, H. (2021). Housing and health: housing and health challenges in rural and remote communities. In R. Schiff & H. Møller (Eds.), *Health and health care in northern Canada*. (57-88). University of Toronto Press. ISBN 978-1-4875-2179-0

Kaur, A., Hornberger, L. K., Fruitman, D., Ngwezi, D., & Eckersley, L. G. (2022a). Impact of rural residence and low socioeconomic status on rate and timing of prenatal detection of major congenital heart disease in a jurisdiction of universal health coverage. *Ultrasound in Obstetrics & Gynecology, 60*(3), 359–366. https://doi.org/10.1002/uog.26030

Keenan-Lindsay, L., Sams, C. A., & O'Connor, C. (2022). *Perry's maternal child nursing in Canada* (3rd ed.). Elsevier.

Kerber, K., Kolahdooz, F., Otway, M., Laboucan, M., Jang, S. L., Lawrence, S., Aronyk, S., Quinn, M., Irlbacher-Fox, S., Milligan, C., Broadhead, S., DeLancey, D., Corriveau, A., & Sharma, S. (2019). Opportunities for improving patient experiences among medical travellers from Canada's far north: a mixed-methods study. *BMJ Open, 9*(12), e030885. https://doi.org/10.1136/bmjopen-2019-030885

Khoshhal, S., Al-Harbi, K., Al-Mozainy, I., Al-Ghamdi, S., Aselan, A., Allugmani, M., Salem, S., El-Agamy, D., & Abo-Haded, H. (2019). Assessment of quality of life among parents of children with congenital heart disease using WHOQOL-BREF: a cross-sectional study from Northwest Saudi Arabia. *HEALTH AND QUALITY OF LIFE OUTCOMES*, *17*(1). https://doi.org/10.1186/s12955-019-1249-z

Knecht, C., Hellmers, C., & Metzing, S. (2015). The perspective of siblings of children with chronic illness: a literature review. *Journal of PaediatricNursing, 30*(1), 102–116. https://doi.org/10.1016/j.pedn.2014.10.010

Knowles, R. L., Day, T., Wade, A., Bull, C., Wren, C., & Dezateux, C. (2014). Patient-reported quality of life outcomes for children with serious congenital heart defects. *Archives of Disease in Childhood*, *99*(5), 413–419. https://doi.org/10.1136/archdischild-2013-305130

Knowles, R. L., Tadic, V., Hogan, A., Bull, C., Rahi, J. S., Dezateux, C., & UK Collaborative Study of Congenital Heart Defects (UKCSCHD) (2016). Self-reported health experiences of children living with congenital heart defects: including patient-reported outcomes in a national cohort study. *PloS one*, *11*(8), e0159326. https://doi.org/10.1371/journal.pone.0159326

Koch, T. (1999). An interpretive research process: revisiting phenomenological and hermeneutical approaches. *Nurse Researcher, 6*(3), 20–34. https://doi.org/10.7748/nr1999.04.6.3.20.c6085

Kolt, G., Ferdman, B., Choi, J., Henson, J., Nguyen, V., Farkas, E., Nina, V., Nina, R., CiFuentes, R., Zeman, W., Connett, J., & Marath, A. (2020). Emotional quality-of-life and patient-reported limitation in sports participation in children with uncorrected congenital and acquired heart disease in healthcare-restricted settings in low- and middle-income countries. *CARDIOLOGY IN THE YOUNG*, *30*(2), 188–196. https://doi.org/10.1017/S1047951120000220

Koopman, H. M., Baars, R. M., Chaplin, J., & Zwinderman, K. H. (2004). Illness through the eyes of the child: the development of children's understanding of the causes of illness. *Patient Education and Counseling, 55*(3), 363–370. https://doi.org/10.1016/j.pec.2004.02.020

Koster, J. R., Majani, N. G., Kalezi, Z. E., Hoefnagels, J. W., Letara, N., Nkya, D., Mongela, S., Sharau, G., Kubhoja, S., Mlawi, V., Chillo, P., Slieker, M. G., Grobbee, D. E., & Janabi, M. (2025). The quality of life of children with heart disease in Tanzania: a single center study. *BMC Pediatrics, 25*(1), Article 436. https://doi.org/10.1186/s12887-025-05761-y

Kovesi, T., Mallach, G., Kulka, R., Schreiber, Y., McKay, M., Lawlor, G., Barrowman, N., Tsampalieros, A., Root, A., Kelly, L., Kirlew, M., & Miller, J. D. (2022). Housing conditions and respiratory morbidity in Indigenous children in remote communities in Northwestern Ontario, Canada. *Canadian Medical Association Journal (CMAJ), 194*(3), E80–E88. https://doi.org/10.1503/cmaj.202465

Krishnan, A., Jacobs, M. B., Morris, S. A., Peyvandi, S., Bhat, A. H., Chelliah, A., Chiu, J. S., Cuneo, B. F., Freire, G., Hornberger, L. K., Howley, L., Husain, N., Ikemba, C., Kavanaugh-McHugh, A., Kutty, S., Lee, C., Lopez, K. N., McBrien, A., Michelfelder, E. C., Pinto, N. M., … Fetal Heart Society (2021). Impact of Socioeconomic Status, Race and Ethnicity, and Geography on Prenatal Detection of Hypoplastic Left Heart Syndrome and Transposition of the Great Arteries. *Circulation*, *143*(21), 2049–2060. https://doi.org/10.1161/CIRCULATIONAHA.120.053062

Kruszecka-Krówka, A., Cepuch, G., & Micek, A. (2024). Stress coping strategies in parents of newborns and infants with congenital cyanotic heart disease with regard to stress levels and negative emotions. *Children (Basel), 11*(5), 508. https://doi.org/10.3390/children11050508

Kulig, J. C., & Williams, A. M. (Eds.). (2012). *Health in Rural Canada*. UBC Press.

Lavenant, P., Cacioppo, M., Ansquer, H., Guillaumont, S., Houx, L., Brochard, S., Amedro, P., & Pons, C. (2023). Participation in physical activity of adolescents with congenital heart disease. *Child : Care, Health & Development, 49*(2), 311–320. https://doi.org/10.1111/cch.13045

Lee, J., Blais, A., Jackson, J., Patel, B., Lai, L., Goldfield, G., Sananes, R., & Longmuir, P. (2021). Higher Child-Reported Internalizing and Parent-Reported Externalizing Behaviors were Associated with Decreased Quality of Life among PaediatricCardiac Patients Independent of

Diagnosis: A Cross-Sectional Mixed-Methods Assessment. *CONGENITAL HEART DISEASE*, *16*(3), 255–267. https://doi.org/10.32604/CHD.2021.014628

Leo, D. G., Lane, D. A., Riley, M., Lotto, A. A., & Lotto, R. R. (2023). Facilitators and barriers of physical activity participation in children with a single ventricle physiology: a mixed-methods study. *Cardiology in the Young, 33*(10), 1992–1999. https://doi.org/10.1017/S1047951122003754

Lepage, C., Bayard, J., Gaudet, I., Paquette, N., Simard, M., & Gallagher, A. (2025a). Parenting stress in infancy was associated with neurodevelopment in 24-month-old children with congenital heart disease. *Acta Paediatrica, 114*(1), 164–172. https://doi.org/10.1111/apa.17421

Lepage, C., Tremblay, L., Bernier, A., Simard, M.-N., Matte-Gagné, C., & Gallagher, A. (2025b). Trajectories of behavioral and emotional problems in preschoolers with congenital heart disease. *Journal of PaediatricPsychology, 50*(9), 897–909. https://doi.org/10.1093/jpepsy/jsaf057

Li, L., & Lee, Y. (2020). Employment adjustment and mental health of employed family caregivers in Canada. *Aging & Mental Health, 24*(12), 2073–2081. https://doi.org/10.1080/13607863.2019.1647136

Licht-Ardila, M., Hurtado-Ortiz, A., Manrique-Hernández, E. F., & Santiago Peña, J. J. (2024). Physical, social, and emotional impact on patients with congenital heart disease undergoing cardiac catheterization. *Anales de Pediatría, 101*(6), 378–387. https://doi.org/10.1016/j.anpede.2024.10.006

Lin, P., Liu, Y., Huang, C., Huang, S., & Chen, C. (2021). Caring perceptions and experiences of fathers of children with congenital heart disease: A systematic review of qualitative evidence.

INTERNATIONAL JOURNAL OF NURSING PRACTICE, *27*(5). https://doi.org/10.1111/ijn.12952

Lin, W.H., Chen, Y.-K., Lin, S.-H., Cao, H., & Chen, Q. (2024). The association between religious belief and postoperative psychological status and quality of life of parents of children with congenital heart disease: a single center experience in southeast China. *Journal of Religion and Health, 63*(3), 2413–2422. https://doi.org/10.1007/s10943-023-01874-9

Lincoln, Y. S., Lynham, S. A., & Guba, E. G. (2018). Paradigmatic controversies, contradictions, and emerging confluences, revisited. In N. K. Denzin & Y. S. Lincoln (Eds.), *The SAGE handbook of qualitative research* (5th ed., pp. 213-263). SAGE Publications.

Lisanti, A. J., Demianczyk, A. C., Vaughan, K., Martino, G. F., Ohrenschall, R. S., Quinn, R., Chittams, J. L., & Medoff-Cooper, B. (2021). Parental role alteration strongly influences depressive symptoms in mothers of preoperative infants with congenital heart disease. *Heart & Lung*, *50*(2), 235–241. https://doi.org/10.1016/j.hrtlng.2020.12.003

Little, M., Jordens, C. F. C., Paul, K., Montgomery, K., & Philipson, B. (2022). Liminality: A major category of the experience of cancer illness. *Journal of Bioethical Inquiry, 19*(1), 37–48. https://doi.org/10.1007/s11673-022-10175-x

Liu, H.-C., Chaou, C.-H., Lo, C.-W., Chung, H.-T., & Hwang, M.-S. (2022). Factors Affecting Psychological and Health-Related Quality-of-Life Status in Children and Adolescents with Congenital Heart Diseases. *Children*, *9*(4), 578. https://doi.org/10.3390/children9040578

Liu, Q., Jiang, M., Li, S., & Yang, Y. (2021). Social support, resilience, and self-esteem protect against common mental health problems in early adolescence: A nonrecursive analysis from a two-year longitudinal study. *Medicine*, *100*(4), e24334. https://doi.org/10.1097/MD.0000000000024334

Liu, S., Yen, W., Chang, Y., & Ku, M. (2021). Impact of educational videos on maternal anxiety caused by children's heart surgery. *NURSING IN CRITICAL CARE*. https://doi.org/10.1111/nicc.12786

Liu, Y., Li, P., Gao, Q., Liu, B., Qi, Y., Guan, W., Zhang, N., & Lu, Y. (2025). Financial toxicity in pediatric cancer: lived experiences and coping strategies of parents. *BMC health services research*, *25*(1), 1594. https://doi.org/10.1186/s12913-025-13760-z

Llewelyn-Williams, J., Oliver, A., Wright, K., Runalls, S., Lahti, D., Bradley, T., Kakadekar, A., Pharis, S., Pockett, C., Erlandson, M., & Tomczak, C. (2022). Health anxiety and associated constructs in school-age children and adolescents with congenital heart disease and their parents: A children's healthy-heart activity monitoring program in Saskatchewan cohort study. *JOURNAL OF CHILD HEALTH CARE*. https://doi.org/10.1177/13674935221075896

LoBiondo-Wood, G., Haber, J., Cameron, C., & Singh, M. D. (Eds.). (2018). *Nursing research in Canada: Methods, critical appraisal, and utilization* (4th ed.). Toronto, ON: Elsevier

Lopez-Barreda, R., Schaigorodsky, L., Rodríguez-Pinto, C., Salas, W., Muñoz, Y., Betanco, B., Angulo, O., Huamán, M., Lejbusiewicz, G., Pedrero, V., Pavlova, M., Groot, W., & Ibla, J. C. (2024). Barriers to healthcare access for children with congenital heart disease in eight Latin American countries. *PaediatricAnesthesia, 34*(9), 893–905. https://doi.org/10.1111/pan.14880

López, R., Frangini, P., Ramírez, M., Valenzuela, P. M., Terrazas, C., Pérez, C. A., Borchert, E., & Trachsel, M. (2016). Well-Being and Agency in Parents of Children With Congenital Heart Disease: A Survey in Chile. *World Journal for Paediatric& Congenital Heart Surgery*, *7*(2), 139–145. https://doi.org/10.1177/2150135115623284

Ludomirsky, A., Bucholz, E., & Newburger, J. (2021). Association of Financial Hardship Because of Medical Bills With Adverse Outcomes Among Families of Children With Congenital Heart Disease. *JAMA CARDIOLOGY*, *6*(6), 713–717. https://doi.org/10.1001/jamacardio.2020.6449

Lumsden, M. R., Smith, D. M., & Wittkowski, A. (2019). Coping in parents of children with congenital heart disease: A systematic review and meta-synthesis. *Journal of Child and Family Studies, 28*(7), 1736–1753. https://doi.org/10.1007/s10826-019-01406-8

Maag, B., Phelps, R. A., & Kiel, E. J. (2021). Do maternal parenting behaviors indirectly link toddler dysregulated fear and child anxiety symptoms?. *Child psychiatry and human development, 52*(2), 225–235. https://doi.org/10.1007/s10578-020-01004-6

Majani, N. G., Koster, J. R., Nkya, D., Kalezi, Z. E., Letara, N., Hoefnagels, J. W., Mongela, S., Kubhoja, S., Sharau, G., Mlawi, V., Chillo, P., Janabi, M., Grobbee, D. E., Slieker, Martijn. G., & Kisenge, P. (2025). Translation and validation of the Swahili Paediatricquality of life family impact module for caregivers of children with congenital heart disease. *Scientific Reports, 15*(1), Article 20935. https://doi.org/10.1038/s41598-025-04838-z

Mamasoula, C., Pennington, L., Adesanya, A. M., & Rankin, J. (2024). A systematic review and meta-analysis of school and cognitive function domains of health-related quality of life measures for children and young adults with congenital heart disease. *Birth Defects Research, 116*(1), e2275-n/a. https://doi.org/10.1002/bdr2.2275

Marcin, J. P., Shaikh, U., & Steinhorn, R. H. (2016). Addressing health disparities in rural communities using telehealth. *Pediatric Research, 79*(1–2), 169–176. https://doi.org/10.1038/pr.2015.192

Marino, L. V., Wagland, R., Culliford, D. J., Bharucha, T., Sodergren, S. C., & Darlington, A.-S. E. (2021). “No Official Help Is Available”—Experience of Parents and Children With

Congenital Heart Disease During COVID-19. *World Journal for Paediatric& Congenital Heart Surgery, 12*(4), 500–507. https://doi.org/10.1177/21501351211007102

Massel, P., Jawanda, S., Sohi, D., McMillian, M. H., & Jaworsky, D. (2023). Health care providers perspectives on medical travel in northwestern British Columbia. *BCMJ, 65*(5), 210-215. https://bcmj.org/articles/health-care-providers-perspectives-medical-travel-northwestern-british-columbia

Marshall, K. H., d'Udekem, Y., Winlaw, D. S., Zannino, D., Celermajer, D. S., Justo, R., Iyengar, A., Weintraub, R., Wheaton, G., Cordina, R., Sholler, G. F., Woolfenden, S. R., & Kasparian, N. A. (2024). Wellbeing in children and adolescents with fontan physiology. The *Journal of Pediatrics, 273*, Article 114156. https://doi.org/10.1016/j.jpeds.2024.114156

Martin, G. M. (2019). Draw(Me) and tell: use of children's drawings as elicitation tools to explore embodiment in the very young. *International Journal of Qualitative Methods, 18*, 160940691881623–. https://doi.org/10.1177/1609406918816230

Martin, M. I., Mauer-Vakil, D., Borkhoff, C. M., Parkin, P. C., & Bayoumi, I. (2024). Connecting families: a qualitative study examining the experiences of parenting young children under financial strain in Ontario, Canada. *BMC Public Health, 24*(1), Article 913. https://doi.org/10.1186/s12889-024-18463-4

Mathu-Muju, K. R., McLeod, J., Walker, M. L., Chartier, M., & Harrison, R. L. (2016). The Children's oral health initiative: an intervention to address the challenges of dental caries in early childhood in Canada's First Nation and Inuit communities. *Canadian Journal of Public Health, 107*(2), 188–193. Canadian Business & Current Affairs Database; Nursing & Allied Health Database. https://doi.org/10.17269/CJPH.107.5299

McClung, N., Glidewell, J., & Farr, S. (2018). Financial burdens and mental health needs in families of children with congenital heart disease. *CONGENITAL HEART DISEASE*, *13*(4), 554–562. https://doi.org/10.1111/chd.12605

Meleis, A. I., Sawyer, L. M., Im, E. O., Hilfinger Messias, D. K., & Schumacher, K. (2000). Experiencing transitions: an emerging middle-range theory. *Advances in Nursing Science, 23*(1), 12–28. https://doi.org/10.1097/00012272-200009000-00006

Mermelshtine, R. (2017). Parent–child learning interactions: A review of the literature on scaffolding. *British Journal of Educational Psychology, 87*(2), 241–254. https://doi.org/10.1111/bjep.12147

Mew, E. J., Ritchie, S. D., VanderBurgh, D., Beardy, J. L., Gordon, J., Fortune, M., Mamakwa, S., & Orkin, A. M. (2017). An environmental scan of emergency response systems and services in remote First Nations communities in Northern Ontario. *International Journal of Circumpolar Health, 76*(1), 1320208–1320210. https://doi.org/10.1080/22423982.2017.1320208

Miao, Q., Dunn, S., Wen, S. W., Lougheed, J., Reszel, J., Lavin Venegas, C., & Walker, M. (2021). Neighbourhood maternal socioeconomic status indicators and risk of congenital heart disease. *BMC Pregnancy and Childbirth, 21*(1), 72–72. https://doi.org/10.1186/s12884-020-03512-8

Miao, Q., Dunn, S., Wen, S. W., Lougheed, J., Yang, P., Davies, M., Venegas, C. L., & Walker, M. (2023). Association between maternal marginalization and infants born with congenital heart disease in Ontario Canada. *BMC Public Health, 23*(1), Article 790. https://doi.org/10.1186/s12889-023-15660-5 Møller, H. (2016). Culturally safe communication and the power of language in Arctic nursing. *Etudes Inuit, 40*(1), 85–104. https://doi.org/10.7202/1040146ar

Miles, M. B., Huberman, A. M., & Saldaña, J. (2020). *Qualitative data analysis : a methods sourcebook* (Fourth edition.). SAGE.

Millen, S. E., Dempster, M., & Casey, F. (2025). Educational experience of children living with congenital heart disease: a systematic scoping review. *Cardiology in the young*, *35*(8), 1549–1557. https://doi.org/10.1017/S1047951125101327

Millen, S. M., Olsen, C. H., Flanagan, R. P., Scott, J. S., & Dobson, C. P. (2023). The effect of geographic origin and destination on congenital heart disease outcomes: a retrospective cohort study. *BMC Cardiovascular Disorders, 23*(1), 99–99. https://doi.org/10.1186/s12872-023-03037-w

Miller, B., Baptist, J., & Johannes, E. (2018). Health needs and challenges of rural adolescents. *Rural and Remote Health, 18*(3), 4325–4325. https://doi.org/10.22605/RRH4325

Milligan, C., Greenland, S., Storr, L., Pascal, A., Irlbacher-Fox, S., & Dobrow, M. J. (2025). Bridging the distance: understanding access to healthcare through stories from Gwich'in medical travellers in Northwest Territories. *International Journal of Circumpolar Health, 84*(1), 2438430. https://doi.org/10.1080/22423982.2024.2438430

Møller, H. (2018). Circumpolar health and well-being. In M. Nuttall., T. R. Christensen., & M. Siegret (Eds.), *The Routledge Handbook of the Polar Regions* (1st ed., pp. 90–106). Routledge. https://doi.org/10.4324/9781315730639-8

Mombach Barreto, T. S., Moraes Sakamoto, V. T., Scremin Magagnin, J., Fernandes Coelho, D., Waterkemper, R., & Travi Canabarro, S. (2016). Experience of parents of children with congenital heart disease: Feelings and obstacles. *Rev Rene*, *17*(1), 120–136. https://doi.org/10.15253/2175-6783.2016000100012

Moola, F. (2020). Passive on the periphery: Exploring the experience of physical activity among children and youth with congenital heart disease using the draw-and-write technique. *ARTS IN PSYCHOTHERAPY*, *69*. https://doi.org/10.1016/j.aip.2020.101662

Moola, F. J., Faulkner, G., White, L., & Kirsh, J. (2015). Kids with special hearts: The experience of children with congenital heart disease at Camp Willowood. *Qualitative Research in Sport, Exercise and Health*, *7*(2), 271. https://www.proquest.com/docview/1647432223/A834398C80034838PQ/180

Moorman, E., Williams, C., Christofferson, J., McWhorter, L. G., Demianczyk, A. C., Kazak, A. E., Karpyn, A., & Sood, E. (2025). Loss and grief in parents of children hospitalized for congenital heart disease. *Hospital pediatrics, 15*(5), 433–441. https://doi.org/10.1542/hpeds.2024-008133

Morse, J. (2012). *Qualitative health research: Creating a new discipline*. Coast Press.

Mussatto, K. A., Trachtenberg, F. L., Wang, K., Uzark, K., Sood, E., Lambert, L., Hamstra, M., Clarke, S., Morrison, T., Otto, M., Picart, A., Rathge, K., Walter, P., Woodard, F., & Pemberton, V. L. (2023). The relationship of family factors to psychosocial outcomes in children with hypoplastic left heart syndrome at 6 years of age. *The Journal of Pediatrics, 255,* 50-57.e2. https://doi.org/10.1016/j.jpeds.2022.10.016

Nakazuru, A., Sato, N., & Nakamura, N. (2017). Stress and coping in Japanese mothers whose infants required congenital heart disease surgery. *INTERNATIONAL JOURNAL OF NURSING PRACTICE*, *23*. https://doi.org/10.1111/ijn.12550

Narvey, M., Wong, K. K., & Fournier, A. (2017). Pulse oximetry screening in newborns to enhance detection of critical congenital heart disease. *Paediatrics & Child Health, 22*(8), 494–498. https://doi.org/10.1093/pch/pxx136

National Collaborating Centre for Aboriginal Health. (2014). *Indigenous experiences with racism and its impacts*. Prince George, BC: Author.

National Collaborating Centre for Aboriginal Health. (2017). *Employment as a social determinant of First Nations, Inuit and Métis health*. Prince George, BC: National Collaborating Centre for Aboriginal Health.

National Collaborating Centre for Determinants of Health. (2022). *Let's talk intersectionality*. NCCDH, St. Francis Xavier University, https://nccdh.ca/wp-content/uploads/2024/10/NCCDH_Lets-Talk-Intersectionality_EN.pdf

National Association of Friendship Centers. (2021). *Urbanization and Indigenous peoples in Canada responses for the questionnaire from the special rapporteur on the rights of Indigenous peoples*. https://nafc.ca/downloads/un-questionnaire-from-the-special-rapporteur-on-the-rights-of-indigenous-peoples-2021.pdf

Nayeri, N. D., Roddehghan, Z., Mahmoodi, F., & Mahmoodi, P. (2021). Being parent of a child with congenital heart disease, what does it mean? A qualitative research. *BMC Psychology*, *9*(1), 33. https://doi.org/10.1186/s40359-021-00539-0

Nematollahi, M., Bagherian, B., Sharifi, Z., Keshavarz, F., & Mehdipour-Rabori, R. (2020). Self-care status in children with congenital heart disease: A mixed-method study. *Journal of Child and Adolescent Psychiatric Nursing, 33*(2), 77–84. https://doi.org/10.1111/jcap.12265

Nembhard, W. N., Bourke, J., Leonard, H., Eckersley, L., Li, J., & Bower, C. (2016). Twenty-five-year survival for aboriginal and caucasian children with congenital heart defects in Western Australia, 1980 to 2010. Birth Defects Research. *A Clinical and Molecular Teratology, 106*(12), 1016–1031. https://doi.org/10.1002/bdra.23572

Nemes, F. D., Bennett, E. V., Harris, K. C., Wall, N., & Voss, C. (2025). Growing up with congenital heart disease: a qualitative research study of parents' and clinicians' experiences and perspectives. *CJC Paediatricand Congenital Heart Disease, 4*(1), 22–33. https://doi.org/10.1016/j.cjcpc.2024.10.006

Nordic Council of Ministers. (2026). *Parental leave in Denmark*. https://pub.norden.org/temanord2025-547/parental-leave-in-denmark.html

North West Local Health Integrated Network. (2015). *Population health profile.* Population_Profile_December-2015 (1).pdf

North West Local Health Integrated Network. (2018). *Building a healthy future together north west LHIN annual report 2017-2018*. file:///Users/aedampie/Downloads/14-2017-18-NWLHIN-AR-EN.pdf

Northern Policy Institute. (2019). *Northern Projections Thunder Bay District: Himan Capital Series*. https://www.northernpolicy.ca/upload/documents/publications/reports-new/thunder-bay-19.12.17.pdf

Northern Policy Institute. (2020). *Northern Ontario's state of mental health and why*. https://www.northernpolicy.ca/northern-ontario-mental-health

Northwestern Health Unit. (2025). *COMPASS:2024-2025 report, Northwestern Health Unit region*. https://www.nwhu.on.ca/reports-and-publications/?tx_attachment_category=2025

Nygård, C., Clancy, A., & Kitzmüller, G. (2025). "I am forever changed": a phenomenological study of the existential experiences of parents of children and young people with complex care needs. *Journal of Advanced Nursing, 81*(5), 2631–2643. https://doi.org/10.1111/jan.16509

O'Donovan, A., & Nixon, E. (2019). "Weathering the storm:" mothers' and fathers' experiences of parenting a preterm infant. *Infant Mental Health Journal, 40*(4), 573–587. https://doi.org/10.1002/imhj.21788

O'Connor, A. M., Cassedy, A., Wray, J., Brown, K. L., Cohen, M., Franklin, R. C. G., Gaynor, J. W., MacGloin, H., Mahony, L., Mussatto, K., Newburger, J. W., Rosenthal, D. N., Teitel, D., Ernst, M. M., Wernovsky, G., & Marino, B. S. (2023). Differences in quality of life in children across the spectrum of congenital heart disease. *The Journal of Pediatrics, 263*, Article 113701. https://doi.org/10.1016/j.jpeds.2023.113701

Oorsouw, R., Klooster, E., Koenders, N., Van Der Wees, P. J., Van Den Boogaard, M., & Oerlemans, A. J. M. (2022). Longing for homelikeness: A hermeneutic phenomenological analysis of patients' lived experiences in recovery from COVID-19-associated intensive care unit acquired weakness. *Journal of Advanced Nursing, 78*(10), 3358–3370. https://doi.org/10.1111/jan.15338

Organization for Economic Co-operation and Development. (2020). *Linking Indigenous Communities with Regional Development in Canada*, OECD Rural Policy Reviews, OECD Publishing, Paris, https://doi.org/10.1787/fa0f60c6-en.

Organization for Economic Co-operation and Development. (2011). OECD extended regional typology the economic performance of remote rural regions. *OECD Regional Development Working Papers*, No. 2011/06, OECD Publishing, Paris, https://doi.org/10.1787/5kg6z83tw7f4-en.

Office of the Auditor General of Ontario. (2023). *Value for money audit: hospitals in northern Ontario: delivery of timely and patient cantered care*.

https://www.auditor.on.ca/en/content/annualreports/arreports/en23/AR_hospitalsnorth_en23.pdf

Office of the Auditor General of Ontario. (2025). *Hospitals in northern Ontario: delivery of timely and patient centred care overall conclusion.* https://www.auditor.on.ca/en/content/annualreports/arreports/en25/1-04FU_northernhospt_en25.pdf

Oliver, A., Wright, K., Kakadekar, A., Pharis, S., Pockett, C., Bradley, T., Tomczak, C., & Erlandson, M. (2020). Health anxiety and associated constructs in children and adolescents with congenital heart disease: A CHAMPS cohort study. *JOURNAL OF HEALTH PSYCHOLOGY*, *25*(10–11), 1355–1365. https://doi.org/10.1177/1359105318755263

Olugbuyi, O., Smith, C., Kaul, P., Dover, D. C., Mackie, A. S., Islam, S., Eckersley, L., & Hornberger, L. K. (2022). Impact of Socioeconomic Status and Residence Distance on Infant Heart Disease Outcomes in Canada. *Journal of the American Heart Association*, *11*(18), 1–13. https://doi.org/10.1161/JAHA.122.026627

Ontario Government. (2022). *Personal Health Information Protection Act*. https://www.ontario.ca/laws/statute/04p03/v42#BK62

Ontario Health. (2026). *Ontario health north west*. https://ontariohealth.ca/about/who-we-are/regions/ontario-health-north-west

Ontario Ministry of Health and Long-Term Care. (2023). *Northern health travel grants (NHTG).* https://www.health.gov.on.ca/en/public/publications/ohip/northern.aspx

Ontario Ministry of Health. (2026). *Northern Health Travel Grant Program.* https://www.ontario.ca/page/northern-health-travel-grant-program

Oppenheim, D. (2006). Child, parent, and parent–child emotion narratives: Implications for developmental psychopathology. *Development and Psychopathology, 18*(3), 771–790. https://doi.org/10.1017/S095457940606038X

Ozdemir Koyu, H., & Tas Arslan, F. (2021). The effect of physical and psychosocial symptoms on caregiver burden of parents of children with cancer. *European Journal of Cancer Care, 30*(6), e13513-n/a. https://doi.org/10.1111/ecc.13513

Parahoo, K. (1997). *Nursing research, principles, process and issues.* Macmillan Press.

Parker, D. M., Stabler, M. E., MacKenzie, T. A., Zimmerman, M. S., Shi, X., Everett, A. D., Bucholz, E. M., & Brown, J. R. (2024). Population-based estimates of the prevalence of children with congenital heart disease and associated comorbidities in the United States. *Circulation: Cardiovascular Quality and Outcomes*, *17*(9). https://doi.org/10.1161/circoutcomes.123.010657

Patel, B., Lai, L., Goldfield, G., Sananes, R., & Longmuir, P. (2017). Psychosocial health and quality of life among children with cardiac diagnoses: Agreement and discrepancies between parent and child reports. *CARDIOLOGY IN THE YOUNG*, *27*(4), 713–721. https://doi.org/10.1017/S1047951116001141

Patton, M. Q. (2015*). Qualitative Research & Evaluation Methods*. SAGE Publications Inc.

Peterson, A., Cochran, E., Tumin, D., & Sarno, L. A. (2022). Association of family characteristics with health status and needs among children with congenital heart disease. *Cardiology in the Young*, *32*(8), 1276–1284. https://doi.org/10.1017/S1047951121004042

Persaud, J. N., Wannamaker, K., Stark, K., Lambert, C., Harrison, C., & Keller, N. (2025). Decolonizing education: advancing Indigenous student success through culturally responsive

practices in Ontario. *AlterNative : An International Journal of Indigenous Peoples, 21*(2), 264–273. https://doi.org/10.1177/11771801251340657

Pfitzer, C., Helm, P. C., Blickle, M. J., Rosenthal, L.-M., Berger, F., Abdul-Khaliq, H., Bauer, U. M. M., & Schmitt, K. R. L. (2019). Educational achievement of children with congenital heart disease: Promising results from a survey by the German National Register of Congenital Heart Defects. *Early Human Development*, *128*, 27–34. https://doi.org/10.1016/j.earlhumdev.2018.11.003

Pickles, D. M., & Keller, K. (2025). The economic burden of complex CHD in the United States. *Cardiology in the Young, 35*(9), 1751–1758. https://doi.org/10.1017/S1047951125109256

Pillay, P., Pefile, N., Cobbing, S., & Gurayah, T. (2020). The quality of life, health needs and knowledge of children living with congenital heart disease in KwaZulu-Natal Province, South Africa. *SOUTH AFRICAN JOURNAL OF CHILD HEALTH*, *14*(1), 20–24.

Pinto, N. M., Lasa, J., Dominguez, T. E., Wernovsky, G., Tabbutt, S., & Cohen, M. S. (2012). Regionalization in Neonatal Congenital Heart Surgery: The Impact of Distance on Outcome After Discharge. *PaediatricCardiology, 33*(2), 229–238. https://doi.org/10.1007/s00246-011-0116-4

Pinto, N. M., LuAnn Minich, L., Yoo, M., Floyd, A., Wilkes, J., VanDerslice, J., Yamauchi, M., & Nelson, R. (2021). Influence of Geographic Access on Surgical Center Readmissions After Index Congenital Heart Surgery. *Journal of Pediatrics*, *234*, 195–195. https://doi.org/10.1016/j.jpeds.2021.03.026

Phillips-Beck, W., Eni, R., Lavoie, J. G., Avery Kinew, K., Kyoon Achan, G., & Katz, A. (2020). Confronting racism within the Canadian healthcare system: systemic exclusion of first nations

from quality and consistent care. *International journal of environmental research and public health*, *17*(22), 8343. https://doi.org/10.3390/ijerph17228343

Ponizovsky-Bergelson, Y., Dayan, Y., Wahle, N., & Roer-Strier, D. (2019). A qualitative interview with young children: what encourages or inhibits young children's participation? *International Journal of Qualitative Methods, 18,* 160940691984051–. https://doi.org/10.1177/1609406919840516

Pridham, K., Harrison, T. M., McKechnie, A. C., & Brown, R. (2018). Motivations and Features of Co-Parenting an Infant With Complex Congenital Heart Disease. *Western Journal of Nursing Research*, *40*(8), 1110–1130. https://doi.org/10.1177/0193945917712693

Public Health Agency of Canada. (2018). *Key health inequalities in Canada a national portrait.* https://www.canada.ca/content/dam/phac-aspc/documents/services/publications/science-research/key-health-inequalities-canada-national-portrait-executive-summary/key_health_inequalities_full_report-eng.pdf

Racher, F., Robinson, S., 2003. Are phenomenology and postpostivism strange bedfellows? *Western Journal of Nursing Research 25* (5), 464–481

Raj, M., Sudhakar, A., Roy, R., Soman, S., Antony, L., Champaneri, B., & Kumar, R. K. (2018). Health-related quality of life in infants and toddlers with congenital heart disease: A cross-sectional survey from South India. *Archives of Disease in Childhood*, *103*(2), 170–175. https://doi.org/10.1136/archdischild-2017-313165

Raphael, D. (2016). *Social determinants of health: Canadian perspectives* (3rd ed.). Canadian Scholars' Press.

Ravitch, S. M., & Carl, N. M. (2016). *Qualitative research bridging the conceptual, theoretical, and methodological*. SAGE publications.

Reading, C., & Wien, F. (2009). *Health inequalities and the social determinants of Aboriginal people's health*. National Collaborating Centre for Aboriginal Health

Reiner, B., Oberhoffer, R., Ewert, P., & Müller, J. (2019). Quality of life in young people with congenital heart disease is better than expected. *Archives of Disease in Childhood, 104*(2), 124–128. https://doi.org/10.1136/archdischild-2017-314211

Rempel, G. R., & Harrison, M. J. (2007). Safeguarding precarious survival: parenting children who have life-threatening heart disease. *Qualitative Health Research, 17*(6), 824–837. https://doi.org/10.1177/1049732307303164

Rempel, G. R., Ravindran, V., Rogers, L. G., & Magill-Evans, J. (2013). Parenting under Pressure: a grounded theory of parenting young children with life-threatening congenital heart disease. *Journal of Advanced Nursing, 69*(3), 619–630. https://doi.org/10.1111/j.1365-2648.2012.06044.x

Rich, S., Graham, M., Taket, A., & Shelley, J. (2013). Navigating the Terrain of Lived Experience: The Value of Lifeworld Existentials for Reflective Analysis. *International Journal of Qualitative Methods, 12*(1), 498–510. https://doi.org/10.1177/160940691301200125

Richard, J., Azar, R., Doucet, S., & Luke, A. (2020). Pediatric patient and family advisory councils: A guide to their development and ongoing implementation. *Journal of patient experience, 7*(6), 1476–1481. https://doi.org/10.1177/2374373520902663

Robinson, M., Coehlo, D. P., & Smith, P. S. (2022). *Family health care Nursing: Theory, practice, and research* (7th ed.). F. A. Davis.

Rockman-Greenberg, C., Avard, D., Hanvey, L., Marcotte, M., & Fitzpatrick, J. (2014). *Genetics and paediatric health: Section 5: Congenital anomalies*. In The Health of Canada's Children and

Youth: A CICH Profile. Retrieved from https://cichprofile.ca/wp-content/uploads/2017/10/2.5-congenital-anomalies-en.pdf

Rollins, J. A. (2005). Tell me about it: drawing as a communication tool for children with cancer. *Journal of PaediatricOncology Nursing, 22*(4), 203–221. https://doi.org/10.1177/1043454205277103

Rosa, E. M., & Tudge, J. (2013). Urie Bronfenbrenner's theory of human development: Its evolution from ecology to bioecology. *Journal of Family Theory & Review, 5*(4), 243–258. https://doi.org/10.1111/jftr.12022

Roubinov, D. S., Luecken, L. J., Curci, S. G., Somers, J. A., & Winstone, L. K. (2021). A prenatal programming perspective on the intergenerational transmission of maternal adverse childhood experiences to offspring health problems. *The American Psychologist, 76*(2), 337–349. https://doi.org/10.1037/amp0000762

Rössler, E., Wicklein, K., Deffner, T., Proquitté, H., & Rosendahl, J. (2026). Acute stress and need for psychological follow-Up care in parents of children treated at the paediatric intensive care unit. *Nursing in Critical Care, 31*(1), e70272-n/a. https://doi.org/10.1111/nicc.70272

Ruban, S., Lloyd, L., Badal, T., Strange, G., Celermajer, D. S., & Bonner, C. (2026). Understanding barriers and facilitators of transition to adult care among adolescents with congenital heart disease (CHD): A qualitative study of adult perspectives. *Patient Education and Counseling, 142*, Article 109364. https://doi.org/10.1016/j.pec.2025.109364

Runeson, I., Enskär, K., Elander, G., & Hermerén, G. (2001). Professionals' perceptions of children's participation in decision making in healthcare. *Journal of Clinical Nursing, 10*(1), 70–78. https://doi.org/10.1046/j.1365-2702.2001.00433.x

Rural Ontario Institute. (2019). *Rural Ontario foresight papers access to quality medical and health services & northern perspectives*. https://www.ruralontarioinstitute.ca/uploads/userfiles/files/Access%20to%20Quality%20Medical%20Services%20and%20Northern%20Perspective_Rural%20Ontario%20Foresight%20Papers.pdf

Saldaña, J. (2021). *The coding manual for qualitative researchers* (4th Ed.). SAGE.

Salmon, K., & Reese, E. (2016). The benefits of reminiscing with young children. *Current Directions in Psychological Science : A Journal of the American Psychological Society, 25*(4), 233–238. https://doi.org/10.1177/0963721416655100

Sanker, S., Guarino, K., & Feit, L. (2022). Self-Perception of Transition Readiness Amongst PaediatricPatients with Childhood Heart Disease. *PAEDIATRICCARDIOLOGY*, *43*(8), 1838–1847. https://doi.org/10.1007/s00246-022-02921-0

Santrock, J.W, Mondloch, C., Mackenzie, A. (2020). *Essentials of Life-span development.* Canadian 1st Ed. Toronto, ON: McGraw-Hill Ryerson.

Sansone, G., Williams, C.C., Crowe, A., Kartusch, M.,Vandermorris, A., Fallon, B., D'Angiulli, A. & Maxie, J. (2024). *Supports and systems to principal researchers: respond to complex needs among children and youth in Ontario.* Toronto, Ontario:Policy Bench, Fraser Mustard Institute of Human Development, University of Toronto. https://socialwork.utoronto.ca/wp-content/uploads/2024/06/Policy-Brief-Complex-Needs-June2024-Final.pdf

Savaş, E. H., Semerci, R., Ay, A., Kızılkaya, M. H., & Morey, A. Ö. (2024). Heart at the center of life: An in-depth examination of the experiences in the life journeys of adolescents diagnosed with congenital heart disease. *Journal of PaediatricNursing, 79*, 107–115. https://doi.org/10.1016/j.pedn.2024.08.027

Scearbo, M. J., & Mayrovitz, H. N. (2025). The lived experiences of family members caring for Paediatricpatients with extremely rare congenital heart conditions. *Cureus*, *17*(12), e99391. https://doi.org/10.7759/cureus.99391

Schamong, A. S., Liebermann-Jordanidis, H., Brockmeier, K., Sticker, E., & Kalbe, E. (2022). Psychosocial well-being and quality of life in siblings of children with congenital heart disease: A systematic review. *Journal of Child Health Care: For Professionals Working with Children in the Hospital and Community*, *26*(2), 319–337. https://doi.org/10.1177/13674935211012933

Schiff, R., and Møller, H. (2021a). Introduction: health and health care in northern Canada. (2021). In R. Schiff & H. Møller (Eds.), *Health and health care in northern Canada*. (57-88). University of Toronto Press. ISBN 978-1-4875-2179-0

Schiff, R., and Møller, H. (2021b). Social and ecological dimensions of health and wellness in the north. (2021). In R. Schiff & H. Møller (Eds.), *Health and health care in northern Canada*. (57-88). University of Toronto Press. ISBN 978-1-4875-2179-0

Schnellmann, A., Balmer, C., Lehmann, P., & Werner, H. (n.d.). Cardiac rhythm devices in Paediatricpatients: Impact on family functioning and parent's health-related quality of life. *JOURNAL OF CHILD HEALTH CARE*. https://doi.org/10.1177/13674935221085388

Sileshi, L., & Tefera, E. (2017). Health-related quality of life of mothers of children with congenital heart disease in a sub-Saharan setting: Cross-sectional comparative study. *BMC Research Notes*, *10*(1), 513. https://doi.org/10.1186/s13104-017-2856-6

Simmons, L., Beck, L., Young, E., Brower, L., & Fanta, M. (2026). Overcoming geographic barriers: enhancing pediatric sub specialty access for rural families. *Hospital pediatric, 16* (3): 263-

269. https://publications.aap.org/hospitalpediatrics/article/16/3/263/206322/Overcoming-Geographic-Barriers-Enhancing-Pediatric?autologincheck=redirected

Simeone, S., Platone, N., Perrone, M., Marras, V., Pucciarelli, G., Benedetti, M., Dell'Angelo, G., Rea, T., Guillari, A., Da Valle, P., Gargiulo, G., Botti, S., Artioli, G., Comentale, G., Ferrigno, S., Palma, G., & Baratta, S. (2018). The lived experience of parents whose children discharged to home after cardiac surgery for congenital heart disease. *Acta Bio-Medica de l'Ateneo Parmense, 89*(Suppl 4), 71–77. https://doi.org/10.23750/abm.v89i4-S.7223

Sneddon-Ghosal, S., Norwich, B., Brown, Z., Poirier, E., & Lei, A. (2024). *Policy paper: rural & northern students*. Toronto: Ontario Undergraduate Student Alliance. https://assets.nationbuilder.com/ousa/pages/2324/attachments/original/1724083325/Rural_and_Northern_Students_2023_document.pdf?1724083325

Skivenes, M., & Strandbu, A. (2006). A child perspective and children's participation. *Children, Youth and Environments, 16*(2), 10–27. https://doi.org/10.1353/cye.2006.0005

Sloan, A., Sloan, A., Bowe, B., & Bowe, B. (2014). Phenomenology and hermeneutic phenomenology: the philosophy, the methodologies, and using hermeneutic phenomenology to investigate lecturers' experiences of curriculum design. *Quality & Quantity, 48*(3), 1291–1303. https://doi.org/10.1007/s11135-013-9835-3

Søndergaard, E., & Reventlow, S. (2019). Drawing as a Facilitating Approach When Conducting Research Among Children. *International Journal of Qualitative Methods, 18*, 160940691882255–. https://doi.org/10.1177/1609406918822558

Sood, E., Karpyn, A., Demianczyk, A., Ryan, J., Delaplane, E., Neely, T., Frazier, A., & Kazak, A. (2018). Mothers and fathers experience stress of congenital heart disease differently:

recommendations for Paediatriccritical care. *PAEDIATRICCRITICAL CARE MEDICINE*, *19*(7), 626–634. https://doi.org/10.1097/PCC.0000000000001528

Spillmann, R., Polentarutti, S., Ehrler, M., Kretschmar, O., Wehrle, F., & Latal, B. (2021). Congenital heart disease in school-aged children: Cognition, education, and participation in leisure activities. *PAEDIATRICRESEARCH*. https://doi.org/10.1038/s41390-021-01853-4

Sprong, M. C. A., Noordstar, J. J., Slieker, M. G., de Vries, L. S., Takken, T., & van Brussel, M. (2023). Physical activity in relation to motor performance, exercise capacity, sports participation, parental perceptions, and overprotection in school aged children with a critical congenital heart defect. *Early Human Development, 186*, Article 105870. https://doi.org/10.1016/j.earlhumdev.2023.105870

Sprong, M. C. A., Zwagerman, I. R., Soeters, L., Slieker, M. G., Takken, T., van den Hoogen, A., & van Brussel, M. (2024). Prioritizing family-centered developmental care: insights from parents of children with critical congenital heart disease: a qualitative study. *European Journal of Pediatrics, 183*(9), 3863–3876. https://doi.org/10.1007/s00431-024-05600-9

Speyer, L. G., Hall, H. A., Hang, Y., Hughes, C., & Murray, A. L. (2022). Within-family relations of mental health problems across childhood and adolescence. *Journal of Child Psychology and Psychiatry, 63*(11), 1288–1296. https://doi.org/10.1111/jcpp.13572

Stagg, A., Giglia, T., Gardner, M., Offit, B., Fuller, K., Natarajan, S., Hehir, D., Szwast, A., Rome, J., Ravishankar, C., Laskin, B., & Preminger, T. (n.d.). Initial Experience with Telemedicine for Interstage Monitoring in Infants with Palliated Congenital Heart Disease. *PAEDIATRICCARDIOLOGY*. https://doi.org/10.1007/s00246-022-02993-y

Statistics Canada. (2020). *Household food security by living arrangement*. https://www150.statcan.gc.ca/t1/tbl1/en/tv.action?pid=1310038501

Statistics Canada. (2021). *Census profile, 2021 census of population*. https://www12.statcan.gc.ca/census-recensement/2021/dp-pd/prof/details/page.cfm?Lang=E&SearchText=Northwest&DGUIDlist=2021S05003595&GENDERlist=1,2,3&STATISTIClist=1&HEADERlist=0

Statistics Canada. (2022a). *Census in brief population growth in Canada's rural areas, 2016 to 2021 census of population, 2021*. https://www12.statcan.gc.ca/census-recensement/2021/as-sa/98-200-x/2021002/98-200-x2021002-eng.pdf

Statistics Canada. (2022b). *Indigenous population continues to grow and is much younger than the non-Indigenous population, although the pace of growth has slowed*. https://www150.statcan.gc.ca/n1/daily-quotidien/220921/dq220921a-eng.htm

Statistics Canada. (2024).*How the census counts Indigenous people in urban areas*. https://www150.statcan.gc.ca/n1/pub/11-627-m/11-627-m2022059-eng.htm#n1-refa

Statistics Canada. (2023b). *Leading causes of deaths, infants*. https://www150.statcan.gc.ca/t1/tbl1/en/tv.action?pid=1310039501

Streubert, H. J., & Carpenter, D. R. (2011). *Qualitative research in nursing advancing the humanistic imperative*. Wolters Kluwer.

Strobel, S., Burcul, I., Dai, J. H., Ma, M., Jamani, S., & Hossain, R. (2021). Characterizing people experiencing homelessness and trends in homelessness using population-level emergency department visit data in Ontario, Canada. *Statistics Canada, 32* (1). https://www.doi.org/10.25318/82-003-x202100100002-eng

Subedi, R., Roshanafshar, S., & Lawson Greenberg, T. (2020). *Developing Meaningful Categories for Distinguishing Levels of Remoteness in Canada.* Statistics Canada. https://www150.statcan.gc.ca/n1/pub/11-633-x/11-633-x2020002-eng.pdf

Tecar, C., Chiperi, L. E., & Muresanu, D. F. (2025). Parental psychological response to prenatal congenital heart defect diagnosis. *Children (Basel, Switzerland)*, *12*(8), 1095. https://doi.org/10.3390/children12081095

Tracy, S. J. (2010). Qualitative Quality: Eight "Big-Tent" Criteria for Excellent Qualitative Research. *Qualitative Inquiry, 16*(10), 837-851.

Thunder Bay Regional Health Sciences Center. (2025). *Ontario expanding access to cardiac care and Thunder Bay*. https://tbrhsc.net/ontario-expanding-access-to-cardiac-care-in-thunder-bay/

Truth and Reconciliation Commission of Canada. (2012). *Truth and reconciliation commission of Canada: calls to action*. https://ehprnh2mwo3.exactdn.com/wp-content/uploads/2021/01/Calls_to_Action_English2.pdf

Tuval-Mashiach, R. (2017). Raising the curtain: the importance of transparency in qualitative research. *Qualitative Psychology (Washington, D.C.), 4*(2), 126–138. https://doi.org/10.1037/qup0000062

Thomas, S., Ryan, N. P., Byrne, L. K., Hendrieckx, C., & White, V. (2023). Unmet supportive care needs of families of children with chronic illness: A systematic review. *Journal of Clinical Nursing, 32*(19–20), 7101–7124. https://doi.org/10.1111/jocn.16806

Thompson, A. L., & Smith, S. L. (2025). The process of adaptation: Parents' journey navigating their child's chronic health condition diagnosis. *Journal of Pediatric Rehabilitation Medicine, 18*(1), 78–86. https://doi.org/10.1177/18758894241292147

Turner, V. W. (1967). Betwixt and between: the liminal period in rites de passage. In *the forest of symbols: Aspects of ndembu ritual* (pp. 93-111). Cornell University Press.

Udine, M. L., Evans, F., Burns, K. M., Pearson, G. D., & Kaltman, J. R. (2021). Geographical variation in infant mortality due to congenital heart disease in the USA: a population-based

cohort study. *Lancet Child Adolescent Health, 5*(7), 483–490. https://doi.org/10.1016/S2352-4642(21)00105-X

Uzark, K., Jones, K., Burwinkle, T. M., & Varni, J. W. (2003). The Pediatric Quality of Life InventoryTM in children with heart disease. Progress in Pediatric Cardiology, 18(2), 141–149. https://doi.org/10.1016/S1058-9813(03)00087-0

Varni, J. W., Seid, M., & Kurtin, P. S. (2001). PedsQLTM 4.0: reliability and validity of the pediatric quality of life inventoryTM version 4.0 generic core scales in healthy and patient populations. *Medical Care, 39*(8), 800–812. https://doi.org/10.1097/00005650-200108000-00006

van Buuren, A. L., Best, L. M., Braschel, M., Udall, B., Sage, A., Kim, M., Sernoskie, A., Seaton, C., McLaughlin, T., & Carwana, M. (2026). Far from home: the impact of geographic distance from a tertiary paediatric hospital in Canada on family stress and financial expenses. *Paediatrics & Child Health*. https://doi.org/10.1093/pch/pxag033

van der Watt et al.,, R., Pheiffer, C., & Brown, S. (2017). The psychosocial themes of children with a congenital heart defect. *Journal of Child & Adolescent Mental Health*, *29*(3), 231–244. https://doi.org/10.2989/17280583.2017.1405815

Van Gennep, A. (1960). *The rites of passage*. University of Chicago Press. https://ia903106.us.archive.org/16/items/theritesofpassage/The%20Rites%20of%20Passage.pdf

van Manen, & van Manen, M. (2021). Doing Phenomenological Research and Writing. *Qualitative Health Research, 31*(6), 1069–1082. https://doi.org/10.1177/10497323211003058

van Manen, M. (2007). *Researching lived experience human science for an action sensitive pedagogy* (2nd ed.). The Althouse Press. ISBN 0-920354-42-4.

van Manen, M. (2016). Phenomenology of practice : meaning-giving methods in phenomenological research and writing. Routledge, Taylor & Francis Group.

van Manen, M. (2017). But Is It Phenomenology?. *Qualitative Health Research, 27*(6), 775–779. https://doi.org/10.1177/1049732317699570

van Driessche, A., La Rondelle, L., Boelen, P. A., Brunetta, J., Kars, M. C., Spuij, M., Nijhof, S. L., & Fahner, J. C. (2025). Characteristics of child development in the context of serious illness: a scoping review. *BMC palliative care*, *24*(1), 133. https://doi.org/10.1186/s12904-025-01751-0

VanderBurgh, D., Savage, D. W., Dubois, S., Binguis, N., Maxwell, S., Bocking, N., Farrell, T., Tien, H., Ritchie, S. D., & Orkin, A. (2020). Epidemiologic features of medical emergencies in remote First Nations in northern Ontario: a cross-sectional descriptive study using air ambulance transport data. *CMAJ open*, *8*(2), E400–E406. https://doi.org/10.9778/cmajo.20190186

Vasilescu, S., Vasilescu, D. I., Dan, A. M., Munteanu, O., Enyedi, M., Slavu, I. M., & Cirstoiu, M. M. (2024). Comprehensive review of the psychosocial impact on parents of newborns with congenital heart disease: a significant problem in low- and middle-income countries. *Curēus (Palo Alto, CA), 16*(9), e68532. https://doi.org/10.7759/cureus.68532

Vestal, E., Newman, S., & Phillips, S. (2024). Barriers and facilitators to accessing pediatric specialty care for rural-dwelling children with complex chronic conditions: An integrative review. *Journal of Pediatric Nursing, 77*, e385–e393. https://doi.org/10.1016/j.pedn.2024.05.001

Venna, A., d'Udekem, Y., & Figueiredo, S. (2025). Understanding the barriers and facilitators that impact physical activity levels in children and adolescents with congenital heart disease

(CHD): a rapid review. *BMC Public Health, 25*(1), Article 1180. https://doi.org/10.1186/s12889-025-22152-1

Vodden, K. and Cunsolo, A. (2021). *Rural and remote communities; chapter 3 in Canada in a changing climate: national issues report*, (ed.) F.J. Warren and N. Lulham; Government of Canada, Ottawa, Ontario

Voss, S., Bauer, J., Jung-Sievers, C., Moore, G., Rehfuess, E., Wagner, L. C., & Coenen, M. (2024). "A place where I have lost and made friends": A photovoice study on adolescents' perspectives on health in a new residential development area in Munich, Germany. *Health & Place*, 90, Article 103384. https://doi.org/10.1016/j.healthplace.2024.103384

Walker, D. K. (2021). Parenting and social determinants of health. *Archives of Psychiatric Nursing, 35*(1), 134–136. https://doi.org/10.1016/j.apnu.2020.10.016

Waegemakers Schiff, J., Schiff, R., & Turner, A. (2016). Rural Homelessness in Western Canada: Lessons Learned from Diverse Communities. *Social Inclusion, 4*(4), 73–85. https://doi.org/10.17645/si.v4i4.633

Wald, B., & Johnson, P. (2024). *First Nations health data landscape in Ontario*. Chiefs of Ontario. https://chiefs-of-ontario.org/wp-content/uploads/2024/05/2024_08_16_RP_Data_Landscape_Paper_BW_PJ_final_Ack.pdf

Werner K. M. (2023).The gender gap in caring for children with medical complexity. *Journal of perinatology : official journal of the California Perinatal Association*, *43*(7), 835–836. https://doi.org/10.1038/s41372-023-01652-1

Wangmo, T., De Clercq, E., Ruhe, K. M., Beck-Popovic, M., Rischewski, J., Angst, R., Ansari, M., & Elger, B. S. (2017). Better to know than to imagine: Including children in their health care. *AJOB Empirical Bioethics, 8*(1), 11–20. https://doi.org/10.1080/23294515.2016.1207724

Watkins, S., Isichei, O., Gentles, T., Brown, R., Percival, T., Sadler, L., Gorinski, R., Crengle, S., Cloete, E., de Laat, M., Bloomfield, F., & Ward, K. (2022). What is known about critical congenital heart Disease diagnosis and management experiences from the perspectives of family and healthcare providers? A Systematic Integrative Literature Review. *PAEDIATRICCARDIOLOGY*. https://doi.org/10.1007/s00246-022-03006-8

Wei, H., Roscigno, C. I., Hanson, C. C., & Swanson, K. M. (2015). Families of children with congenital heart disease: A literature review. *Heart & Lung, 44*(6), 494–511. https://doi.org/10.1016/j.hrtlng.2015.08.005

Wei, H., Roscigno, C. I., Swanson, K. M., Black, B. P., Hudson-Barr, D., & Hanson, C. C. (2016). Parents' experiences of having a child undergoing congenital heart surgery: An emotional rollercoaster from shocking to blessing. *Heart & Lung, 45*(2), 154–160. https://doi.org/10.1016/j.hrtlng.2015.12.007

White, L., Moola, F., Kirsh, J., & Faulkner, G. (2016). A Therapeutic Recreation Camp for Children with Congenital Heart Disease: Examining Impact on the Psychosocial Well-Being of Parents. *JOURNAL OF CHILD AND FAMILY STUDIES*, *25*(10), 3034–3043. https://doi.org/10.1007/s10826-016-0474-x

Wiersman, E., & Dupuis, S. L. (2010). Becoming institutional bodies: Socialization into a long-term care home. *Journal of Aging Studies, 24*(4), 278–291. https://doi.org/10.1016/j.jaging.2010.08.003

Wilson, C. R., Rourke, J., Oandasan, I. F., Bosco, C., On behalf of the Rural Road Map Implementation Committee, & Au nom du Comité sur la mise en œuvre du Plan d'action sur la médecine rurale (2020). Progress made on access to rural health care in Canada [Progrès

réalisés dans l'accès aux soins de santé ruraux au Canada]. *Canadian Family Physician*, *66*(1), 31–36.

World Heart Federation. (2026). Most children have 0 access to life saving cardiovascular care says new report from world heart federation. https://world-heart-federation.org/news/most-children-have-zero-access-to-life-saving-cardiovascular-care-says-new-report-from-world-heart-federation/

World Health Organization. (2025). *World report on social determinants of health equity*. https://www.who.int/publications/i/item/9789240107588

World Health Organization. (2008). *Closing the gap in a generation health equity through action on the social determinants of health*. https://iris.who.int/bitstream/handle/10665/69832/WHO_IER_CSDH_08.1_eng.pdf?sequence=1

Woolf-King, S. E., Anger, A., Arnold, E. A., Weiss, S. J., & Teitel, D. (2017). Mental health among parents of children with critical congenital heart defects: a systematic review. *Journal of the American Heart Association, 6*(2). https://doi.org/10.1161/JAHA.116.004862

YANG, Y. T., WALLINGTON, S. F., & MORAIN, S. (2022). Paid leave for fathers: policy, practice, and reform. *The Milbank Quarterly, 100*(4), 973–990. https://doi.org/10.1111/1468-0009.12590

Yang, J., Ma, F., Wang, Y., Yang, X., Zhou, M., Zhang, Y., YangLan, R., & Li, Q. (2025). Health Information Behavior in parents of children with congenital heart disease in China: qualitative study through the lens of Chinese culture. *Journal of Medical Internet Research, 27*(4), e80784–e80784. https://doi.org/10.2196/80784

Yang, Y., Niu, L., Amin, S., & Yasin, I. (2024). Unemployment and mental health: a global study of unemployment's influence on diverse mental disorders. *Frontiers in public health*, *12*, 1440403. https://doi.org/10.3389/fpubh.2024.1440403

Young, A., Nicholas, D. B., Chamberlain, S.-P., Suapa, N., Gale, N., & Bailey, A. J. (2019a). Exploring and building autism service capacity in rural and remote regions: Participatory action research in rural Alberta and British Columbia, Canada. *Autism: The International Journal of Research and Practice, 23*(5), 1143–1151. https://doi.org/10.1177/1362361318801340

Young, T. K., & Chatwood, S. (2011). Health care in the north: what Canada can learn from its circumpolar neighbours. *Canadian Medical Association Journal (CMAJ), 183*(2), 209–214. https://doi.org/10.1503/cmaj.100948

Young, T., Chatwood, S., Ng, C., Young, R., & Marchildon, G. (2019b). The north is not all the same: comparing health system performance in 18 northern regions of Canada. *International Journal of Circumpolar Health, 78*(1), 1-10. https://doi.org/10.1080/22423982.2019.1697474

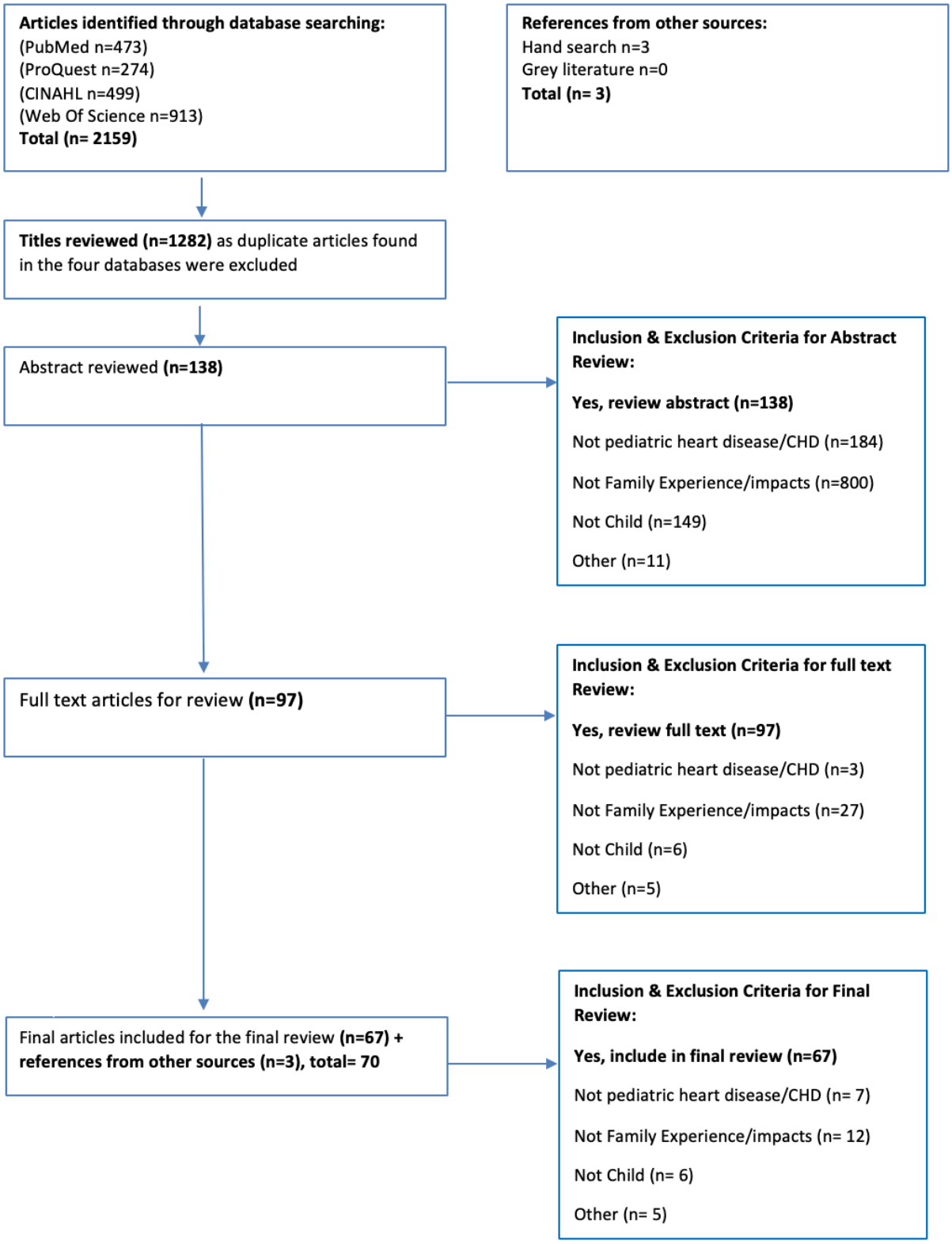
Yu, D., Feng, Y., Yang, L., Da, M., Fan, C., Wang, S., & Mo, X. (2014). Maternal Socioeconomic Status and the Risk of Congenital Heart Defects in Offspring: A Meta-Analysis of 33 Studies. *PloS One, 9*(10), e111056–. https://doi.org/10.1371/journal.pone.0111056

Zarifa, D., Seward, B., & Milian, R. P. (2019). Location, location, location: examining the rural-urban skills gap in Canada. *Journal of Rural Studies, 72*, 252–263. https://doi.org/10.1016/j.jrurstud.2019.10.032

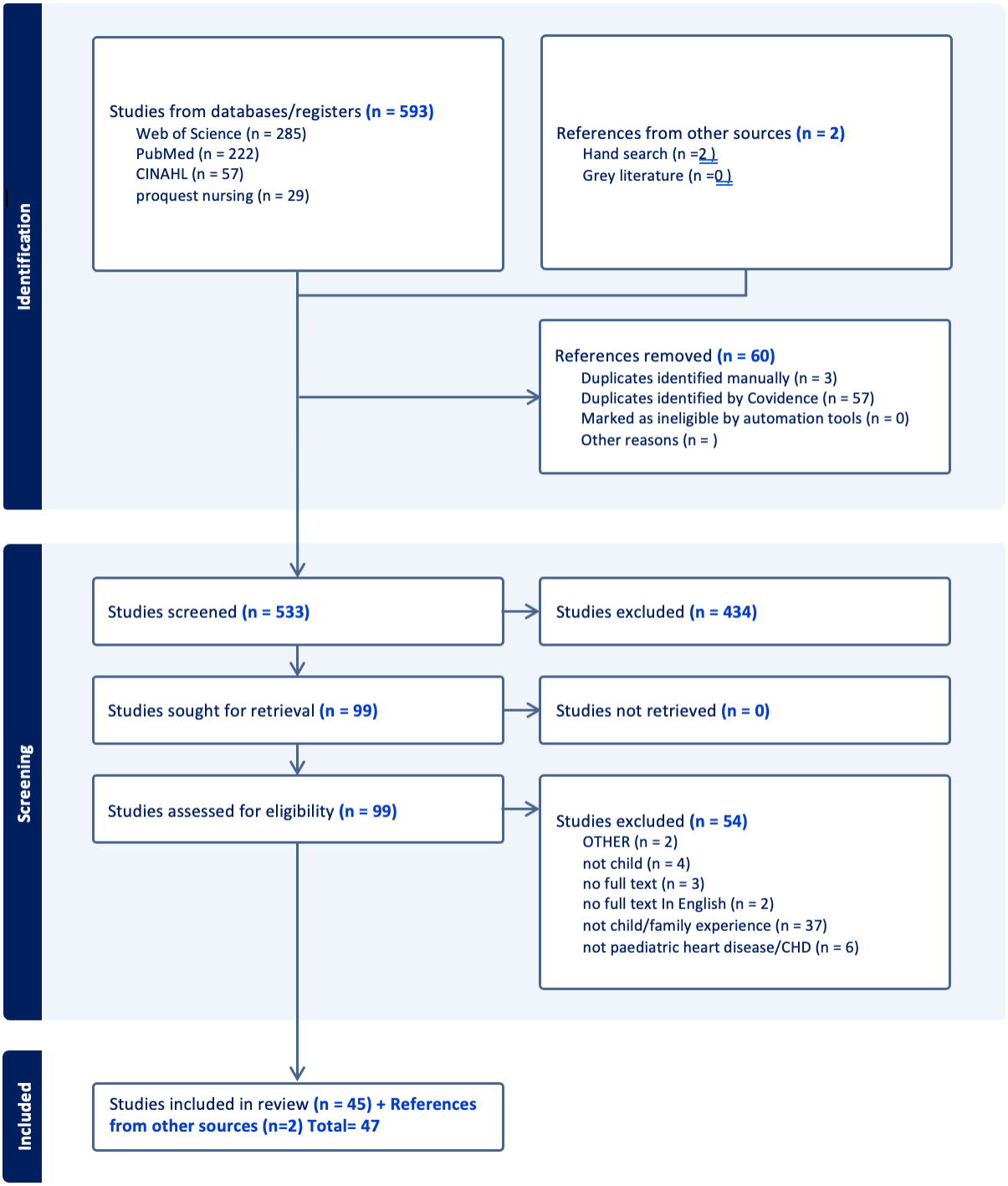
Zhang, Y., Zhou, H., Bai, Y., Chen, Z., Wang, Y., Hu, Q., Yang, M., Wei, W., Ding, L., & Ma, F. (2023). Families under pressure: A qualitative study of stressors in families of children with congenital heart disease. *Stress and Health, 39*(5), 989–999. https://doi.org/10.1002/smi.3240

Zhu, J., Jin, C., & Tang, X. (2022). Psychological needs of parents of children with complicated congenital heart disease after admitting to Paediatricintensive care unit: A questionnaire study. *WORLD JOURNAL OF CLINICAL CASES*, *10*(24), 8578–8586. https://doi.org/10.12998/wjcc.v10.i24.8578

Appendix A: PRISMA Diagram



Appendix B: Covidence Updated Literature Review PRISMA



Appendix C: Interview Guides

Introduction

Hello, my name(s) is Alexandra Dampier I am currently a PhD student in the Health Sciences program at Lakehead University.

I want to thank you for agreeing to be interviewed for this study 'Children and family's experiences while living with congenital heart disease within NWO'. I am interested in your experiences living with CHD and also your families experience of living and caring for CHD in your home and community environment. The information you provide will contribute to the knowledge of health care practices and health policy implementation. Your participation in this research is voluntary.

Before I start, I want to be sure all your questions have been answered about the process and the consent that you have signed.

I want to remind you that during the interview you can refuse to answer any question and you may withdraw at any time. If you are uncomfortable answering any questions asked of you, just say 'Pass' and I will move on in the interview. There will be no repercussions if you choose not to take part in the study.

Your information will only be seen by researcher. I will ensure that the information collected from you will be kept private and used only for the purposes of the research study.

Central Research Question

- What are the lifeworld experiences of children diagnosed with CHD and their families living and caring for their child in rural, remote, and or northern areas of NWO?

Appendix C1

Parent Interview: Prompts and Probes (Sub questions)

Introduction:

Researcher to first introduce self, role and study. Then researcher to ask the following introductory questions to establish a comfortable and open environment.

1. Tell me about your family?
    a. Who is part of your family unit?
2. How are you feeling today?
3. Is there anything I should know before we get started?
    a. Is there any recent illness or complications with your child?
    b. How are feeling lately?

Lived Space:

4. How does your home environment impact your experiences of living and caring for a child with CHD?
    a. How are you currently managing at home?
5. Tell me about your experiences within the hospital (TBRHSC and or primary care services e.g. London Hospital)?
    a. Tell me about your discharge teaching from the health care team?
6. Who were you connected with for follow-up care and how has that care been?
    a. How do you access services such as physio, OT, PT, and home care nursing care? Or any other services I may have missed?
7. If your child became sick at home, what are your health care resources available to you in your home community?
    a. How would you manage to access services outside of your community if needed?
    b. How far do you have to travel and by what mode?

Lived Body:

8. How does living and caring for a child with CHD affect activities of daily living and routines?
    a. How have they changed since the diagnosis?
9. Has the illness affected your child's overall development in any way?
    a. Specially in relation to school, physical activity, nutrition, emotional responses, and physical growth?
10. How has the illness affected your families' routines?
    a. If so how? And has it caused shifts in other family members roles and dynamics?

Lived Time:

11. Tell me about how your child first became sick?
    a. Did you notice a rapid or slow progression of your child's illness?
12. Since the initial diagnosis of CHD what have been your experiences living and caring for your child with CHD?

Lived Other:

13. What are your experiences with the health care teams?
    a. Including both TBRHSC POP & tertiary specialty care center?
14. How are your relationship with your family?

   a. Including extended family
   b. Can you describe your supports or needed supports?
15. How has your life adjusted including balancing home and work commitments?
16. What are the families' relationships like between outside community supports and school services?

Final Question:

- Was there anything I didn't ask that I should have asked? Or you would like to share?
- Am I able to collect demographic information for you and your child?
    - Age
    - Gender
    - Education
    - Marital Status
    - Employment
    - Location
    - Household income

Appendix C2

Child Interview Pre-Operational Stage (2-7 years): Prompts and Probes (Sub questions)

Introduction:

Researcher to first introduce self, role and study. Then researcher to ask the following introductory questions to establish a comfortable and open environment.

**The draw and tell method will be used with children participants within the study who are between the ages of four and seven or if they are older than seven yet upon assessment have not reached the concrete operational stage.*

1. Can you pick your favorite colours and draw a picture of your family?
    a. Who is part of your family?
2. How are you feeling today?
3. Is there anything you would like to share with me before we get started?

Lived Space:

4. Can you tell me about where you live?
    a. Who lives in your house?
5. What was it like when you went to hospital?
    a. What do you like about the hospital? What do dislike?

Lived Body:

6. How do you feel when you are sick?

Lived Time:

7. Tell me about when you got sick?

Lived Other:

8. Tell me about the nurses and doctors you meet at the hospital?
    a. Was there anyone else you met that you want to tell me about?
9. Tell me about people in your family?
    a. Can ask about friends within this area.
10. Can you tell me about day care/school?

Appendix C3

Child Interview Concrete Operational Stage (ages 7-11): Prompts and Probes (Sub questions)

Introduction:

Researcher to first introduce self, role and study. Then researcher to ask the following introductory questions to establish a comfortable and open environment.

1. Tell me about your family?
    a. Who is part of your family unit?
2. How are you feeling today?
3. Is there anything you would like to share before we get started?
    a. How are feeling lately?

Lived Space:

4. How does your home environment impact your experiences of living with CHD?
    a. How are you currently managing at home?
5. Tell me about your experiences within the hospital (TBRHSC and or primary care services e.g. London Hospital)?
6. What's you experience like when you have to travel for your care?

Lived Body:

7. How does living with CHD affect what you do every day?
    a. Have they changed since the diagnosis? Does it impact activities with your family?
8. How has your illness made you feel?

Lived Time:

9. Tell me about how you first became sick?

Lived Other:

10. Tell me about the nurses and doctors you see at the hospital?
    a. Or anyone else you may have helped you?
    b. Including both TBRHSC POP & tertiary specialty care center?
11. Tell me about your family and friends?
    a. Including extended family
    b. Do you feel supported or how do they support you?
12. What are your relationships like between friends and school?

Final Question:

- Was there anything I didn't ask that I should have asked? Or you would like to share?

Appendix C4

Child Interview Formal Operational Stage (ages 11-16): Prompts and Probes (Sub questions)

Introduction:

Researcher to first introduce self, role and study. Then researcher to ask the following introductory questions to establish a comfortable and open environment.

1. Tell me about your family?
    a. Who is part of your family unit?
2. How are you feeling today?
3. Is there anything you would like to share before we get started?
    a. How are feeling lately?

Lived Space:

4. How does your home environment impact your experiences of living with CHD?
    a. How are you currently managing at home?
5. Tell me about your experiences within the hospital (TBRHSC and or primary care services e.g. London Hospital)?
    a. Tell me about your discharge teaching from the health care team?
6. Who were you connected with for follow up care and how has that care been?
    a. How do you access services such as physio, OT, PT, and home care nursing care? Or any other services I may have missed?
7. What's you experience like when you have to travel for your care?

Lived Body:

8. How does living with CHD affect your activities of daily living and routines?
    a. Have they changed since the diagnosis?
9. Has the illness affected how you see/view yourself?
    a. Do you notice any changes to your body?
10. Has the illness affected your families' routines?
    a. If so how? And has it caused shifts in other family members roles and dynamics?

Lived Time:

11. Tell me about how you first became sick?
12. Since the initial diagnosis of CHD what have been your experiences living with CHD?

Lived Other:

13. What are your experiences with the health care teams?
    a. Including both TBRHSC POP & tertiary specialty care center?
14. How are your relationships with your family?
    a. Including extended family
    b. Do you feel supported?
15. How has your life adjusted including balancing your school and possible work commitments?
16. What are your relationships like between friends and school?

Final Question:

- Was there anything I didn't ask that I should have asked? Or you would like to share?

Debrief Information for Children and Families:

Thank you for your time and sharing your experiences with me. This information will be kept in a locked and secure area by the study Principal Investigator for 7 years. Only the researcher will be allowed to look at the data. Any personal information presented to the public will be anonymous. Your name will not be used in any reports, publications, or presentations that may come from this study. Pseudonyms will be used in any publication.

The results of the study will be shared with you, the participant, professional nursing bodies and further disseminated to the academic community, conferences and in peer reviewed publications. If you decide you do not want your information used, contact the researcher Alexandra Dampier at (807) 632-5497.

Thank you!

Appendix D: Recruitment Poster

Children and Family's Experiences While Living with Congenital Heart Disease in Northwestern Ontario

Who can participate?

- Are you a child or adolescent with congenital heart disease?
- Or a parent or caregiver of a child with congenital heart disease?
- Do you live in Northwestern Ontario?

We want to hear from you!



What are the study details?

- We would like to hear about your experience living with congenital heart disease or caring for your child.
- Will include an interview (in-person or via ZOOM),
- The interview will take a maximum of 30 minutes (for child or adolescent) and 1 hour (for parents or caregivers)
- Your participation in the study will be confidential
- Each family will receive a $60 grocery gift card or cash for participating.

Questions?

Please contact Alexandra Dampier if you have questions or want to join the study.

(807) 343-8010 ext 8994

aedampie@lakeheadu.ca

Thunder Bay Regional Health Sciences Centre | Thunder Bay Regional Health Research Institute

Lakehead University

REB #---------

Appendix E: Participant Information Letter

Letter of Information: Children and Family's Experiences While Living with Congenital Heart Disease in Northwestern Ontario

Dear Families of Northwestern Ontario,

We would love to hear from you!

We are contacting you because we are conducting a study and we believe your participation could significantly contribute to our understanding of this important topic.

Our goal is to learn more about the challenges and experiences faced by children and families living with congenital heart disease in our region. Your experiences will help us identify areas where support and resources may be needed, ultimately improving the well-being of children and families in our communities.

Who can participate?

If you are a child or adolescent with congenital heart disease and or a parent or caregiver of a child with congenital heart disease living in northwestern Ontario, we would love to hear about your experiences.

What are the study details?

Participating in the study involves sharing your experiences through interviews. The interviews can be done in person or on Zoom, on a day and time that works best for you and your family. The interview will take around 30 minutes (for a child or adolescent) and 1 hour (for parents or caregivers). We understand how sensitive sharing your experiences may be. If you decide to share any personal health information with the researcher during the interview, it will be kept confidential.

If you choose to participate, your involvement will be entirely voluntary, and you can withdraw from the study at anytime. Families who participate will be given a $60 grocery gift card or cash for sharing their time.

We genuinely appreciate your consideration of this request; we hope we can make a meaningful impact on the well-being of children and families living with congenital heart disease in Northwestern Ontario. If you and your family are interested or want to learn more about the study, please contact Alexandra Dampier at aedampie@lakeheadu.ca or (807) 632-5497. We encourage you to ask any questions before deciding to participate.

Sincerely,

Alexandra Dampier

Appendix F: Scripts for Child Research Assent

Appendix F1

Research Assent Script: Pre-operational Children aged 2-7 years

Title: Children and Family's Experiences While Living with Congenital Heart Disease within Northwestern Ontario.
Principal Investigator: Dr. Helle Møller, Lakehead University
Co-Investigator: Alexandra Dampier, Lakehead University
Research Team: The research study will be supported by the research team of Dr. Helle Møller and Alexandra Dampier from Lakehead University, who can be reached by phone at (807) 632-5497.
Funding Sponsor: N/A
What is the purpose of this study?
We're asking families with kids who have a special heart called CHD to help us understand how they feel in certain parts of Ontario. We want to know what makes them happy and healthy. Your thoughts can help all kids get good care, even if they live far from big cities. We hope this will make life better for kids with CHD and their families.
Why am I being asked to participate?
We're doing a special study, and we'd love for you to be a part of it! You have a special heart called CHD, and we want to know all about your experiences living with it in Northwestern Ontario. Your thoughts and feelings can help other kids and families too! But remember, it's totally up to you if you want to join in or not.
What is being asked of me?
If you say yes to talk with me today, If you want, you can draw or tell me about your special heart. You can talk as much or as little as you like. Your mom or dad will be with you the whole time. And remember, you can say no to any questions or stop whenever you want.
How long will I be involved in the study?
We will talk and draw for about 30 minutes but if you want, we can stop earlier. You can also say if you don't want to answer any questions, or if you want to stop talking or drawing altogether.
Are there benefits if I decide to participate?
Taking part in this study might help other kids and families with CHD in our area. If you ever feel sad or upset, we can stop anytime.
Are there any potential harms involved with participating?
Talking about your health, hospital visits, or feeling sick or worried might make you feel sad or upset. If that happens, you can say you don't want to talk anymore, and it's okay. You won't get in trouble. If you need help, the researcher can help you talk to your doctor**.**
What will be done with the information I give?
I have a recorder with me, I will press play and it will record our conversations. I will store this information and keep it safe for 7 years.
Child Assent:
Please sign your name OR choose yes or no below. If you say no, you will not be in trouble.
Name: _____
OR:
Yes: ☐ **No:** ☐

The researcher has read the above script to the child and parent/legal guardian and has obtained assent from the child:
Witness to child assent from researcher (parent/legal guardian) please sign below:
Name: (Printed)_____

Signature: _____

Childs Full Name: _____
Date: _____

The research has been approved by the Thunder Bay Regional Research Ethics & Authorization Office. If you have any questions related to the ethics of the research and would like to speak to someone outside of the research team please contact the Research Ethics Board by email at TBR_REO@tbh.net or telephone #: 807-684-6422. Everything you discuss with the REB will be kept confidential.

Appendix F2

Research Assent Script: Concrete Operations Children aged 7-11 years

Title: Children and Family's Experiences While Living with Congenital Heart Disease within Northwestern Ontario.

Principal Investigator: Dr. Helle Møller, Lakehead University

Co-Investigator: Alexandra Dampier, Lakehead University

Research Team: The research study will be supported by the research team of Dr. Helle Møller and Alexandra Dampier from Lakehead University, who can be reached by phone at (807) 632-5497.

Funding Sponsor: N/A

What is the purpose of this study?

We're doing a study to learn more about how kids with CHD (a heart problem) and their families feel about living in certain areas of Ontario. We want to know about their experiences and what they need to stay healthy and happy. By sharing your thoughts, you can help make sure that all kids get the best care possible, no matter where they live. We hope this will make life better for kids with CHD and their families in places that are far away from big cities.

Why am I being asked to participate?

You are being asked to take part in a research study as a child diagnosed with CHD. As the researcher I am interested in your experiences while living with CHD in Northwestern Ontario. It is hoped that the information you share with me with help other children and families. Please note that your participation in this research is totally up to you.

What is being asked of me?

If you agree, you will draw/tell me about your experiences of living with your cardiac illness. We can talk as long or as little as you like. Your parents will be here the whole time if you choose. During the interview, you can refuse to answer any questions or stop the interview at any time.

How long will I be involved in the study?

The interview will last a maximum of 30 minutes depending on how much we talk. During the interview, you can say that you don't want to answer any questions or stop the interview at any time.

Are there benefits if I decide to participate?

Being involved in this study may assist in helping other children and families living with CHD Northwestern Ontario and surrounding areas. If you are upset at any point, we can stop.

Are there any potential harms involved with participating?

There are some potential risks for emotional distress as we will be asking questions about your health, when you visit the hospital, and when you may feel sick or worried. If you became emotionally distressed of any kind you have the right to refuse or stop the interview, you can end the interview at any time without being in trouble. If needed the researcher will help you in accessing your primary health care provider for assistance.

What will be done with the information I give?

I have a recorder with me, I will press play and it will record our conversations. I will store this information and keep it safe for 7 years.

Child Assent:

Please sign your name OR choose yes or no below. If you say no, you will not be in trouble.

Name: _____

OR:

Yes: ☐ **No:** ☐

The researcher has read the above script to the child and parent/legal guardian and has obtained assent from the child:
Witness to child assent from researcher (parent/legal guardian) please sign below:
Name: (Printed)_____

Signature: _____

Childs Full Name: _____
Date: _____
If you have any questions regarding your rights as a research participant, or related to the ethics of the research and would like to speak to someone outside of the research team please contact:

Chair, Research Ethics Board
Thunder Bay Regional Health Sciences Centre
Phone: 807-684-6422 Fax: 807-684-5904
Email: TBRSHC.ResearchEthicsChair@tbh.net

Appendix F3

Research Assent Script: Formal Operations Children aged 11-16 years

Title: Children and Family's Experiences While Living with Congenital Heart Disease within Northwestern Ontario.

Principal Investigator: Dr. Helle Møller, Lakehead University
Co-Investigator: Alexandra Dampier, Lakehead University
Research Team: The research study will be supported by the research team of Dr. Helle Møller and Alexandra Dampier from Lakehead University, who can be reached by phone at (807) 632-5497.

Funding Sponsor: N/A

What is the purpose of this study?

This study aims to understand the experiences and viewpoints of children diagnosed with CHD (Congenital Heart Disease) and their families who live in rural, remote, or northern communities in Northwestern Ontario. We want to explore what daily life is like for them and what support they need. By sharing your experiences, you can help shed light on the challenges faced by families living in these areas and contribute to improving healthcare practices and policies. Our goal is to enhance the well-being of all children, especially those living with CHD or families caring for a sick child in regions that may have limited access to resources and services. Your input will play a crucial role in shaping a better future for healthcare in these communities.

Why am I being asked to participate?

You are being asked to take part in a research study as a child diagnosed with CHD. As the researcher I am interested in your experiences while living with CHD in Northwestern Ontario. It is hoped that the information you share with me with help other children and families. Please note that your participation in this research is voluntary.

What is being asked of me?

If you agree, you will draw/tell me about your experiences of living with your cardiac illness. We can talk as long or as little as you like. Your parents will be here the whole time if you choose. During the interview you can refuse to answer any questions or stop the interview at any time.

How long will I be involved in the study?

The interview will last a maximum of 30 minutes depending on the amount of discussion we have. During the interview, you can refuse to answer any questions or stop the interview at any time.

Are there benefits if I decide to participate?

Your involvement in this study may assist in helping other children and families living with CHD Northwestern Ontario and surrounding areas. If you are upset at any point, we can stop.

Are there any potential harms involved with participating?

There are some potential risks for emotional distress we will be asking questions about your health, when you visit the hospital, and when you may feel sick or worried. If you became emotionally distressed of any kind you have the right to refuse or stop the interview, you can end the interview at any time without any repercussions. If needed the researcher will assist you in accessing your primary health care provider for assistance.

What will be done with the information I give?

I have a recorder with me, I will press play and it will record our conversations. I will store this information and keep it safe for 7 years.

Child Assent:
Please sign your name OR choose yes or no below. If you say no, you will not be in trouble.
Name: _____
OR:
Yes: ☐ **No:** ☐

The researcher has read the above script to the child and parent/legal guardian and has obtained assent from the child:
Witness to child assent from researcher (parent/legal guardian) please sign below:
Name: (Printed)_____
Signature: _____

Childs Full Name: _____
Date: _____
If you have any questions regarding your rights as a research participant, or related to the ethics of the research and would like to speak to someone outside of the research team please contact:

Chair, Research Ethics Board
Thunder Bay Regional Health Sciences Centre
Phone: 807-684-6422 Fax: 807-684-5904
Email: TBRSHC.ResearchEthicsChair@tbh.net

Appendix G: Research Participants Information and Consent Form for Parents

Research Participants Information and Consent Form for Parents

Title: Children and Family's Experiences While Living with Congenital Heart Disease within Northwestern Ontario.
Principal Investigator: Dr. Helle Møller, Lakehead University
Co-Investigator: Alexandra Dampier, Lakehead University
Research Team: The research study will be supported by the research team of Dr. Helle Møller and Alexandra Dampier from Lakehead University, who can be reached by phone at (807) 632-5497.
Funding Sponsor: N/A
Dear Potential Participants:
You are being asked to take part in a research study if you are a child diagnosed with congenital heart disease (CHD) and or, a parent or caregiver of a child diagnosed with CHD.
Taking part in this study is voluntary. You may refuse to take part or stop taking part at any time. Your decision will not change your care at the Thunder Bay Regional Health Sciences Centre or other health organizations within Thunder Bay.
Before you decide whether you would like to take part in this study, please read this letter carefully to understand what is involved. After you have read the letter, please ask any questions you may have. This information and consent form has been reviewed and approved by the Research Ethics Board at Thunder Bay Regional Health Sciences Center.
What is the purpose of this study?
The purpose of this study is to explore the lived experiences and overall perceptions of children diagnosed with CHD and their families living in rural, remote, or northern communities within Northwestern Ontario. This will help gain a better understanding of the experiences and needs of children and their families living with CHD. It is hoped that the information you share will contribute to help address health care inequalities and inform heath care practices and policies. We hope to improve the overall well-being within communities, especially for those children and adolescents living with a disease such as CHD or families caring for a sick child in rural or remote regions.

Why am I being asked to participate?
You are being asked to take part in a research study as a parent or caregiver of a child diagnosed with congenital heart disease (CHD). The researcher is interested in your lived experiences and perceptions while living and caring for your child who has CHD in Northwestern Ontario. It is hoped that the information you elicit will contribute to help address health care inequalities and inform heath care practices and policies. Please note that your participation in this research is totally voluntary.
What is being asked of me?
If you agree, you will have an individual interview in person within your home, community or the PaediatricOutpatient Clinic at the TBRHSC. If these options do not work for you and your family, I can arrange a ZOOM online interview.
How long will I be involved in the study?
The interview will last from 45 minutes to 1 hour depending on the amount of discussion. The interview with your child will be a maximum of 30 minutes, both on a day and time that is at

your convenience. During the interview you can refuse to answer any questions or stop the interview at any time.

What are the alternatives to taking part?

If you choose not to participate, you will continue to receive the best care that is given to all patients at the TBRHSC and surrounding health care organizations. Your decision to take part in this study will in no way affect the quality of care that is provided.

Are there benefits if I decide to participate?

Your involvement in this study may assist in addressing health care inequalities and aid in informing heath care practices and policies for children and families living with CHD in Northwestern Ontario and surrounding areas.

Are there any potential harms involved with participating?

There are some potential risks for emotional distress as you will be asked questions about your experiences when your child first became sick, the progression of your child's illness, and your experiences living and caring for your child with CHD. If you became emotionally distressed of any kind you have the right to refuse or stop the interview, you can end the interview at any time without any repercussions. If needed the researcher will assist you in accessing your primary health care provider for assistance.

What will be done with the information I give?

Interviews will be audio taped verbatim. This information will be kept in a locked and secure area by the study Principal Investigator for 7 years. Only the researcher will be allowed to look at the data.

Confidentiality:

Your privacy is very important to us. If you decide to share any personal health information with the researcher during the interview, it will be kept confidential. No information from your health records will be obtained, although family demographics will be collected at the end of the interview if you choose to agree. This includes information such as your name, address, age, gender, education, marital status, employment, and household income . All personal health information shared will be kept confidential.

To protect your identity, you will be assigned a unique ID number for this research study. The ID number will be used on any research related forms. The link between your personal information and ID number will be only available to qualified members of the research team and will not leave the TBRHSC. The TBRHSC Research Ethics Board may require access to your study-related records to monitor the conduct of the research. No identifiable information will be copied or taken from our office.

Participation & Withdrawal:

It is important for you to know that participation is entirely **voluntary.** You may refuse to participate, refuse to answer questions or choose to withdraw from the study at any time. You do not waive any legal rights by signing this consent form. If you were part of an interview and decide you do not want your information used or wish to withdraw from the study, please contact the research team member Alexandra Dampier at (807) 632-5497.

Costs:

There will be no associated costs involved for participating in this study. There will be a token of cash or a grocery gift worth $60 for participant families to acknowledge the time and effort you have given to the research project.

In Case of Injury:

If you suffer injury as a result of taking part in this study, you will be provided necessary treatment of the injury at the TBRHSC. You will not receive any other financial compensation.

Conflicts of Interest:
This research will be done in kind, with no conflicts of interest to disclose.
Commercialization:
There is no direct potential for commercialization in this study.

Publication of Data:

The results of this research study may be presented at meetings or conferences, and/or published in journals. Any results presented or published will not contain your identity.

Copy of Information Letter and Consent Form:

You will be given a copy of this signed consent form to keep.

Questions About the Study:
If you have any questions or concerns or would like to speak to the research team for any reason, please call: Alexandra Dampier, at (807)-632-5497.
If you have any questions regarding your rights as a research participant, or related to the ethics of the research and would like to speak to someone outside of the research team please contact:

Chair, Research Ethics Board
Thunder Bay Regional Health Sciences Centre
Phone: 807-684-6422 Fax: 807-684-5904
Email: TBRSHC.ResearchEthicsChair@tbh.net

Research Participant Information and Consent Form

Title: Children and Family's Experiences While Living with Congenital Heart Disease within Northwestern Ontario.
Research Participant's Consent
This research study has been fully explained to me and all of my questions answered to my satisfaction.
I agree to the following:

- ✓ I have read and understand the information contained in the Information Letter
- ✓ I agree to participate in this research study.
- ✓ I have been informed of the risks and benefits, if any, of participating in this research study.
- ✓ That I am a volunteer and can withdraw from the study at any time until the point of submitting the data and may choose not to answer any question.
- ✓ That the data will be securely stored for a minimum period of 7 years following

completion of the research project

- ✓ I have been informed of any alternatives to participating in this research study.
- ✓ I have been informed of the rights of research participants.
- ✓ I have read each page of this form.
- ✓ I understand that the research findings will be made available to me upon request.
- ✓ I will remain anonymous.
- ✓ All of my questions have been answered.
- ✓ I agree to allow for the interview to be audio recorded.

By consenting to participate, I have not waived any rights to legal recourse in the event of research-related harm.

If you would like to be involved in the study, please sign below:

_____	_____	_____/_____/_____
Name of Research Participant *(print)*	Signature of Research Participant	Day Month Year

If you agree for your child to be involved in the study, please sign below:

_____	_____	_____
Name of parent or legal guardian *(print)*	Signature of parent or legal guardian	Childs full name

_____/_____/_____
Day Month Year

Signature of Person Obtaining Consent

I have explained the terms of this information and consent form to the research participant. All questions asked by the participant have been answered. I will give a copy of this signed document to the participant.

_____	_____	_____/_____/_____
Name of person obtaining consent *(print)*	Signature of person obtaining consent	Day Month Year

Email address:
(For request of a copy of the research results) _____

Appendix H: Observation Tool

Participant #: **Date:** **Start:** **End:**		
Participants:	**Descriptive Notes:**	**Reflective Notes:**
Behaviors		
Expressions and body language		
Activities and time spent		
Processes throughout		
Physical setting		

Physical appearance		