The Lived Experiences of Families of Children with Long-Term Immunosuppression Following Paediatric Solid-Organ Transplantation

By

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Abstract

The goal of the study was to explore the lived experiences and parental perceptions of families with children who are immunosuppressed following paediatric solid organ translation. The research questions sought to generate new knowledge and understanding of the following: how families manage acute and chronic stress; how families manage the accumulation of stress; how their functioning is impacted by the immunosuppression and the related recommendations; what are the challenges that they face as immunosuppressed families; and what are the strengths of the children and their families? Study participants were families living across two provinces in Canada (Manitoba and Saskatchewan), who have a child who is immunosuppressed long-term following a paediatric solid organ transplant. The research design was qualitative autoethnography as well as interpretative phenomenological analysis, which utilized the family stress theory and the double ABC-X model within the analysis. The study focused on providing insight and developing a theoretical lens into how different facets of immunosuppression may impact families in all areas of functioning post-transplant, including those identified within the social determinants of health. The findings suggested families experienced stress and financial implications as individual concerns, and vaccine hesitancy and the current state of the organ registry as systemic concerns. Study participants indicated a need for more accessible supports for families, such as family counselling. A preliminary framework was created based on the findings of the study, in order to guide clinicians during the initial assessment of families entering into the transplant procedures to determine their inventory of current resources, their ability to access additional resources, and whether or not the family may be vulnerable to crisis and mal-adaptation, as a means to provide more holistic care to families.

Keywords: paediatric immunosuppression, lived experience, family health, Canada
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CHAPTER ONE

INTRODUCTION
Introduction

The subject of the dissertation was the study of paediatric immunosuppression, with a focus on how long-term immunosuppression in children following solid-organ transplantation impacts the lives of the children and their families. In addition to the required medications, immunosuppressed individuals and their families receive numerous recommendations from healthcare professionals in order to promote health and wellness regarding diet, hygiene, cleanliness, and social interactions. These recommendations, coupled with the risks associated with a compromised immune system, can be difficult to manage for both the children and their families. Although previous academic literature focused on other childhood medical conditions may be able to be generalized to this phenomenon in part, as all conditions are unique and present specific challenges, it is imperative to explore the impacts of long-term paediatric immunosuppression exclusively. Currently, there is limited accessible research pertaining specifically to paediatric immunosuppression, the experiences of managing paediatric immunosuppression long-term, and how this impacts the children and their families in their day-to-day lives. This study explored the everyday challenges and triumphs of families living with immunosuppression, and the recommendations associated with the condition, by utilizing autoethnography, interpretative phenomenological analysis, and the family stress theory, in order to gain an understanding of the parental perceptions and the lived experiences of these families.

Within the first chapter I have provided an overview of the study, and then transitioned to the purpose and positionality statements. As I am a researcher with lived experience in the topic, the positionality statement was included for context and to provide complete transparency regarding my experiences with the subject matter. Within the second chapter I have provided the background information pertaining to the study, as well as the literature review.
Immunosuppression is a multifaceted concern; thusly I included a brief overview of the background information for the condition to ensure that the study could be more accessible for all readers, regardless of previous medical knowledge. Within the third chapter I have included the research questions, objectives, and the theoretical frameworks of the study. The primary theory that I utilized was the family stress theory; the double ABC-X model and social determinants of health were integrated as a secondary focus. Within the fourth chapter I focused on the methods of the study, including: the research design and procedures, participants, data collection, data analysis, and ethical considerations. In the fifth chapter I presented the findings of the study, which are organized utilizing the social determinants of health. The findings section includes verbatim quotes from the participants to support each superordinate theme and underlying theme; the autoethnography is also included within this section. Within the sixth chapter I provided a conceptual exploration of stress, health, and health equity. In the seventh chapter I provided the discussion, which is categorized again by the social determinants of health. I focused on two areas within this chapter: the overall discussion of each area of interest, and each area of interest explored using the family stress theory and the double ABC-X model. Within the final chapter, chapter eight, I presented the recommendations from the participants, strengths and weaknesses of the study, and the implications.

In addition to identifying several areas that would likely benefit from future research, I created a framework based on the findings of the study, to be used as a guide for clinicians during the initial assessment of families entering into the transplant process. The purpose is to assist clinicians in determining the current inventory of resources of the family, their ability to access additional resources, and whether or not the family may be vulnerable to crisis and maladaptation, as a means to provide more holistic care to families.
Positionality Statement

I believe that it is important for context to note that I am a person with lived experience in this area, and would likely be considered an insider researcher in this circumstance. Our child was born with biliary atresia and had a Kasai procedure at six weeks of age. We were informed that the procedure was not successful shortly after it occurred, and that our child would require a liver transplant. I volunteered to be the living donor, and after extensive testing we were both cleared for the procedures. The transplant was successful and our child now has a fully functional liver. I am forever grateful for the opportunity to be the living donor and for the team of healthcare providers who saved my baby. We are now an immunosuppressed family and live not only with the medications, but also with the clinical recommendations for immunosuppressed individuals.

The recommendations required for those living with chronic immunosuppression, in our experience, are as challenging to manage as the medications and the side effects. Although it has been difficult, especially initially, it is of course worth it to make sure that our child is healthy and safe. As a mother and an academic, I often look for research articles on immunosuppression following paediatric solid organ transplantation for information and to stay current on the most recent recommendations and advancements. It was throughout this process, over the course of several years, that I found myself continuously wishing for more qualitative research to review to complement the existing quantitative research. Although there is accessible qualitative research within the field of organ transplantation, I found that it was often eclipsed by the vast amount of quantitative research. Also, the available qualitative research did not focus on immunosuppression as a condition and thus often did not explore the recommendations and impacts of immunosuppression in great detail (such as the need for increased hygiene...
cleanliness, and the potential risks associated with social interactions, and attending work or school).

As a result, I chose this phenomenon for my research topic, with the intent of addressing these aforementioned opportunities for further research and gaps in the existing literature, to further investigate all aspects of immunosuppression, as well as the perceptions and lived experiences of the families living with immunosuppression, in order to contribute to the existing understanding of the impacts of long-term immunosuppression.

**Purpose Statement**

The goal of the study was to better understand parent’s perspectives and the lived experiences of families of children with long-term immunosuppression following paediatric solid-organ transplantation. The study focused on how the condition of immunosuppression and the recommendations associated with the condition influence the overall health and wellness of immunosuppressed children and their families. I believe that this research is necessary in order to generate new knowledge and ways of understanding this phenomenon; there is a need for more research specific to this important topic, as immunosuppression impacts a number of families for various reasons. Although exact numbers of immunosuppressed people in Canada and/or the United States are not readily accessible, a study found that based on the 2013 National Health Interview Survey via the Centers for Disease Control and Prevention, an estimated 2.7% of people in the United States self-reported that they were immunosuppressed (Harpaz, Dahl, & Dooling, 2016, p. 2547). If we were to extrapolate this percentage to the Canadian context, this would mean an estimated one million people in Canada are immunosuppressed.
In conclusion, within this chapter I outlined the introduction and purpose of the study, including the positionality statement. It is important for context to note that I (the primary researcher that conducted this study) have lived experience in this matter.
CHAPTER TWO

RESEARCH QUESTIONS AND THEORETICAL FRAMEWORKS
Research Questions and Objectives

There were several areas of interest and questions that were examined in the study. The first objective was to explore how families live with the condition of long-term immunosuppression, and how families believe that the condition interacts with the overall wellness of the child and the family. The second objective was to explore how the social determinants of health interacted with the ability of the families to cope with the aforementioned recommendations, such as how the recommendations impacted the families in terms of their socioeconomic status, housing, food security, and other aspects of the social determinants of health. Furthermore, how the social determinants of health interact with the ability of the families to follow the recommendations and to maintain wellness was also explored. The primary research question was: what is the lived experience of families with children who are immunosuppressed long-term following solid organ transplantation? An additional theory-driven research question was: to what extent can the experiences of the families of children who are immunosuppressed be validated by the family stress theory?

Additional objectives included the generation of new knowledge and ways of understanding the following: how do these families manage acute and chronic stress, how do these families manage the accumulation of stress, how is their functioning impacted by the immunosuppression, what are the challenges that they face as immunosuppressed families, and what are the strengths of the children and their families? For example, an acute stressor that was noted by families was their child developing complications and/or a co-occurring illness that resulted in the child’s health declining, and at times also resulted in an unplanned admission to a hospital for their child. An example of a chronic stressor that was noted by families was
managing the daily requirements associated with the condition of immunosuppression, such as increased cleaning and laundry.

I focused on the strengths of families, to ensure that the study reflected strength-based research, as opposed to exclusively deficits-based research. Deficits-based research may not be “politically neutral,” and has the potential to support “ideologies of efficiency and effectiveness” (Gharabaghi & Anderson-Nathe, 2017, p. 177). Deficits-based research can also exploit power differentials between the researchers and those who are participants within the research, compounded by the possible effect of “entrenching an expert-driven knowledge generation process” (Gharabaghi & Anderson-Nathe, 2017, p. 177). Consequently, deficits-based research has the potential to alienate individuals as “objects of research initiatives,” and may negatively impact self-determination and self-actualization (Gharabaghi & Anderson-Nathe, 2017, p. 177). Thusly, I believe that it is crucial to explore the strengths of families, so that this information can ideally be used to inform how these strengths may assist in planning, support, and resources for families and individuals living with immunosuppression moving forward.

**Theoretical Frameworks**

**Family Stress Theory and the Double ABC-X Model**

Family stress theory was ultimately selected as the preferred means to analyze the acute/chronic stress and coping of the families, resulting from or impacted by the condition of immunosuppression. The theory was also used to provide further insights into the experiences of families with children who are immunosuppressed, as they navigate multiple stressors and continuously adapt their resources to address the concerns in real time, while concurrently attempting to implement coping processes to achieve or restore family balance. The theory was first indicated as having potential to be utilized within this study during the autoethnography
process, at which time my lived experiences were the focal point of the initial stages of the study. It was through the examination of these experiences that stress was noted as a considerable factor, and as a result of this process the research questions were formulated. The research questions that became the basis for this study are focused on exploring the parental perceptions of stressors, as identified in the lived experiences of the participants, that were disclosed during the open-ended interview process.

Family stress theory arose from the study of family stress, which first began in response to the Great Depression of the 1930s; scholars at the time found that families who were “organized and cohesive” prior to the Depression were better able to cope during the Depression, and were more stable afterwards (Smith & Hamon, 2017, p. 111). In 1943, Rueben Hill developed the rollercoaster profile of adjustment, which identified that families experience four stages when under stress: crisis, disorganization, recovery, and reorganization (Hill, 1943; Smith & Hamon, 2017). Hill later revised the model to create the ABC-X model of family stress, which became the basis of the family stress theory (Hill, 1943; Smith & Hamon, 2017). In this model A represents the stressor, B represents the resources and/or strengths of the family, and C represents the family’s perception of the stressor; if the family cannot successfully address the stressor this will lead to X, which represents the crisis stage (Hill, 1943; Smith & Hamon, 2017). The model has been changed and further built upon over the following decades by academics, creating various versions and additional frameworks, but the basics of the model have largely remained intact (Smith & Hamon, 2017).

Family stress theory has evolved in four major phases; each phase has been impacted by the academics that have utilized the theory and the studies that have employed and refined the theory during the specific period. The first phase spanned from the 1920s to the late-1940s, and
notable interactions with the theory include: Angell (a sociologist from the University of Michigan) who wrote the first published study using the theory in 1936, Cavan (a sociologist) and Ranck (a psychiatric social worker) who used the theory within their research in 1938 and identified the importance of studying individual members of the family as well as the family as a whole, and Koos (a sociologist) who used the theory to develop further understandings of the impact of stress (notably negative stress) on family functioning (Weber, 2011, p. 5). Throughout this initial phase, which included the conceptual conception of the theory, it is evident that the theory progressed significantly as a result of the primary and subsequent academic engagements with the theory.

The second phase spanned from the late-1940s to the late-1970s, and significant contributions to the theory include: Hill (a sociologist) who developed the profile of families in trouble the Truncated Roller Coaster Profile of Adjustment in 1949, and Hill again in 1958 when he further developed the theory and introduced the ABCX Formula (Weber, 2011, p. 8). The third phase spanned from the late-1970s to the mid-1980s, and notable developments include: McCubbin (family social scientist) and Patterson (also a family social scientist) who developed the Double ABCX Model in 1982 and later the FAAR Model in 1983, and McCubbin and McCubbin in 1987 when they developed the Typology Model (Weber, 2011, p. 8).

Finally, the fourth phase spans from the mid-1980s to the current state, and significant contributions during this phase include: Burr (family social scientist) who used the general ecosystemic theory to explain family stress, McCubbin and McCubbin in 1991 when they developed the Resiliency Model, the development of The Family Distress Model that by Cornille & Boroto in 1992, and the Contextual Model of Family Stress that was developed by Burr and Associates in 2002 (Weber, 2011, p. 9). Within this final phase, which is the present phase, it is
apparent that the theory has progressed considerably from the antecedent formulation, but the basic building blocks of the model remain consistent, and it continues to be utilized in modern research almost 100 years beyond the initial conception.

Family stress theory operates through several basic assumptions. The first is that “stressors have their own characteristics that influence the degree to which they affect the family,” as the stressor is considered neutral until the family defines and interprets the stressor, and both positive and negative stressors can cause stress and turmoil (Smith & Hamon, 2017, p. 115). Stressors can also be perceived as normative or non-normative, ambiguous or clear, and volitional or non-volitional based on the assessment of the stressor by the family encountering the situation (McCubbin & Patterson, 1985; Smith & Hamon, 2017).

A second assumption of the family stress theory is that “being able to access existing and new resources during times of stress impacts a family’s resilience or vulnerability to crises” (Smith & Hamon, 2017, p. 116). When a family experiences a stressor they must utilize their resources in order to prevent entering a crisis stage, this may also vary depending on the nature of the crisis; an acute crisis may require less long-term resources than a chronic crisis (McCubbin & Patterson, 1985; Smith & Hamon, 2017).

A third assumption is that “an individual and/or family’s cognitive appraisal of, or definition of, their stressor impacts the degree of crisis they are likely to encounter” (Smith & Hamon, 2017, p. 117). If a family frames the stressor as something that they can address, handle, or manage in some way, these families may see more positive outcomes than families who may frame the stressor as something that is completely unmanageable (Lazarus & Launier, 1978; Smith & Hamon, 2017).
A fourth assumption is that “whether a family will enter a state of crisis is determined by the A, B, and C components of the model” (Smith & Hamon, 2017, p. 118). The X in the model represents the crisis stage, and this stage typically indicates that the family was significantly impacted and had difficulties managing the stressor in the previous stages (Hill, 1943; Smith & Hamon, 2017). However, not all families who experience stress will enter a crisis stage, and not all families in the crisis stage will be broken within the stage, as it has been shown that families who manage to leave the crisis stage are typically more cohesive than they were beforehand (Hill, 1943; Smith & Hamon, 2017).

One criticism of the family stress theory is that it is “too static,” as it is a linear model that is attempting to explain and assess complex families and non-linear situations (Smith & Hamon, 2017, p. 124). Furthermore, it is typically not one isolated incident that causes the stress within the family, but rather an accumulation of stressors and events that contribute to the overall stress (Smith & Hamon, 2017; Smith, 1984). It has also been said that the theory does not capture how chronic stress ebbs and flows for families over time, or how “pervasive and consistent discrimination” may impact stress and coping (Smith & Hamon, 2017, p. 124). However, a notable strength of the theory is that advancements by academics since the theory’s conception in 1930 have largely addressed these concerns, including the double ABC-X model which captures stress over time, and the family adjustment and adaptation response (FAAR) model which captures environmental stressors (McCubbin & Patterson, 1983; Smith & Hamon, 2017).

Family stress theory has served as an effective approach in previous research of families with complex care needs, as it captures how the families address acute stress and manage chronic stress over time, as well as how families utilize resources during the process (Smith & Hamon,
Accordingly, family stress theory was chosen for the study, and was utilized throughout the examination of the data from the autoethnography as well as the interpretative phenomenological analysis, in order to analyze and explore aspects of the phenomenon, such as levels of stress, expressed in the data.

As noted in the autoethnography, the stress resulting from the initial procedure and subsequent requirement for immunosuppression does not necessarily subside within the recovery period, as the clinical recommendations for immunosuppressed individuals remain and need to be implemented by the family independently following discharge from the hospital. To further explore stress throughout all stages of the phenomenon, the double ABC-X model, adapted from Hill’s ABC-X model (1958, p. 143) by McCubbin and Patterson (1983, p. 7) was ultimately deemed suitable for the study, because the focus is on families and functioning following the initial crisis period and how existing and accessible resources may influence coping, as opposed to families who are currently within the acute crisis period or within a state of chronic crisis.

This model was utilized to “identify, describe, and integrate the process components of family behavior in response to a stressor and to a family crisis” (McCubbin & Patterson, 1983, p. 7). This was conceivable because the double ABC-X model has expanded upon the ABC-X model to include a post-crisis period of adjustment for families, as they not only have to address the acute crisis stage but also the resulting events and chronic stress subsequent to the acute crisis period (McCubbin & Patterson, 1983; Smith & Marmon, 2017). Within the analysis and discussion, the model was employed to examine each family’s functioning within each theme, in order to assess how they utilized their resources and how their current and previous levels of functioning may be interpreted (bon-adaptive versus mal-adaptive).
Social Determinants of Health and Health Equity

The social determinants of health were chosen as a means of organizing and labelling the superordinate themes and supporting themes, in order to explore the entirety of the experiences of the participants, regarding all aspects of functioning. The goal was that the analysis moves beyond surface concerns to develop an in-depth understanding of how immunosuppression impacts families, and would also capture how the social determinants of health intersect with the perceptions of the families, which may influence and frame family experiences. As identified within the autoethnography process, considerable levels of stress were noted that occurred consistently throughout the stages of crisis and post-crisis periods, and the impact of the stress was not isolated to any one level of functioning. It was determined throughout this examination that the implications resulting from living with long-term immunosuppression can at times be insidious, and it is not necessarily obvious how this may be impacting the family in regards to processes and societal structures external to the family. Consequently, the social determinants of health were selected for implementation as a guiding framework for the examination of the lived experiences and the experiences of the participant families, in order to explore how the implications of immunosuppression and accompanying stress interact with the factors identified within the framework. This approach produced a comprehensive picture of how long-term immunosuppression interacted with the social determinants of health, and the results were utilized within the creation of the framework that was developed within the study.

The social determinants of health consist of the “primary factors that shape the lives of Canadians,” beyond medical treatments and lifestyle choices, with a focus on the living conditions that Canadians experience (Mikkonen & Raphael, 2010, p. 7). The Government of Canada identifies eleven social determinants of health for Canadians: income and social status,
employment and working conditions, education and literacy, childhood experiences, physical
environments, social supports and coping skills, healthy behaviours, access to health services,

The exploration of the social determinants of health within the autoethnography and the
interpretative phenomenological analysis resulted in the detection of the concept of health equity,
and how this applied to the families within the study. Health inequity was initially noted
throughout the examination of the responses of participants, and then subsequently also explored
within the autoethnography. Through the further exploration, several indications of health
inequity were recognized within the data. Examples of health inequity were noted as a result of
the community disadvantages to families (such as a lack of policies protecting
immunosuppressed individuals from risks within the community) and the recommendations
associated with immunosuppression, as well as within financial implications to the families as a
result of the medical condition and subsequent long-term immunosuppression, that are not
otherwise covered by their governing bodies (such as ongoing medication costs and required
medical travel costs).

Health equity has been defined as: “attainment of the highest level of health for all
people” (Patient Engagement, 2019). Health equity strives to ensure that everyone has the same
chance to be healthy, and also acknowledges that the health of individuals is impacted by “the
quality of care delivered, the patient’s ability to self-manage, and overall genetic makeup”
(Patient Engagement, 2019). Where the social determinants of health and health equity are
interconnected is in how the social determinants of health impact overall health, including the
access to health services, which in turn impacts health equity. How the condition of
immunosuppression interacts with the social determinants of health of the study participants
ultimately intersects with health equity, as this can impact various aspects of the social determinants of health (such as income, social supports and coping skills, experiences within physical environments, and broader systemic interactions).

In conclusion, within this chapter I outlined the research questions and objectives of the study, as well as the theoretical frameworks. This chapter also included an overview of the social determinants of health in Canada and health equity and inequity.
CHAPTER THREE

BACKGROUND AND LITERATURE REVIEW
Background of the Study

Paediatric Solid Organ Transplantation

Evaluations of quality of life post-transplant can be difficult, as the practitioner must consider quality of life pre-transplant and various other factors, such as the social determinants of health (Ratcliffe, 2002; Sokal, 1993). Although transplants can greatly improve life for organ recipients, preexisting conditions can reoccur and complications can arise. For example, in liver donor recipients hepatitis B, C or NANB, and/or tumours can reoccur if this was a concern for the patient pre-transplant, and extra-hepatic manifestations or sequelae may persist after transplantation (Ratcliffe, 2002; Sokal, 1993).

Potential complications of transplants include: renal function impairment, hypertension, viral and opportunistic diseases, and post-transplant lymphoproliferative syndrome (Sokal, 1993, p. 171). Transplants can restore growth and development in children, for example children who have received a liver transplant can experience the following positive results post-transplantation: fewer admissions to hospital, fewer medications required, the ability to return to school, increased independence, and increased opportunities for social interactions with peers (Sokal, 1993, p. 171).

Kidney transplantation in children is widely conducted, utilizing organs from living or deceased donors; and survival rates continue to improve showing excellent long-term outcomes for children who have received a kidney transplant (Anthony et al., 2010; Sweet et al., 2006; Hellgren et al., 1999; Goldstein et al., 2008; Bartosh et al., 2003). Although many studies indicate positive long-term psychosocial outcomes for these children, research also identifies negative impacts including: headaches, fatigue, decreased growth, weight gain, and poor general
health caused by the medication regimen (Anthony et al., 2010; Anthony et al., 2009; Hellgren et al., 1999, Neu, 2006; Shenoy & Webb, 2009; Simons et al., 2008).

Additional studies have reported that mental health concerns may be linked to the medications (including somatic complaints and social/emotional problems), and found that negative side effects of the medications can lead to medication non-adherence (Anthony et al., 2010; Beck et al., 1986; Dobbels et al., 2009; Neu, 2006; Noohi et al., 2007; Qvist et al., 2004). Children experiencing end-stage kidney disease have been found to experience increased rates of anxiety and depression, however it has been shown that this risk typically decreases post-transplant (Anthony et al., 2010; Bakr et al., 2006; Berney-Martinet et al., 2009). Nonetheless, the recommendation is that children continue to be monitored for symptoms (Anthony et al., 2010; Bakr et al., 2006; Berney-Martinet et al., 2009).

Prognosis following liver transplantation in children has also improved, “long-term survival after paediatric liver transplantation is now the rule rather than the exception” (Anthony et al., 2010, p. 564). Research has found that child recipients of liver transplants have “decreased quality of life compared with healthy children peers in the specific domains of physical, psychosocial, social, and family functioning,” and “equal or better quality of life than comparison groups of children and adolescents with other chronic illnesses, such as paediatric juvenile arthritis, asthma, and epilepsy” (Anthony et al., 2010, p. 564).

Previous research on family functioning has indicated that there were no identifiable differences between the functioning of families with a child who is a liver transplant recipient as compared to families with a child who has a chronic illness (Anthony et al., 2010; Alonso et al., 2003; Apajasalo et al., 1997; Bucuvalas, 2003; Hellgren et al., 1999).
Factors that have been shown to contribute to positive outcomes for children who received a liver transplant include: a primary diagnosis of biliary atresia, Caucasian race, and the maternal education level (Anthony et al., 2010, p. 565). Additionally, older age at time of liver transplant has been associated with decreased quality of life post-transplant (Anthony et al., 2010; Bucuvalas, 2003; Taylor et al., 2009).

Research focusing on children who are post-transplant also indicates that other positive outcomes can include: minimal hospitalizations following transplant, normal development in height, and adequate self-esteem (Anthony et al., 2010; Bucuvalas, 2003; Taylor et al., 2009). Considerations that were associated with decreased quality of life include: impacts of medication side effects, reoccurring headaches, development of a secondary comorbid condition, and parental conflicts (Anthony et al., 2010, p. 565).

Qualitative research with children post liver transplant noted that the concerns of children included: restrictions due to physical health concerns, social stressors (bullying), emotional stress (such as anxiety and concern regarding future health, anguish regarding the wellbeing of their parents, and the children blaming themselves for imposing stress on their families resulting from their illness), school (attendance), potential post-transplant complications, body image (such as scars from surgeries), potential for infection, potential for organ rejection and/or need for further surgical intervention, living with a donated organ, treatment specific issues (such as side effects of immunosuppressant medications), long-term care needs, and behavioural responses (such as medication adherence) (Anthony et al., 2010; Ng et al., 2009; Bucuvalas, 2003; Taylor et al., 2009).

Paediatric heart transplantation has increased survival rates and has a better prognosis presently than in the past, and so the primary focus must now fortunately shift from mortality
risks to an assessment of quality of life (Anthony et al., 2010; Kirk et al., 2008). Research has shown that children typically return to age appropriate activities after transplantation, and most report a positive outcome in terms of quality of life, with notable increases reported in physical health and psychological wellbeing (Anthony et al., 2010; Fricker & Lawrence, 1987; Green et al., 2007; Serrano-Ikkos et al., 1999; Uzark et al., 1992; Wray, Radley-Smith, & Yacoub, 1992).

A previous qualitative study found that children described their lives post heart transplant as “mostly good” and “fun” (Anthony et al., 2010, p. 567). However, negative symptoms following heart transplant have also been reported by researchers, including: psychological distress (anxiety, depression, behavioural difficulties, and low self-esteem), increased stress, negative affect, difficulties with social competence, and poor coping (Anthony et al., 2010; Serrano-Ikkos et al., 1999; Uzark et al., 1992; Wray et al., 2005; Wray et al., 2006).

Paediatric lung transplants have become more commonplace, and the prognosis is also improving with time (Anthony et al., 2010; Sweet, 2017; Boucek et al., 2007; Wray et al., 2001). Issues specific to lung transplant include: “a high need for mechanical ventilation before transplant, challenges in surveillance of rejection and chronic rejection using spirometry in younger children, and increased complication related to infection both before and after transplant” (Anthony et al., 2010, p. 568). Research has found that children with cystic fibrosis who received a lung transplant were typically goal oriented and hopeful, but also reported that their concerns included difficulties with returning to normality, anxiety regarding potential rejection, fear regarding prognosis, and discord with parents regarding overprotectiveness (Anthony et al., 2010; Durst et al., 2001).

Paediatric small bowel transplantation provides a quality of life for a child recipient that is “equal to or better than quality of life on parenteral nutrition” (Anthony et al., 2010, p. 568).
Children who have received this transplant typically report a quality of life on par with the general population of school children (Anthony et al., 2010; Sudan et al., 2004). Children are generally capable of tolerating enteral feeding and age appropriate activities after receiving this transplant (Anthony et al., 2010; Sudan et al., 2004).

Decreased functioning at school has been noted across all cohorts of child transplant recipients; however, this could be compounded by missed school days because of surgical appointments, doctor appointments, and/or illness (Anthony et al., 2010, p. 564). Research has also shown that quality of life oriented disclosure of children and adolescents across all cohorts is not consistently congruent with the disclosure of parents, as youth often minimize symptoms, and consequently researchers have made recommendations for additional qualitative research in this field for further clarification (Anthony et al., 2010; Sundaram et al., 2007).

Adolescents may struggle with potential impacts to self-esteem caused by the aesthetic side effects of the treatments (Korsch, Fine, & Negrete, 1978; Meyers, Thomson, & Weiland, 1996; Watson, 2000; Warady et al., 1996). Side effects include: decreased growth, acne, moon-facies, accelerated weight gain, and scarring from catheter insertion, and/or scarring from surgery (Dobbels et al., 2005, p. 385). Interventions that may be beneficial for aforementioned concerns include referring individuals to counselling, dietary counselling, and/or exercise facilitators, as well as providing general support across all domains as needed, such as academic counselling and family counselling (Dobbels et al., 2005; Nevins, 2000; Warady et al., 1996). It is also imperative to offer psychological assistance as required; depression, post-traumatic stress disorder (PTSD), anger, and behavioral problems can occur, and can escalate if not addressed (Dobbels et al., 2005; Griffin & Elkin, 2001; Nevins, 2000). Other concerns that require monitoring in immunosuppressed paediatric individuals can include low self-esteem, minimal
social support from peers, bullying, and family discord (Dobbels et al., 2005; Griffin & Elkin, 2001; Nevins, 2000).

**Paediatric Immunosuppression Post-Transplant**

Immunosuppressant medications are widely used to prevent organ rejection for individuals following solid organ transplantation, and these medications do not impact children the same way as adults, as children metabolize medications differently (Schonder et al., 2010, p. 36). These medications do have adverse effects that can negatively impact the lives of patients (Fridell et al., 2002; Schonder et al., 2010). Side effects can also be fatal; “drug adverse effects are now the leading cause of mortality following transplant” (Schonder et al., 2010, p. 36). One of the common concerns for children following a transplant is infection (Fridell et al., 2002; Schonder et al., 2010). Infections can be the result of “exposure to nosocomial and community pathogens, transmission from the donor organ, or reactivation of previous viral pathogens in the recipient” (Schonder et al., 2010, p. 36).

Children are at risk of developing malignancies while on immunosuppressant medication following transplantation (Schonder et al., 2010; Vajdic et al., 2006). Types of cancerous malignancies that can occur include: skin carcinomas, anogential carcinomas, Kaposi’s sarcoma, and lymphomas, including non-Hodgkin’s lymphoma, and post-transplant lymphoproliferative disorders (Schonder et al., 2010, p. 39). The types of cancers and the severity of risk can depend on the type of transplant, and also on the type of immunosuppression medication prescribed (Schonder et al., 2010; Vajdic et al., 2006).

Post-transplant lymphoproliferative disorders can occur in individuals who are immunosuppressed post-transplant, and mortality can be as high as 50% to 90% (Faye & Vilmer, 2005; Schonder et al., 2010). As with general malignancies, the type of transplant as well as the
type of medication prescribed can alter the risk for post-transplant lymphoproliferative disorders (Fine, 2014; Schonder et al., 2010). Growth abnormalities can occur in children who are immunosuppressed, and these abnormalities can be present before transplant due to the impacts of the initial disease (Fine, 2014; Schonder et al., 2010).

Developmental delays can arise within the spheres of physical, cognitive, and psychosocial development (Schonder et al., 2010). After solid organ transplantation, children typically experience catch-up growth to varying degrees, where their growth percentiles begin to approach normalcy, as compared to children who have not undergone a transplant (Fine, 2014; Schonder et al., 2010).

Children who have received a transplant have higher rates of hypertension than found in the general population due to immunosuppressant medications (Schonder et al., 2010; Siirtola et al., 2005). These rates are known to be highest for recipients of kidney transplants, and hypertension can contribute to risk for cardiovascular disease and graft failure (Schonder et al., 2010; Sorof et al., 1999). Dyslipidemia can also develop post-transplant, which also contributes to the risk for cardiovascular disease; it has been known to be highest for recipients of heart and kidney transplants, and is a major cause of death (Schonder et al., 2010; Seeman et al., 2006; Tejani, 1994).

Post-transplant diabetes mellitus is less prevalent for children than it is for adults, and is caused by long-term immunosuppression (Schnitzler, 2003; Schonder et al., 2010). The rates of post-transplant diabetes mellitus are higher for recipients of heart transplants, as compared to individuals who received liver or kidney transplants (Al-Uzri, Stablein, & Cohn, 2001; Bartosh et al., 2003; Paolillo, 2001; Schonder et al., 2010). Renal function is known to decline for those who received transplants other than kidney (Alonso, 2004; Schonder et al., 2010).
In liver transplant recipients, “the incidence of end-stage renal disease that requires dialysis or kidney transplantation is reported to be 3% at five years and 9.5% at thirteen years after transplantation” (Schonder et al., 2010, p. 43). The risk for renal failure also varies based on what type of immunosuppressant medication is prescribed (Filippo, Cochat, & Bozio, 2006; Schonder et al., 2010).

Neurological adverse effects, that can include symptoms from insomnia to hallucinations, can be caused by immunosuppressant medication; intravenous corticosteroids are of high risk for the development of adverse neurological effects (Schonder et al., 2010). Cosmetic adverse effects caused by immunosuppressant medication in paediatric transplant recipients can include: “gingival hyperplasia, acne, hirsutism, and infections, such as folliculitis and warts” (Schonder et al., 2010, p. 44). Electrolyte imbalance is also of concern with the long-term use of immunosuppressant medication, “serum magnesium and potassium levels can be affected by Ciclosporin and Tacrolimus” (Schonder et al., 2010, p. 45).

**Immunosuppressant Medications**

The field of transplantation has seen significant gains and developments within the last few decades, including advancements in “surgical technique, graft perseveration, critical care management, understanding of immune response, and immunosuppression management” (Blondet et al., 2017, p. 193). Immunosuppressant medications are a class of drugs that “suppress, or reduce, the strength of the body’s immune system” (Giorgi, 2016). The role of immunosuppression following transplant is to prevent allograft rejection and/or immune-mediated graft injury by “altering or inhibiting the normal host immune response to foreign antigen” (Blondet et al., 2017, p. 193). Immunosuppressant medications are not only prescribed to patients post-transplant to prevent rejection of the transplanted organ, but also prescribed to
patients to treat autoimmune disorders, such as lupus, psoriasis, and rheumatoid arthritis (Giorgi, 2016).

Immediately following a transplant patients are typically provided with higher doses of immunosuppressant medications, called induction immunosuppression, and with time patients are usually titrated to a lower dose of a medication for maintenance immunosuppression (Giorgi, 2016). All immunosuppressant medications increase the risk for infection due to the weakened state of the immune system, and infections in those who are immunosuppressed can be harder to treat and occur more frequently (Blondet et al., 2017; Giorgi, 2016). It is imperative for practitioners to achieve an appropriate balance with immunosuppressant medications, with the goal of “preventing rejection, yet avoiding excess immunosuppression and incurring risk of infection, malignancy, and drug-specific toxicities” (Blondet et al., 2017, p. 193).

Immunosuppressant medications have a “narrow therapeutic index,” and “pharmacokinetic variability negatively affects long-term transplantation outcomes” (Filler, 2007, p. 1241). Side effects from immunosuppressant medications can include: tremor, diarrhea, nausea, constipation, dyspepsia, insomnia, edema, dyspnea, arthralgia, acne, mouth sores, and paresthesia (Harrison et al., 2017, p. 1). Immunosuppressant medication can cause risks for birth defects as well as risks during pregnancy and breastfeeding (Giorgi, 2016). Interventions to manage potential side effects can include: adjustment of immunosuppressant or other medications, drug therapy, and non-pharmacologic approaches and varied according to perceived causal attribution (Harrison et al., 2017, p. 1).

The process of metabolizing drugs, including immunosuppressant medications, differs in children as compared to adults, as children have increased pharmacokinetic variability due to “developmental changes of enzyme activities,” and also age-related physiological changes can
impact “absorption, distribution, metabolism, and elimination” of immunosuppressant medications (Filler, 2007, p. 1241). Due to the complexity of the metabolism of immunosuppressant medications in children, routine pharmacokinetic monitoring is required and is highly important (Filler, 2007; Giorgi, 2016; Harrison et al., 2017).

Medication non-adherence is a serious and potentially fatal concern post-transplant, “the effectiveness of any treatment does not only depend on the right choice of therapy, but largely also on the active cooperation of the patient in the therapeutic regimen” (Bunzel & Laederach-Hofmann, 2000, p. 711). Variables that may be used as predictors for post-transplant non-adherence include: demographic variables (age, marital status, gender), psychological variables (anxiety, denial), psychiatric disorders (major depression, anxiety, body dysmorphia, and personality disorders), poor social support, pre-transplant non-adherence, obesity, substance abuse, and health-related variables (distance from transplant center, indication for transplantation, required pre-transplant assist device) (Bunzel & Laederach-Hofmann, 2000, p. 711). Medication non-adherence can become a critical concern for paediatric patients; non-adherence can cause late graft failure, a need for a re-transplantation, and can be fatal (Rianthavorn et al., 2004, p. 778).

Disengagement with medical recommendations from healthcare providers is a complicated issue, as well as incredibly important to address in order to maintain the health of individuals receiving care and their families. Research has shown that disengagement with medical recommendations is a “stable personality attribute” that persists over time, and so disengagement must be handled directly with the patients in order to address the behaviours and to provide early intervention (Rianthavorn et al., 2004, p. 778).
Transplant recipients “should be regarded as a chronically ill patient population in whom behavioural and psychosocial management is equally important as state-of-the-art medical management” (Dobbels et al., 2005, p. 381). As immunosuppression is often regarded by medical practitioners as an acute side effect, as opposed to recognized as a chronic medical condition, moving towards a chronic disease management model would likely be beneficial. This would put the individual in the center of care, maintain continuity in care, address psychosocial and behavioral concerns, and actively involve the individual in their own care, which has been shown to improve health outcomes (Bodenheimer, 2002; Bodenheimer, Wagner, & Grumbach, 2002; Dobbels et al., 2005; World Health Organization, 2002).

A chronic disease management model is defined as: “ongoing care and support to assist individuals impacted by a chronic health condition with the medical care, knowledge, skills and resources they need to better manage on a day to day basis” (Interior Health, 2020). A chronic disease management model includes regular visits and care from existing professional supports, including but not limited to: the family physician, other primary care provider (such as nurse practitioners), community-based programs, specialist programs, and/or other services (such as counseling and dietary support) (Interior Health, 2020).

Research has indicated that education alone is not effective in preventing disengagement with medical recommendations, and a combination of educational, behavioral, and social support oriented interventions is likely most beneficial (Dobbels et al., 2005; Haynes et al., 2002; Mcdonald, Garg, & Haynes, 2002; Peterson, Takiya, & Finley; 2003; Roter et al., 1998;). Educational sessions for individuals should be engaging, and healthcare providers should involve the individual seeking care actively within the educational process, while acknowledging and
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respecting the individuals’ experiences, preexisting knowledge, wishes, and beliefs (Dobbels et al., 2005; EBPG Expert Group on Renal Transplantation; 2002).

Recommendations and Guidelines for Immunosuppressed Patients

There are numerous clinical recommendations, provided by medical experts specializing in post-transplant care and management to immunosuppressed individuals and their families, in order to promote health and wellness. These recommendations are primarily regarding diet, hygiene, cleanliness, and social interactions. The recommendations are predominately consistent across organizations and facilities; this clinical guidance is mutually agreed upon and not outwardly disputed by any leading accredited medical professionals at time of writing.

There are ninety-three recommendations for the best-practice management of liver donation recipients as per the American Association for the Study of Liver Diseases. However, these recommendations for patient management of immunosuppression would likely be transferrable to all organ donation recipients (Lucey et al., 2012, p. 3). Recommendations for immunosuppressed patients of all ages can vary based on levels on immunosuppression (Sick Kids Hospital, 2012). Some examples of recommendations for maintaining hygiene include: frequent hand washing (Lucey et al., 2012, p. 3) and/or carrying hand sanitizer at all times (John Hopkins Hospital, 2015); avoiding artificial fingernails, manicures, and pedicures (John Hopkins Hospital, 2015); and avoiding the sharing of personal items, such as nail clippers (John Hopkins Hospital, 2015).

Examples of recommendations for diet include avoiding raw or undercooked foods (John Hopkins Hospital, 2015); avoiding improperly refrigerated foods (Sick Kids Hospital, 2012); avoiding consumption of untreated or minimally treated water, such as lakes, rivers, and wells (Lucey et al., 2012, p. 3); avoiding unwashed fruit, vegetables, or fresh herbs (UC Davis Medical
Center, 2015); avoiding unpasteurized foods (UC Davis Medical Center, 2015); avoiding consumption of leftover food (John Hopkins Hospital, 2015); and avoiding the consumption of food that has past the expiry date (John Hopkins Hospital, 2015). The recommendations regarding cleanliness include avoiding direct contact with animal feces and urine, such as cleaning a litter box (John Hopkins Hospital, 2015); vacuuming, mopping, and dusting the home weekly (Sick Kids Hospital, 2012); washing linens, pajamas, and towels weekly (Sick Kids Hospital, 2012); washing all dishes and utensils in a dishwasher, or in very hot water if there is no access to a dishwasher (Sick Kids Hospital, 2012); and cleaning all surfaces, especially commonly touched surfaces, with disinfectant regularly (Sick Kids Hospital, 2012).

Social and lifestyle recommendations include limiting contact with soil and sun (Lucey et al., 2012, p. 3); avoiding contact with wood-ticks and/or mosquitos (Lucey et al., 2012, p. 3); avoiding people at risk for transferring illness (John Hopkins Hospital, 2015); avoiding travel to developing countries and people who have recently travelled to developing countries (Lucey et al., 2012, p. 3); avoiding crowds or crowded places, such as public transportation, when prescribed high doses of immunosuppressant medication (Lucey et al., 2012, p. 3); avoiding herbal or “alternative” medications and treatments (John Hopkins Hospital, 2015); and avoiding high-risk behaviours, such as unprotected sex (John Hopkins Hospital, 2015). Other important recommendations include avoiding aspirin-like products, avoiding probiotics, avoiding enemas or suppositories, avoiding grapefruit (can decrease effectiveness of medications), carrying a list of medications at all times, and considering wearing a medical alert bracelet to inform of one’s immunosuppression (John Hopkins Hospital, 2015). As there are many recommendations for individuals who are immunosuppressed, following these recommendations may be more difficult for children and adolescents than for adults.
Sick Kids Hospital, located in Toronto, Ontario, provides recommendations via their website for children who are immunosuppressed specifically. Sick Kids Hospital stresses the importance of hand washing (for both children and family members) and keeping the home clean, such as wiping down toys regularly (2012). Sick Kids urges families with immunosuppressed children to avoid contact with those who may have an infection, avoid crowds (as able), avoid communal play areas and daycare or school (when immunosuppression doses are high), avoid the sharing of personal and household items (such as drinking glasses), request to be kept away from other patients if visiting the doctor or hospital (such as waiting within a private room rather than in the waiting room), and to screen any potential visitors for illnesses (Sick Kids Hospital, 2012). Sick Kids Hospital also emphasizes the importance of regular vaccinations for all family members in order to reduce the risks of contracting an infection for children who are immunosuppressed (2012).

**Literature Review**

The purpose of this review is to explore the existing literature that is associated with, or has influenced, the understanding of children who are immunosuppressed and their families. There are many influential studies on families and children who are experiencing medical concerns, however a bulk of the most renowned research appears to have been conducted over a decade ago, thus more current research would likely be beneficial. The review concludes with a brief overview of the gaps within the existing research, as well as a recommendation for additional research in the field of immunosuppression. Traditionally, literature reviews associated with interpretative phenomenological analysis studies are notably condensed and evaluative (Smith, Flowers, & Larkin, 2013, p. 45). This literature review abided by this custom, and through this process I ultimately recognized a potential gap in the literature regarding
exploring immunosuppression as a condition, as opposed to a side effect of required medications, which subsequently became one of the main features of the study. Additionally, although the previous research that has been conducted on families and stress associated with medical conditions can be applied to families living with immunosuppression, much of this research was written with a focus on a specific illness (such as childhood cancer), and an opportunity for more focused research on immunosuppression was indicated, in order to investigate the impacts specific to this condition.

**Children Experiencing a Medical Crisis and the Parental Response**

A medical crisis was defined within this study as an acute medical event that has significant potential for harm and/or fatality. Although each case is unique, parents of ill children face significant stress and potential risk for the development of mental health concerns (Board & Ryan-Wenger, 2003; Colville et al., 2009; Jee et al., 2012). Previous research has found that common stressors reported by parents with children who are experiencing a medical crisis include: “the hospital environment, inconsistent communication, alterations in a child's appearance and parental role, and uncertainty relating to a child's illness and future prognosis” (Stremler et al., 2017, p. 36). Additional research has shown that parents of children who are admitted to paediatric intensive care units (PICU) are at risk for considerable psychological stress, including anxiety, depressive symptoms, and conflict regarding decision making (Board & Ryan-Wenger, 2002; Colville et al., 2009; Rees et al., 2004; Stremler et al., 2017).

Research has also found that parents of hospitalized children can experience concerns including, but not limited to: increased stress, decreased sleep, disrupted sleep, restlessness, and difficulties falling asleep (Matthews, Neu, Cook, & King, 2014; McCann, 2008; McLoone, Stremler et al., 2017; Wakefield, Yoong, & Cohn, 2013). Sleep deprivation can lead to decreased
psychological and cognitive functioning, increased anxiety, increased depression, and decreased decision-making abilities (Nilsson et al., 2005; Stremler et al., 2017). A previous study that sampled 188 parents (74 mothers and 44 fathers) of 91 children admitted to a PICU, ultimately found that about 25% of the parents in the sample presented with symptoms of anxiety, over 50% presented with symptoms of depression, and over 25% reported difficulties regarding decision making (Stremler et al., 2017, p. 42). The study also found that potentially effective means to mitigate these risks and to promote wellness include: consistency in schedule, sleep hygiene, and adequate social supports (Stremler et al., 2017, p. 42).

Archival studies conducted in the 1970s had identified possible causes of significant stress for parents with children who are admitted that include: anxiety and fear regarding the prognosis and general outcome for the child; transitioning to a new environment outside of the home; and distress regarding the role of the parent and the child, including changes in the responsibilities of the parents and changes in the behaviour of the child (Miles, 1979; Miles et al., 1984). It has been noted in the archival studies, and corroborated by more recent research, that mothers and fathers may potentially react differently to stress; and practitioners should consider that parents need to be educated on how their children will change, how their roles will change, and how their lives will change when a child is admitted to hospital (Board, 2004; Miles et al., 1984; Miles, 1979). Although this venerable research remains beneficial to understanding the complete embodiment of the phenomenon of families and stress, as noted previously it appears that an appreciable amount of the most renowned research in this area was conducted ten or more years ago, and so maintaining a focus on generating current research is imperative to ensure that the evolution of the literature and the phenomenon continue to occur concurrently.
Research indicates that stress levels are generally higher for families with a child admitted to a PICU versus families with a child admitted to a general ward, with increases in parental response symptoms including: poor coping, depression, anxiety, and anger (Board & Ryan-Wenger, 2002; Board, 2004; Stremler et al., 2017). The stress that families face while a child is admitted to a PICU does not always end after discharge, families can continue to experience significant stress, as well as report that their families are dysfunctional compared to their functioning pre-admission, for up to six months (or longer) after discharge (Board & Ryan-Wenger, 2002; Colville et al., 2009; Rees et al., 2004; Stremler et al., 2017). The stress experienced by families with children in a PICU was shown to continue to be elevated post-discharge, as compared to families with children admitted to a general ward (Rees, Gledhill, Garralda, & Nadel, 2004; Stremler et al., 2017). Research has shown that stress levels and the longevity of stress for families appeared to increase with the severity of the illness, however, additional longitudinal research is imperative to further investigate how these outcomes and stress for families evolve over time in response to specific aspects of illness and recovery (Board & Ryan-Wenger, 2002; Stremler et al., 2017). Although there is a number of valuable studies concentrating on the children experiencing illness, a majority of the studies that focus on the adult caregivers concentrate primarily on parents (typically the biological parents), however, additional research into other family members and caregivers would likely be beneficial, as this may provide more scope and understanding of how this stress impacts all members of the family (such as extended family, step-parents, and multi-generational cohabitating families).

Notably, more research has been conducted with mothers of ill children than fathers. However, the perspectives of the fathers are equally valid and can provide a more complete picture of family life, and so further research specifically on fathers would likely contribute
valuable insights (Board, 2004; Board & Ryan-Wenger, 2000). Typically, fathers are undersampled, and often their perspectives are not analyzed independently from those of the mothers (Board, 2004; Board & Ryan-Wenger, 2000). Research has shown that fathers tend to show high stress while their children are receiving procedures that can be painful and invasive, particularly in hospital settings (Board, 2004; Miles et al., 1984). A study that consisted of 15 fathers with children admitted to a PICU and 10 fathers with children admitted to a general ward, noted that fathers reported three significant stressors: not knowing the best way to help their child (93%), not being able to hold their child (80%), and not being able to provide care to their child themselves (80%) (Board, 2004, p. 246). Although focusing specifically on fathers within this previous research is critical to refocusing the perspective of gaining information from male caregivers pertaining to family life, it may have also been of interest to compare the results to responses from mothers, in order to explore any potential differences and similarities.

Previous research has found that in addition to being at risk for increased symptoms of anxiety and depression, mothers with children who are admitted to a PICU are also at risk of developing posttraumatic stress symptoms (Colville & Gracey, 2006; Miles et al., 1984; Rees et al., 2004). A descriptive study using mixed methods with mothers who had a child admitted to a PICU found that 18% of the mothers who participated presented with significant posttraumatic stress, and 53% reported psychological stress eight months (or longer) post-discharge (Colville & Gracey, 2006, p. 54). This study also found that mothers who presented with higher stress levels at the time of admission were more prone to posttraumatic stress symptoms than mothers who did not (Colville & Gracey, 2006, p. 49;). The responses of the mothers within this study appeared similar to the responses from fathers within other research (Board, 2004) in reporting that witnessing their child undergo medical procedures was highly stressful, mothers also
reported that reminders of the PICU environment could trigger them to experience trauma-oriented flashbacks after discharge (Colville & Gracey, 2006, p. 49). It also may have been of interest in this study to obtain and include responses from the fathers, in order to provide a more thorough embodiment of the family response, as well as to compare any potential divergences in the responses between parents.

**Children Experiencing Long-Term Illness and/or Disability and the Family Response**

Diagnoses of childhood illness and/or disability represent a challenging and frightening time for families, with a significant risk for trauma for both the child and the family. The primary concern for the family is typically if the child will survive, but other concerns can include numerous procedures for the child (many of which can be invasive and painful), extensive or repeated hospitalizations for the child (this can be short-term or long-term based on the presentation and/or longevity of the illness), changes to the parenting role, changes to the care available for other siblings, and changes to the parent-child relationship (Board & Ryan-Wenger, 2003; Colville et al., 2009; Jee et al., 2012; McCubbin et al., 2002; Stremler et al., 2017). The survival rates of many illnesses are improving. Consequently, practitioners have fortunately been tasked with transitioning from focusing on how a family will cope with an illness causing probable mortality, to how a family will cope with changes and adapt to a potentially chronic, but manageable or curable, illness (Eiser, 1998; McCubbin et al., 2002). As prognoses of illnesses are changing, continued research on individuals and families is imperative to accompany this evolution, to ensure that a comprehensive understanding follows this transition and the resulting outcomes.

Risks to families facing long-term illness include the development of posttraumatic stress symptoms, marital/family discord, marital separation or divorce, depression, and anxiety
Research has shown that families who engage in active coping are less prone to anxiety, depression, and marital discord, and also have better relationships with medical professionals (Dahlquist et al., 1993; McCubbin et al., 2002).

Previous studies have also indicated that families can experience positive outcomes specific to having a child with a chronic illness and/or disability, such as immunosuppression following solid organ transplantation, including: the enhancement of both personal and spiritual growth, a more well-defined sense of purpose, improved relationships and social networks, enhanced coping skills (as compared to baseline functioning before the diagnosis), increased adjustment abilities for the family, more positive attachments, a sense of inner peace and contentment, and a more prominent sense of reward from parenting (Hall et al., 2012; Hastings et al., 2002; Stainton & Besser, 1998). As there appears to be a fair quantity of research regarding negative impacts of families facing medical complications, or deficits-based research, an expanded focus on positive impact, or strength-based research, would likely be beneficial in order to provide a more holistic comprehension of the family response to stress and alternative views into the outcomes associated with the phenomenon, both positive and negative.

Research on chronic illnesses in childhood has shown that there is a correlation between family characteristics (such as coping and resiliency) and child quality of life (Bowden et al., 2017; Fredericks et al., 2007; Shemesh et al., 2000). Families who exhibit high levels of unaddressed parental stress may be at risk for decreased engagement with medical recommendations, decreased health outcomes, increased risk for marital discord, and decreased quality of life (Bowden et al., 2017; Fredericks et al., 2007; Shemesh et al., 2000). Research with families of infants who have been diagnosed with serious liver disease has provided evidence
that families were resilient, for the most part (Bowden et al., 2017; Gavin & Wysocki, 2006). A mixed methods study with 37 parents (mothers and fathers) of infants with liver disease found that predictors for infant emotional outcomes include: “illness severity, diagnosis, and parent perception of the impact of the illness on the family,” and as a result it was indicated that assessments for families with a focus on providing early intervention to prevent negative emotional impacts for the infants would likely be beneficial (Bowden et al., 2017, p. 528).

Although this study focused on families with infants, these results would likely be applicable to families with children of various ages, as other previous research with children has also identified a need for early multifaceted assessments for families to address and mitigate any potential risks to overall functioning and coping (Stremler et al., 2017, Wise, 2002).

Several childhood diseases can lead to the need for a solid organ transplant, such as biliary atresia and liver transplantation. A qualitative descriptive study focused on families of children diagnosed with biliary atresia (18 parents of 12 children diagnosed with biliary atresia) found that families reported “emotional stress, need for social support, lack of education, and financial burden” as well as feelings of “guilt, anger, helplessness, fear of the future, and worry” as significant concerns, but also found that the families reported that they valued support from “hospital staff, friends, family, and co-workers” (Erlichman et al., 2005, p. 395). Research has also shown that addressing the needs of the families can achieve patient and family centered care, improve coping, decrease disengagement with medical recommendations, improve health outcomes, and improve overall individual and family satisfaction with the care experience (Bodenheimer, 2002; Bodenheimer, Wagner, & Grumbach, 2002; Dobbels et al., 2005; Erlichman et al., 2005; World Health Organization, 2002). Several of the aforementioned studies identified the importance and need for thorough assessments of overall family functioning and
subsequent early intervention for families who may be struggling. A clear framework and/or specific recommendations to facilitate these assessments, and to address potential areas of concern, may be beneficial in order to assist practitioners in the implementation of these recommendations in clinical practice.

**Family Cohesiveness and Wellness in Times of Medically Oriented Stress**

Family cohesiveness is extremely important in preserving wellness for the family unit; and although this is true for all families, it is particularly pressing for those facing chronic stress, such as caring for a child with long-term illness and/or additional support needs. Stress can be harmful to all members of the family, including siblings, as the relationships between siblings are some of the most important, and can impact the shaping of identity, the life course experiences, and the social-cognitive development, throughout childhood (Goeke & Ritchey, 2011; Woodgate et al., 2016). Siblings of children with chronic illness and/or complex care needs can experience anxiety, fear, worry, and helplessness when watching their sibling struggle with emotional and physical pain (Besieret al., 2010; Prchal & Landolt, 2012; Woodgate et al., 2016; Woodgate, 2006). Caring for a child with complex care needs also impacts the ability of the family to participate in various aspects of life (such as social engagements), which may also contribute to potential negative outcomes for siblings, including the potential for the development of negative emotional and behavioural problems (Goeke & Ritchey, 2011; Valentine & Lowes, 2007; Woodgate et al., 2016). Actively working together to protect children with additional support needs can increase family cohesion (Prchal & Landolt, 2012; Woodgate et al., 2016). However, it is also important to support the entire family, especially in stressful times, to take care of themselves and to participate in self-care and things that they enjoy as regularly as possible (Prchal & Landolt, 2012; Woodgate et al., 2016).
In addition to the wellness of the child with long-term immunosuppression and their siblings, the wellness of the parents or primary caregivers is also an important consideration. Research focused on children with complex care needs has found that parents take on many roles in caring for their children, and this can lead to increased stress (Alsem et al., 2013; Smith, Swallow, & Coyne, 2015; Woodgate et al., 2015). The roles of parents can include the preexisting roles of caregivers, but also the roles of nurse (assisting with the care required for their child as able), the role of a student (learning about the illness and how to provide care), and a patient advocate role (ensuring that the care their child is receiving is timely, safe, and accurate), in addition to their existing responsibilities, such as employment, the role of spouse, and the role of parent to their other children; these roles can also change with the needs of the child and evolve as the child matures (Black, Holditch-Davis, & Miles, 2009; Bourke-Taylor, Cotter, & Stephan, 2013; Woodgate et al., 2015). This increase in stress, and the demands of the parents, can cause a decline in self-care (such as social activities, time together as a couple, and vacations), create caregiver burnout, and impact the wellness of the entire family by causing a decline in the mental health and ability to function for the parents and an increase in marital discord (Kars et al., 2008; Woodgate et al., 2015). For these reasons it is of utmost importance that families maintain wellness and self-care. In regards to the aforementioned need for a thorough assessment process for practitioners to evaluate family functioning specific to current resources and potential areas for intervention, family cohesiveness would likely be beneficial for consideration within this assessment process, in order to assess the overall health and wellness of all members of the family.
Pediatric Transplantation and Immunosuppression

As there are numerous illnesses that may lead to the need for transplantation, there have been various research studies conducted regarding this topic, and consequently there are number of valuable studies focused on the experiences of living donors and donor recipients. A qualitative interpretative study that concentrated on parents donating a portion of their liver to their child found that several themes emerged regarding the experiences of parents while awaiting surgery: “hope of rebirth, mental negotiation while deciding on surgery and choice of donor, coping with the preparation for surgery, and the possible impact on the family of the surgery” (Chou et al., 2009, p. 1684). Another qualitative study used interpretative phenomenology to “investigate the expressed deeper feelings of parents who donated a part of their liver to their own child,” and found that the parents reported that they were primarily concerned about “the total lack of choice, facing the fear of death, and the transition from health to illness” (Forsberg et al., 2004, p. 372).

Subsequent additional research spanning the entirety of the process of living organ donation (such as the initial potential donor testing process and waiting to be approved/cleared as a living donor for the recipient), with a focus on the whole family (such as how this impacted the marriage and relationships with other children, if applicable), may also be of benefit. This would help to gain a comprehensive understanding of the experiences and perceptions of all the individuals within the family throughout the donation process, from the initial diagnosis to the eventual recovery.

A qualitative study focused specifically on the perspectives of care providers who work exclusively within child liver transplantation in clinical settings noted that “the need for long-term immunosuppression and the need for procedural and monitoring interventions were
highlighted as key challenges for liver transplant recipients,” and families often voice that their primary concern is “fear and anxiety” regarding prognosis and future health care requirements for their children (Miserachs et al., 2017, p. 5). A phenomenological study focused on the perspective of 9 children who had received a liver transplantation reported four major themes: the first theme was that children felt “the same but different” after transplant, the second was the “weird” interactions with the medical system experienced by the children, the third was the pain they felt, and the fourth was worry for the wellbeing of their parents (Wise, 2002, p. 86). This study also found that the predominant theme was that the children were striving for normalcy in their lives, and the recommendations included that psychological support be offered to liver recipients and their families throughout each stage of the transplant process (Wise, 2002, p. 74).

More research done directly with children who are undergoing solid organ transplantation would likely be valuable, as this would provide more information about how children experience the process, which would in turn presumably provide additional useable information for practitioners in assisting to reduce any undue stress or turmoil for the children.

**Opportunities for Further and Continued Research**

A study that analyzed the contributions of qualitative research to the field of organ transplantation noted that although qualitative research is less common than quantitative research in this area, qualitative research can address questions about “the effectiveness of interventions or associations between risk factors and outcomes,” especially given the current transition to an auspicious increased focus on “patient-centered research and decision making” (Tong et al., 2013, p. 1390). This study also found that qualitative research on organ transplantation can provide an understanding of behaviours, attitudes, and values, as well as insight into barriers for organ transplantation, difficulties in accessing care, psychosocial outcomes, and non-adherence
with immunosuppressant regimens (Tong et al., 2013, p. 1390). To ensure that the aforementioned needs for qualitative knowledge continue to be addressed, consistent and perpetual qualitative research within the field of organ transplantation is essential. It is also imperative that the research continues to evolve simultaneously with the advances in medical science and available medical care, to ensure that the qualitative research remains current and valid to the experiences of families in present times.

Many studies have identified that immunosuppression resulting from solid organ transplantation can pose a number of health and psychosocial concerns for children post-transplant; however, a thorough search for studies focused exclusively on the impacts of immunosuppression as a condition returned limited results. This could be compounded by the fact that immunosuppression is typically referred to as a side effect of medication and/or the result of an illness or procedure, rather than a condition in and of itself. Although the results of studies focused on children experiencing medical concerns and their families can likely be generalized to the experiences of families with children who are immunosuppressed following solid organ transplantation, these studies often focus on one specific medical illness (such as childhood cancer), and so immunosuppression would likely also benefit from being the exclusive focus of a study, to ensure that the nuances specific to the illness are captured. Consequently, additional qualitative research with immunosuppression as the focal point could provide further insight unique to the condition, and potentially develop a theoretical lens into how different facets of immunosuppression may impact families in all areas of functioning post-transplant.

It is this opportunity for further research that the study sought to employ by exploring the phenomenon from a qualitative perspective, in order to contribute to the existing research on immunosuppression following solid organ transplantation, and as an effort to propose additional
insights and ways of understanding the perceptions of individuals and experiences of families living with immunosuppression, as well as advocating for immunosuppression to be viewed as a condition.

In conclusion, in this chapter I provided a brief background of the condition of immunosuppression, as it is important for context to take the specifics of the condition into consideration when exploring how the condition impacts individuals and families. Additionally, within the literature review I provided further pertinent information from previous relevant studies, while positioning this study within the previous research, and identified potential opportunities for future research.
CHAPTER FOUR

METHODS AND ETHICAL CONSIDERATIONS
Methods

Research Design and Procedures

The research design for this qualitative study was experiential interpretative phenomenological analysis and autoethnography, making this a multi-methods qualitative study. The methods were employed consecutively, not concurrently. However, aspects of the data analysis did occur simultaneously. A qualitative approach was selected, as the proposed goal of the study was to explore my own lived experiences via the autoethnography process, and the lived experiences of the participants via interpretative phenomenological analysis process.

Interpretative phenomenological analysis is an approach concerned with “understanding the experiences of the person in context,” by focusing on how participants interpret their experiences (Braun & Clarke, 2013, p. 332). Autoethnography was also utilized in order to further explore my lived experience as the mother of an immunosuppressed child following solid organ transplantation. Autoethnography is “an approach to research and writing that seeks to describe and systematically analyze personal experience in order to understand cultural experience” (Ellis, Adams, & Bochner, 2011).

Interpretative Phenomenological Analysis

Interpretative phenomenological analysis is formally defined as: “a qualitative research approach committed to the examination of how people make sense of their major life experiences” (Smith, Flowers, & Larkin, 2013, p. 1). As I am a researcher with lived experience in this matter, it was evident to me through my own experiences that the experiences of families with children who are immunosuppressed following solid organ transplantation are unique and can also be quite challenging; consequently, it was determined that exploring the life experiences of families living with immunosuppression is an important first step to better understand the
essence of this phenomenon. Furthermore, interpretative phenomenological analysis was identified as the most applicable research approach to accomplish the proposed goal of capturing the delicate nuances, and exploring the diverse complexities of these lived experiences.

Interpretative phenomenological analysis is both descriptive and interpretative. The descriptive piece was imperative, because this population has been written about sparsely within academic research with a direct focus on immunosuppression. Thusly, it was decided in the early stages of the research that this would be an important part of this study, in order to give participants a voice, and to allow readers to have a brief window into what it means to live as an immunosuppressed family. The interpretative piece was also crucial to moving beyond a surface description of the experiences of participants, and towards a deeper conceptualization of this phenomenon, and the impacts to individuals and families.

Regarding the fundamental epistemological position of interpretative phenomenological analysis, interpretative phenomenological analysis “rejects the idea that objective knowledge is attainable, and therefore could be described as a form of relativism [and] resists taking a strong relativistic stance, instead advocating an interpretative position” (O’Reilly & Kiyimba, 2015, p. 71). The theoretical underpinnings of interpretative phenomenological analysis consist primarily of three areas of philosophical knowledge: phenomenology, hermeneutics, and idiography (O’Reilly & Kiyimba, 2015; Smith, Flowers, & Larkin, 2013).

Phenomenology as a philosophical approach emphasizes the intentionality of human mental activity, and is a means by which researchers strive to understand the world of the participants from the point of view of each participant, while concurrently generating an understanding of how the participants make meaning and sense of the world around them (O’Reilly & Kiyimba, 2015; Smith, Flowers, & Larkin, 2013). The goal of phenomenology is to
“contribute to a greater understanding of the lived experiences of individuals,” with special attention paid to the validity and the individual perception of current experiences and daily occurrences within the lives of the participants, as the perceptions of participants are influenced by their “expectations, assumptions, anticipations, and sensory input” (O’Reilly & Kiyimba, 2015, p. 14). Phenomenology assists researchers in transitioning beyond preexisting conceptions, so that the researcher may see the reality of each participant objectively, which is a process that is referred to as bracketing within phenomenology (O’Reilly & Kiyimba, 2015; Smith, Flowers, & Larkin, 2013).

In qualitative research, hermeneutics is the theory of interpretation, and refers to “the process of interpretation of data which emphasizes the importance of taking into account the context in which it was collected to inform the credibility of the interpretation” (O’Reilly & Kiyimba, 2015, p. 12). Initially the hermeneutic approach primarily consisted of the interpretation of texts, particularly religious texts, and using a circular process hermeneutics noted that in order to understand the meaning of any part of the text, one must acquire an understanding of the meaning as a whole (O’Reilly & Kiyimba, 2015; Smith, Flowers, & Larkin, 2013). The circular process is referred to as the hermeneutic circle, which is concerned with “the dynamic relationship between the part and the whole” at various levels, which is seen in the ways that researchers using interpretative phenomenological analysis move back and forth throughout the data while adjusting the relationship with the data in the process (Smith, Flowers, & Larkin, 2013, p. 28). Hermeneutics also stresses the importance of understanding text in context, including social and historical context (O’Reilly & Kiyimba, 2015; Smith, Flowers, & Larkin, 2013). The application of hermeneutics has since expanded to an increasingly wider range of texts, including literacy works and historical documents (O’Reilly & Kiyimba, 2015;
Smith, Flowers, & Larkin, 2013). A hermeneutic approach is crucial in seeking an interpretive understanding of the human experience, and has also been notably influential in the formulation of interpretivism as an epistemology (O’Reilly & Kiyimba, 2015; Smith, Flowers, & Larkin, 2013).

The third and final major theoretical underpinning for interpretative phenomenological analysis is idiography, which is “concerned with the particular” (Smith, Flowers, & Larkin, 2013, p. 29). The philosophical approach of idiography focuses on “understanding the individual as unique and complex” (O’Reilly & Kiyimba, 2015, p. 4). This can be seen in interpretative phenomenological analysis, as it is consistently committed to the particular, as well as a “sense of detail” and “depth of analysis” (Smith, Flowers, & Larkin, 2013, p. 29). It can also be seen in the ways that interpretative phenomenological analysis focuses on how a particular experiential experience is understood by a participant, from the perspective of the participant and in the context in which the experience occurred (O’Reilly & Kiyimba, 2015; Smith, Flowers, & Larkin, 2013).

Within this study, the data for the phenomenological analysis component was collected via semi-structured interviews, which were audio recorded. Afterwards, I promptly transcribed the data from the audio recordings, in order to avoid losing any insights or details from the interview; no outside transcription services were used. Once transcribed, the data subsequently underwent a detailed case-by-case interpretative phenomenological analysis, with the goal of generating an understanding of the perceptions of the participants regarding their experiences as immunosuppressed families. Data from each participant’s case was compared and contrasted in relation to the other cases through rigorous analysis throughout the process.
Bracketing is traditionally defined as, “a method used in qualitative research to mitigate the potentially deleterious effects of preconceptions that may taint the research process” (Tufford & Newman, 2010, p. 80). Bracketing occurred throughout the study, and although I am a member of this population with lived experience in the area of interest of this study, this was thoughtfully premeditated throughout the process and addressed by constant reflection and consideration for any potential preconceptions. Although it has been argued that true bracketing may not be possible, bracketing has also been viewed as more of a fluid process; “the extent to which researchers develop their understanding of bracketing before embarking on a research project, and both explore and strategize around the particular challenges they may face as a result of their personal history and experience with the topic at hand, may increase the effectiveness of bracketing in supporting the research investigation” (Tufford & Newman, 2010, p. 91).

As complete bracketing would have been incredibly difficult as an insider researcher, although I did isolate my experiences from those of the participants, I also integrated my lived experience through the autoethnography process, and included the analyzed data from the autoethnography throughout the findings and discussion as appropriate. Bracketing was defined within this study as an active process of maintaining a clear and open-mind, free of a rigid agenda or predetermined outcome, throughout all aspects of the interpretative phenomenological analysis, inclusive of the participant interviewing process, the data collection and interpretation, and the analysis of the data. My lived experience did impact the study design, as it occurred before the study was conceived conceptually, and the social determinants of health was identified as a possible framework to be utilized based on initial note taking on the lived experiences throughout the autoethnography (but was only confirmed as appropriate for use following the analysis of the participant data, which occurred simultaneously with the data collection).
Additionally, the stress documented throughout the note taking process within the autoethnography was the initial indication for the decision to utilize family stress theory for the study, however other theories were also identified for potential use as well at this time. Family stress theory was also confirmed throughout the interpretative phenomenological analysis, based on the participant data.

Participants were recruited from throughout Manitoba and Saskatchewan, Canada. Data was collected via semi-structured interviews held either in-person, or over the phone. All interviews were collaborative, and I did consent to participants to ask questions pertaining to my lived experience during the interview, if this was something that the participant was interested in exploring.

**Autoethnography**

Autoethnography was chosen as a means to capture, and subsequently explore, the researcher’s lived experience as a family with a child who is immunosuppressed following solid organ transplantation. Autoethnography uses principals of both autobiography and ethnography to carry out and write an autoethnography, and so as a research method autoethnography is both process and product (Ellis, Adams, & Bochner, 2011). There are various types of ethnography including classical, critical, and autoethnography, and ethnography as a method has also been utilized by other methodological approaches, including discourse analysis (O’Reilly & Kiyimba, 2015, p. 71). There are varied underpinning epistemological positions of ethnographic approaches, for example academics have indicated that “classical ethnography is linked to objectivism, critical ethnography is underpinned by social constructionism, and autoethnography is associated with subjectivism,” and “notions of objectivism and subjectivism, and other
theoretical frameworks, have not been universally accepted by the research community” (O’Reilly & Kiyimba, 2015, p. 71).

I began the initial autoethnography process by writing down my story from start to finish, using personal journal entries and letters spanning from 2013 to 2015 as a guide. I also used family photos from this time period as a reference. This took me several weeks, as I reviewed specific information (such as dates, times, and numerous old photos) to ensure that my mind was engaged in the information and the context, as this occurred in 2014. I then starting the note taking process on the initial story, which consisted of reading and rereading the story to begin the analysis. Through the note taking process, I began to develop potential notes of significance, in order to illustrate the facets of this particular “cultural experience” (in this case, the experience of living as an immunosuppressed family) (Ellis, Adams, & Bochner, 2011). After the interpretative phenomenological analysis on the participant data was well underway, I compared and contrasted the information within the autoethnography with the experiences of the participants, and intertwined the data sets within the discussion of the study.

In regards to the autoethnography that is included within this paper, the original text was edited in order to exemplify the perspectives and epiphanies that I noted via my own personal experiences, as well as focusing on exploring the initial gap that I identified within the existing accessible academic literature (Ellis, Adams, & Bochner, 2011). While some researchers may use autoethnography to encompass an entire study, in this study the autoethnography process was used in addition to interpretative phenomenological analysis, in order to extend upon the positionality statement to integrate my lived experiences within the study in a regimented manner, as the study was conducted by an insider researcher.
The autoethnography process occurred prior to the interpretative phenomenological analysis, and within this process I identified which areas of this study were preliminarily informed by the analysis of the lived experiences, as indicated throughout the note taking process following the formulation of the autoethnography. Both data sets were compared and contrasted, and subsequently the themes from the interpretative phenomenological analysis were interwoven with the notes of significance from the autoethnography throughout the findings and discussion sections.

**Definition of Family**

The study is focused specifically on families; an understanding of the experiences of families with children who are immunosuppressed was sought by interviewing caregivers directly. The definition of family within the study moved beyond the traditional and anachronous definition commonly consisting of married parents with biological children, in order to encompass the diversity of all families. Families were defined as a person, or group of people, bound by love, care, and/or mutual responsibility, in order to achieve a common goal, such as surviving and thriving collectively, and/or raising children (The Vanier Institute of the Family, 2019). Families with children, biological or non-biological, were the focus of this study. Primary caregivers were defined as adult caregivers providing direct care to the child who is immunosuppressed throughout the course of the illness and subsequent transplant and the resulting state of immunosuppression (American Psychological Association, 2019). Families, regardless of gender, sexual orientation, marital status, and/or any other diversification, were welcomed and encouraged to participate.
Participants

A total of eight participants from Manitoba and Saskatchewan were recruited and interviewed for the study. Interpretative phenomenological analysis studies traditionally have smaller sample sizes as compared to quantitative studies, in order to create a rich data set, and to conduct a thorough analysis of the data sets, with the goal of developing an understanding of the experiences of interest within the contexts in which they occur (Smith, Flowers, & Larkin, 2013, p. 49). As interpretative phenomenological analysis studies typically benefit from a concentrated focus on a smaller amount of cases, the number of participants recruited for this study was eight, which is considered to be a large sample size in interpretative phenomenological analysis (Smith, Flowers, & Larkin, 2013, p. 51).

The participants who were recruited for the study using purposive sampling were families who have a child who is immunosuppressed long-term following solid organ transplantation. Purposive sampling was chosen in order to find specific participants who would be able to provide insight regarding the area of interest for the study. The search for participants was conducted through relevant agencies that were contacted directly, such as the Canadian Transplant Association (online support group), Ronald McDonald House, the David Foster Foundation, and the Children’s Hospital (Health Sciences Centre). Ethics approval from the Health Sciences Centre was obtained before the Children’s Hospital was contacted to request the advertisement of the study within the outpatient clinics.

Participants for the study were sought from throughout Manitoba and Saskatchewan, Canada. Only families living in Canada presently, and who were also living in Canada at the time of the transplant, were considered to participate in the study in order to focus on the experiences within the Canadian health system specifically. Manitoba and Saskatchewan were
chosen because the two provinces have similar resources in regards to paediatric solid organ transplantations, as both provinces must send patients out of province for these procedures, typically to either Alberta or Ontario, due to the fact that the procedures cannot be facilitated within Manitoba or Saskatchewan. All in-person interviews were conducted in the homes of the participants, and all out-of-province interviews were conducted over the phone. The ability to conduct interviews over the phone assisted with the recruitment process, as it opened up the ability to recruit from areas that were not easily geographically accessible.

Only the adult parents and/or caregivers were asked to participate in the study. Children were not interviewed in order to avoid limiting the potential of any family to participate in the study (such as families with babies, young children, and/or a child with additional support needs who would not be able to take part in the interview process). If a family consisted of two or more parents and/or caregivers, all caregivers were invited to participate. Within two of the participant families, both primary caregivers participated in the study. As not every member of each family was interviewed, the interview process provided a parental/caregiver perspective on family experience.

Parents and/or caregivers were invited to participate only if they were consistently a primary care provider from the time of the transplant and throughout immunosuppression. Regardless of whether they are a primary caregiver or not, individuals under the age of 18 (the age of adulthood in Manitoba) were not considered for participation. In the two situations where two caregivers from the same family were being interviewed, I (the sole facilitator of all of the participant interviews) offered to conduct the interviews separately to maintain privacy and confidentiality, but in both situations the participants declined and opted to complete the interviews with the other participant present.
Table One: Descriptive Statistics of the Participants

<table>
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<tr>
<th>Category</th>
<th>Number of Participants (n)</th>
<th>Percentage</th>
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<tbody>
<tr>
<td>Gender</td>
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</tr>
<tr>
<td>Female</td>
<td>6</td>
<td>75%</td>
</tr>
<tr>
<td>Male</td>
<td>2</td>
<td>25%</td>
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<tr>
<td>Age</td>
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</tr>
<tr>
<td>25-29</td>
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<td>12.5%</td>
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<tr>
<td>30-34</td>
<td>2</td>
<td>25%</td>
</tr>
<tr>
<td>35-39</td>
<td>1</td>
<td>12.5%</td>
</tr>
<tr>
<td>40-44</td>
<td>2</td>
<td>25%</td>
</tr>
<tr>
<td>45-49</td>
<td>1</td>
<td>12.5%</td>
</tr>
<tr>
<td>50-64</td>
<td>0</td>
<td>0%</td>
</tr>
<tr>
<td>&gt;65</td>
<td>1</td>
<td>12.5%</td>
</tr>
<tr>
<td>Marital Status</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>6</td>
<td>75%</td>
</tr>
<tr>
<td>Not Married</td>
<td>2</td>
<td>25%</td>
</tr>
<tr>
<td>Number of Children</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>3</td>
<td>37.5%</td>
</tr>
<tr>
<td>2</td>
<td>2</td>
<td>25%</td>
</tr>
<tr>
<td>3</td>
<td>1</td>
<td>12.5%</td>
</tr>
<tr>
<td>4</td>
<td>0</td>
<td>0%</td>
</tr>
<tr>
<td>5</td>
<td>1</td>
<td>12.5%</td>
</tr>
<tr>
<td>6</td>
<td>0</td>
<td>0%</td>
</tr>
<tr>
<td>7</td>
<td>0</td>
<td>0%</td>
</tr>
<tr>
<td>8</td>
<td>0</td>
<td>0%</td>
</tr>
<tr>
<td>9</td>
<td>1</td>
<td>12.5%</td>
</tr>
<tr>
<td>Residence</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Urban</td>
<td>6</td>
<td>75%</td>
</tr>
<tr>
<td>Rural</td>
<td>2</td>
<td>25%</td>
</tr>
<tr>
<td>Education Level</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Attended Post-Secondary Education</td>
<td>8</td>
<td>100%</td>
</tr>
<tr>
<td>Household Income</td>
<td></td>
<td></td>
</tr>
<tr>
<td>0-20,000</td>
<td>1</td>
<td>12.5%</td>
</tr>
<tr>
<td>20,000-40,000</td>
<td>0</td>
<td>0%</td>
</tr>
<tr>
<td>40,000-80,000</td>
<td>1</td>
<td>12.5%</td>
</tr>
<tr>
<td>80,000+</td>
<td>6</td>
<td>75%</td>
</tr>
</tbody>
</table>

The participants in the study are notably diverse. The participants ranged from the ages of 25 to 70 years old. In formal education levels they did not vary, as the participants had all
attended post-secondary education to varying degrees, although specific information regarding the type or duration of the education was not obtained. The participants ranged in annual household income from $20,000 or under, to $80,000 or higher. Information about sexual orientation, race, and cultural background was not obtained, as this information was not required specifically for the study.

**Data Collection**

Data was collected for the autoethnography using personal letters and journal entries spanning from 2013 to 2015. Personal family photographs spanning this time period were also used for reference. The final account for the autoethnography was checked against these materials closely for accuracy (regarding times, dates, and specifics) following the initial writing.

Data was collected for the interpretative phenomenological analysis using semi-structured interviews consisting of both open and closed-ended questions, which is commonly the preferred method of data collection in interpretative phenomenological analysis (Smith, Flowers, & Larkin, 2013, p. 57). The semi-structured interviews involved guiding the interaction with a prepared interview outline, which noted the information of interest that was being sought. I also encouraged participants to elaborate beyond the prepared outline, as the participants are the experts on their experiences, and this provided the ability to explore additional themes that arose throughout the interviews. The interview outline that was developed to guide the interviews was based partially on the social determinants of health (as identified within the autoethnography process) to ensure all aspects of functioning were explored; however, as these were open-ended interviews, the interview outline was not strictly adhered to (see appendix).

Each participant was asked closed-ended questions to capture socio-demographic information for descriptive statistics, including age, marital status, number of children, education
level, and socioeconomic status. The semi-structured interviews were an average of 60 minutes in length, and were focused on the participant’s experiences as an immunosuppressed family. When possible, the interviews were conducted in person. However, due to geographical constraints three of the interviews had to be conducted over the phone. At the end of the interviews, each participant was provided with a $25.00 Loblaw’s (Superstore) gift card, as a token of appreciation for their time following the completion of the interview. The gift card amount was inconsequential and was not considered to have coerced participation in the study.

I brought handouts for mental health resources (such as counselling) to each in-person interview to utilize as required. For each phone interview, I researched mental health resources in the area in which the participant lives, prior to the interview. I informed all participants that the resources were available; however, no participant requested the resources. I often checked in with the participants throughout the interviews, by inquiring if they felt comfortable to continue, or if they needed a break or to stop, in order to reduce the risk of any undue psychological harm in discussing difficult experiences. No participant identified any undue duress or distress at any time throughout the interviews, and no participant requested and/or accepted a break, or to stop the interview process.

The interviews were audio recorded; I transcribed each interview verbatim using the recordings. All paper format data was stored in a locked cabinet, and all electronic data was transcribed into password-protected Microsoft Word documents, and stored within a locked computer. For the purpose of acquiring descriptive information about the participants, limited socio-demographic statistics were collected, including: age, socioeconomic status, gender, marital status, and place of residency. In order to protect the anonymity of the participants, no identifying data was included in the study, and values were presented as ranges (such as age).
Although the potential for a second interview with the participants was explored, due to existing obligations and responsibilities of the participants, the participants who commented on this largely identified that although they would be open to participating in future and subsequent research, they did not have the ability to participate in extensive second interviews at this time. However, all participants accepted the request to be contacted following the interview in order to discuss any necessary aspects of the research process, as a means of member checking.

During the interview process, the participants were consulted as to whether they would prefer being referred to using a number/letter value within the study, or to be referred to by an alternative name or pseudonym. Although the majority participants reported that either was fine, two participants gave a strong preference to the number/letter value for reference within the study. Although using pseudonyms may have contributed to a higher level of reader identification with the participants, the wishes of the two participants was honoured and a number/letter system was ultimately used within the study in reference to each participant, with the intent of providing individual preference when possible, as well as to limit any potential risk for misappropriating the experiences of the participants. For example, although the preference for the number/letter value was not explored in detail with the participants, a name can be a deeply personal topic for some, and so if pseudonyms were used in this study, the preference would have been to allow the participants to choose their name. This would limit the risk of inadvertently choosing an inappropriate alternative name for a participant by chance (such as the name of a problematic person in their life, or a deceased friend or relative).

**Data Analysis**

Notes were taken throughout the compiling of the autoethnography document, using the reference materials as a guide. The data that was compiled for the autoethnography was analyzed
by reading and rereading the notes throughout the process, to develop a more detailed description of the experience, and thereupon the final written account was created. Following the establishment of the autoethnography, the interpretative phenomenological analysis commenced. Both research methods were utilized in this study consecutively, but not concurrently, and thus this was a multi-methods study. However, the data analysis occurred simultaneously with the data collection within both research methods, and these processes did overlap, and so although the majority of the work regarding employing the two approaches occurred separately, the analysis and re-analysis of the data did occur synchronously periodically.

Although the means by which data is analyzed using interpretative phenomenological analysis is at times not consistent, and has been implemented as more open to interpretation than universally agreed upon occasionally, the data within this study was analyzed using the generally accepted steps for an interpretative phenomenological analysis, as frequently identified within the existing literature (Smith, Eatough, & Osborn, 2008). The analytical steps that were followed included: looking for themes (beginning with the first case), connecting the themes, continuing the analysis with the other cases, and writing up the final accounts (Smith, Eatough, & Osborn, 2008).

The participant data was analyzed following the conventional iterative and inductive cycle associated with interpretative phenomenological analysis. The analysis of the data occurred consistently throughout the interview process, to ensure that the data collection and the analysis remained concurrent.

I transcribed all of the data; transcribing took place shortly after each interview to ensure that the information remained current, and to avoid missing any subtleties that could possibly get lost with time. After the transcription was completed, each dataset was read carefully and
thoroughly while listening to the audio recording of each interview, and then re-read, in order for full immersion in the data. Note taking regarding any initial ideas took place throughout this process, and the experiences of the participants remained the main focus through constant bracketing.

The datasets were then preliminarily explored regarding language use and semantic content, and notes were taken regarding anything of interest, while bracketing continued in order to stay free from misconceptions and preconceived notions. Throughout this process a set of comprehensive notes and comments regarding the data were generated, which included a descriptive core of comments that captured the essence of the data. The notes and comments then transitioned to a deeper exploratory analysis and more interpretative content, such as patterns and abstract concepts within the data, using a combination of exploratory descriptive, linguistic, and conceptual commenting. Another form of tool that was used to identify patterns within the data was numeration, in order to reflect the frequency in which the themes were indicated within the data, as well as to identify how many participants indicated each recurrent theme (Smith, Flowers, & Larkin, 2013, p. 98).

After the conclusion of the initial exploratory conceptual commenting the analysis then transitioned to the next phase, developing emergent themes. In this phase the focus was shifted from working with the transcript primarily to working with the notes and comments specifically, while reducing the volume of the texts, maintaining the complexity of the texts, and mapping the interrelationships, patterns, and the connections identified in the data within the previous phase (Smith, Flowers, & Larkin, 2013, p. 91). This involved breaking up the data and grouping interrelated pieces of the interviews together, as per the interpretations of the data throughout the phases, in order to transition the initial notes into themes. Particular attention was paid to the
hermeneutic circle aspect of the process, where the part cannot be assessed without understanding the whole, and the whole cannot be assessed without understanding the part (Smith, Flowers, & Larkin, 2013, p. 92).

The themes were then grouped together based on mapping, and any emergent themes that were not strong or did not add to the greater analysis were cut at this time; subsequently any emergent themes that were kept were deemed to be within the scope of the study. Mapping was accomplished by placing all the themes within an ordered list in a separate document. Afterwards, the themes were grouped into related clusters, and finally a table was created to present the themes. The primary approach utilized within the mapping process was abstraction, and the themes were grouped together based on similarities in order to form overarching superordinate themes. All of the themes came directly from the perceptions and experiences reported by participants. The organization and further conceptualization of the superordinate themes was guided by the social determinants of health and family stress theory; both were initially noted as having potential for utilization within the autoethnography process, and this was later established and confirmed throughout the interpretative phenomenological analysis.

The aforementioned processes were applied to each interview (or case) individually, with the use of bracketing following each case analysis as not to bias the subsequent analysis. The themes that were identified within the first interviews were explored within subsequent interviews, and no new themes were identified within the last interview. The superordinate themes across each case were then used to identify patterns across the cases. Connections were made regarding the themes across the entire dataset and the prevalence of each superordinate theme throughout the entirety of the cases, in order to identify whether any themes were
reoccurring throughout the sample. The tables tracking the themes and superordinate themes were then combined to include all the cases in the dataset.

The data sets from the autoethnography and the interpretative phenomenological analysis were integrated within the discussion. The themes that were identified within the interpretative phenomenological analysis that emerged from the experiences reported by the participants were compared to notes of significance resulting from the analysis of the autoethnography. The themes were presented in the narrative using verbatim quotations within the findings section of the study. The final account for the autoethnography was also presented in the findings section, and both data sets were interwoven throughout the discussion, while situated within existing literature. Verbatim quotes directly from the participants were prioritized for inclusion within the findings, as is common in interpretative phenomenological analysis studies, as to ensure that the participants were represented accurately and meaningfully within the study, and the voices of the participants were captured within the write-up and not lost through the process of interpretation (Smith, Eatough, & Osborn, 2008; Smith, Flowers, & Larkin, 2013). Using extracts from the participants in the write-up of the study is also a means to promote transparency, and to ensure that each interpretative claim made is supported by the material directly from the participants (Smith, Flowers, & Larkin, 2013, p. 110).

Rigour and Validity

In regards to ensuring rigour, triangulation and member checking were used as a means to increase the reliability and trustworthiness of the findings. Triangulation was implemented through the use of multiple academic concepts to guide and strengthen the analysis: family stress theory, the social determinants of health, health equity, and the double ABC-X model. The study also utilized two research methods: autoethnography and interpretative phenomenological
analysis. This generated two data sets: my own lived experiences as the researcher, and the lived experiences of the study participants. Member checking occurred following the participant interviews, as participants agreed to be contacted for follow-up conversations (by email or phone) to discuss various aspects of the data, as the process of analysis was concurrent with the data collection. Transparency was addressed by describing the stages of the analysis clearly and thoroughly, describing the means by which participants were selected, describing the interview process, and prioritizing the use of direct quotes from the participants within the findings section of the study (Smith, Flowers, & Larkin, 2013, p. 182).

Sensitivity to the context of the information provided by the participants was premeditated within the study design, and maintained throughout all aspects of the study, such as in developing rapport with the participants, maintaining respect and empathy throughout the interviews, representing participants accurately by ensuring that a considerable amount of verbatim extracts were included in the written report, and considering the wellbeing of participants at all times (Smith, Flowers, & Larkin, 2013, p. 181). Coherence was ensured by reading and rereading the data and the written study, to ensure that there was adequate flow and that ideas remained coherent (Smith, Flowers, & Larkin, 2013, p. 182). In regards to relevance and significance, it was of utmost importance that the study contributed meaningfully, consisted of information that is likely of interest to a potential reader, and presented novel and valid ways of understanding to the existing knowledge of paediatric long-term immunosuppression following solid-organ transplantation (Smith, Flowers, & Larkin, 2013, p. 183). Finally, auditing of the information presented in the study took place via consistent supervision throughout the process (student dissertation, ongoing support from advisor and committee) and through the external examination process (Smith, Flowers, & Larkin, 2013, p. 183).
Ethical Considerations

This study was approved by the Research Ethics Board of the University of Manitoba (REB# HS23077). A possible risk that was considered for participants was any potential stress or discomfort resulting from discussing their experiences. The plan was that the interviews would be stopped at any time if participants were distressed, however this did not occur. I came prepared to each interview with counselling services available in the geographical area of each participant to offer if required, however these resources were not utilized, and most participants reported that they currently have counsellors. Another risk that was considered was that the Principal Investigator was the sole researcher in this study and conducted the interviews alone. To mitigate this risk, I informed my partner (husband) of my general whereabouts (to avoid breaching confidentiality) and when to expect contact. Fortunately, there was no risk perceived during the interviews at any time.

An indirect benefit of the study to participants is the advancement of knowledge and information generated and presented in the study; this information may ideally be used to improve care provided for children who are immunosuppressed and their families. Participants were assured that their privacy and confidentiality would be protected in order to ensure that they would not experience any negative outcomes by participating in the study; however, it was also indicated that absolute confidentiality could not be guaranteed. Privacy will continue to be considered at all times and participants can request that their information be excluded from the study up until the dissertation draft is finalized.

Informed consent was obtained in writing from each participant. The consent form explained the purpose of the study, outlined all possible risks and benefits of the study, and gave information about confidentiality and the role of participant. Consent forms were sent
electronically to all participants for their review during the initial conversations about their 
interest in participating in the study. The consent form and the participant contact card, to ensure 
that the consent documents can be referenced if needed, were the only instances where a name 
from the participant was collected.

The participants were treated with respect at all times, and it was ensured that they 
remained autonomous throughout the entirety of the study. They were provided with all available 
information in order to make informed decisions, and were not coerced in any way. Beneficence 
was maintained throughout the study; it was made certain that the study did no harm, and risks to 
participants were minimizing throughout the design and operationalization of the study. Fairness 
was consistent throughout the study, and all information collected was of relevance to the 
interests of the study (for example, information on ethnicity was not collected, as the initial study 
design did not indicate for certain that this information would absolutely be utilized).

In conclusion, within this chapter I provided a thorough review of the methods used 
throughout the study, as well as the ethical considerations of the study.
CHAPTER FIVE
FINDINGS
Findings

The lived experiences of the participants were analyzed using the family stress theory and the double ABC-X model, in order to explore how each participant experienced and navigated the stress involved with managing immunosuppression long-term as a family. There were many similarities and differences between the experiences of the participants. Each family in the study was considered to have been within an acute crisis state at the time of the illness and resulting transplant surgery. However, the area of focus for the study was not the acute crisis period, but rather the period that has followed, the post-crisis environment and the process in which the participants utilized resources and facilitated coping. While each family’s perception and journey is unique to them, after the participant data was thoroughly analyzed following the confirmation of family stress theory as a suitable theory to explore this phenomenon within this particular study, each family did appear to have moved through the double ABC-X model effectively, and into a healthy state of adaptation in the post-crisis environment. No family was perceived to be in an acute crisis period at the time of the study, such as acute financial stress or stress resulting from a current acute co-occurring medical concern.

Several superordinate themes with supporting themes were developed from the data, and organized using the social determinants of health as a guiding framework, as the themes were quite broad and covered numerous experiences and psychosocial stressors.
### Table Two: Mapping of Superordinate Themes and Supporting Themes

<table>
<thead>
<tr>
<th>Cluster of Related Themes (Social Determinant of Health)</th>
<th>Superordinate Themes and Supporting Themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td>Differences between Mothers and Fathers</td>
</tr>
<tr>
<td></td>
<td>• Mothers being predominant in the exchanges.</td>
</tr>
<tr>
<td></td>
<td>• Mothers as the house-manager (additional responsibilities impacted by child’s illness).</td>
</tr>
<tr>
<td></td>
<td>• Mothers reducing working hours as opposed to fathers.</td>
</tr>
<tr>
<td>Biology and Genetic Endowment</td>
<td>Managing the Medical Aspect</td>
</tr>
<tr>
<td></td>
<td>• Being born sick.</td>
</tr>
<tr>
<td></td>
<td>• Co-occurring disorders.</td>
</tr>
<tr>
<td></td>
<td>• This is our normal.</td>
</tr>
<tr>
<td></td>
<td>• Chronic medical condition</td>
</tr>
<tr>
<td></td>
<td>• Illnesses are longer and/or more severe.</td>
</tr>
<tr>
<td></td>
<td>The Medical Aspect Manifesting in Life</td>
</tr>
<tr>
<td></td>
<td>• Illnesses causing a disruption to life post-transplant.</td>
</tr>
<tr>
<td></td>
<td>• Experiences on the waiting list for an organ transplant.</td>
</tr>
<tr>
<td>Healthy Behaviours</td>
<td>Long-term Management of Immunosuppression</td>
</tr>
<tr>
<td></td>
<td>• Protecting the children and the maintenance of health.</td>
</tr>
<tr>
<td></td>
<td>• Cleaning.</td>
</tr>
<tr>
<td></td>
<td>• Hygiene.</td>
</tr>
<tr>
<td></td>
<td>• Medications.</td>
</tr>
<tr>
<td></td>
<td>• Diet.</td>
</tr>
<tr>
<td></td>
<td>• Routine medical testing.</td>
</tr>
<tr>
<td>Physical Environments</td>
<td>Leaving the Physical Environment of the Home</td>
</tr>
<tr>
<td></td>
<td>• Admissions as a necessity and a disruption of life at home.</td>
</tr>
<tr>
<td></td>
<td>• Difficulties in leaving for leisure (travel).</td>
</tr>
<tr>
<td></td>
<td>Feeling Secure, Protected, and Validated within the Community</td>
</tr>
<tr>
<td>Employment and Working Conditions</td>
<td>Quality Employment as a Support</td>
</tr>
<tr>
<td>-----------------------------------</td>
<td>-------------------------------</td>
</tr>
<tr>
<td>• Safety in schools and in the community.</td>
<td>• Supportive employer as a resource.</td>
</tr>
<tr>
<td>• Community health and hygiene (school system).</td>
<td>• Reduction of work-related stress.</td>
</tr>
<tr>
<td>• Identity of family within the community.</td>
<td></td>
</tr>
<tr>
<td>• Vaccinations: concerns regarding vaccine hesitancy and the anti-vaccination movement (community health concern).</td>
<td></td>
</tr>
<tr>
<td>• Organ donation registry: concerns regarding a lack of an opt-out system (community health concern).</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Income and Social Status</th>
<th>Decreased Income and Financial Impacts to the Family</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Not being able to work and/or cutting back on working hours to accommodate illness.</td>
<td>• Not being able to work and/or cutting back on working hours to accommodate illness.</td>
</tr>
<tr>
<td>• Decreased income.</td>
<td>• Decreased income.</td>
</tr>
<tr>
<td>• Expenses directly related to the illness.</td>
<td>• Expenses directly related to the illness.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Social Supports and Coping Skills</th>
<th>Decreased Contact with Natural Supports</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Impacts on the ability to see friends and family (having to cancel plans).</td>
<td>• Impacts on the ability to see friends and family (having to cancel plans).</td>
</tr>
<tr>
<td>• Screening for illness.</td>
<td>• Screening for illness.</td>
</tr>
<tr>
<td>• Lost friendships.</td>
<td>• Lost friendships.</td>
</tr>
<tr>
<td></td>
<td>Stress and Impacts to the Family</td>
</tr>
<tr>
<td>• Impacts to the relationship with the other children.</td>
<td>• Impacts to the relationship with the other children.</td>
</tr>
<tr>
<td>• Impacts on relationships among spouses (family discord).</td>
<td>• Impacts on relationships among spouses (family discord).</td>
</tr>
<tr>
<td>• Expanding the family after having a sick child.</td>
<td>• Expanding the family after having a sick child.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Importance of External Supports outside of the Immediate Family</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>• The importance of natural supports.</td>
<td>• The importance of natural supports.</td>
</tr>
<tr>
<td>• Importance of support groups as a means of coping and support, online (social media) and in-person.</td>
<td>• Importance of support groups as a means of coping and support, online (social media) and in-person.</td>
</tr>
<tr>
<td>• Difficulties accessing childcare due to special considerations to protect the immunosuppressed child when making decisions regarding childcare.</td>
<td>• Difficulties accessing childcare due to special considerations to protect the immunosuppressed child when making decisions regarding childcare.</td>
</tr>
<tr>
<td>• Having to cancel childcare.</td>
<td>• Having to cancel childcare.</td>
</tr>
</tbody>
</table>
### Individual Management of Stress

- Coping and self-care.

### Access to Health Services

<table>
<thead>
<tr>
<th>Family Experiences within the Healthcare System</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Effectiveness of health services in province of origin.</td>
</tr>
<tr>
<td>• Effectiveness of health services in province that the transplant occurred.</td>
</tr>
<tr>
<td>• Transition from pediatric to adult care.</td>
</tr>
</tbody>
</table>

### Culture

<table>
<thead>
<tr>
<th>Spirituality</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Spirituality and coping.</td>
</tr>
</tbody>
</table>

### Education and Literacy

<table>
<thead>
<tr>
<th>Family Experiences within the School System</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Concerns regarding the transition to the school system.</td>
</tr>
<tr>
<td>• The children who are immunosuppressed within the school system.</td>
</tr>
<tr>
<td>• Missing school.</td>
</tr>
<tr>
<td>• Difficulties at school.</td>
</tr>
<tr>
<td>• Illness hindering the parent’s ability to return to school.</td>
</tr>
</tbody>
</table>

### Childhood Experiences

<table>
<thead>
<tr>
<th>Impacts to Development from Childhood to Adulthood</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Worries about the long-term impact to the child and concern for potential childhood medical trauma.</td>
</tr>
<tr>
<td>• Worries about potential childhood mortality.</td>
</tr>
<tr>
<td>• Concerns regarding implications in adulthood.</td>
</tr>
</tbody>
</table>

### Race/Racism

<table>
<thead>
<tr>
<th>Impact of Race</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Race impacting ability to find a suitable match for transplant.</td>
</tr>
</tbody>
</table>

Although many of the supporting themes were quite predominant throughout the data, others were less so, but still provided an important perspective into the lived experiences of these families. Consequently, all identified supporting themes that were not deemed redundant were included in order to ensure that the phenomenon was thoroughly described. Based on the
literature review, as this appears to be the possibly first qualitative study of this nature, the
description of the experiences was prioritized concurrently with the analysis of the experiences.
Fortunately, because the participants who were recruited were quite diverse in terms of
socioeconomic status, residency, age, and number of children, this added to the robustness of the
findings, by providing the ability to explore the experiences of divergent families.

**Gender**

The three themes that were identified under the superordinate theme of differences
between mothers and fathers within the gender category of the social determinants of health
were: mothers being predominant in the exchanges, mothers as the house-manager (additional
responsibilities impacted by child’s illness), and mothers reducing working hours as opposed to
fathers. The individuals who identified as married were all currently involved in heterosexual
pairings. Five out of the eight participants reported themes related to gender.

<table>
<thead>
<tr>
<th>Gender (62.5%)</th>
<th>Differences between Mothers and Fathers</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>• Mothers being predominant in the exchanges.</td>
</tr>
<tr>
<td></td>
<td>• Mothers as the house-manager (additional responsibilities impacted by child’s illness).</td>
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<td>• Mothers reducing working hours as opposed to fathers.</td>
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**Mothers being Predominant in the Exchanges**

The first theme, mothers being predominant in the exchanges, was observed during the
interviews with the participants who were within a couple, and both participants within the
couple had signed on to the study. I invited anyone who identified as married or in a relationship
to include their partner if applicable, and out of the four married mothers who reached out in
regards to becoming a participant, two of their spouses also signed on to the study. Although I invited the participants to engage in the interview separately, both families were also caring for their young children, and so to assist with the responsibilities of childcare the interviews were conducted while the other person was in the same room at times, and often at times also contributing to the conversation.

This theme was first observed when the female participants interrupted their male spouses and appeared to dominate the conversations at times. An example occurred when A2 interrupted A1 and stated: “you’re answering this for you,” in order to remind him to answer the question from his perspective (the question was directed at A1 during his interview), to which he responded: “I know.” The female partner answered questions for their male partner throughout the process in both instances where both partners were present. For example, A2 stated in response to a question directed to A1 during his interview: “oh yeah, well, I shouldn’t answer this because it’s yours, but yeah.” Another example occurred when B2 interrupted B1’s interview several times as well, but notably answered a question posed to B1 by stating: “we don’t follow all the rules (laughter).” B1 then contradicted this response by stating: “um, we do follow the rules, but they told us that he does need to be exposed to germs, but I mean, she’s a little more lenient than I am…” B2 responded to this statement by saying: “whatever we are doing is working so, yeah.”

Although this observation was of less consequence in comparison to the other themes that were noted, it was included in this study as it was of interest, and was not anticipated to be as predominant as it was observed. However, it should also be noted that in this theme the observance was only seen within a snapshot of their lives, and within the context of a non-normative situation (being interviewed for a research study). Consequently, it is entirely possible
that the observed behaviour was merely a product of the circumstance as opposed to the baseline functioning level of these families.

**Mothers as the House-Manager**

Although no arguments or aggression of any kind occurred during any of the interviews, it appeared that while the female partners were predominant within the exchanges, this was especially evident regarding questions pertaining to the child or the family. This transitioned to the second theme indicated within this category, the mothers acting as house-manager and having additional responsibilities that are impacted by the child’s illness.

The two fathers within the study both reported that their spouse was the primary care provider and managed the majority of the household responsibilities. For example, A1 stated in response to a question directed to him: “I will kind of have to defer that to (A2), because she is always the one who is always dealing with that, school supports and all that.” He also stated in response to a subsequent question posed to him: “…you may defer, I mean my wife deals with all of her medical appointments and stuff like that.” Similarly, when asked about self-care, B1 responded: “I don’t need much away time myself, she needs more away time than I do, because she’s with him all day long, but whenever I am home with him I want to be home with him, so yeah.” In this response he indicates that B2 is the person providing the majority of the care. Both A2 and B2 corroborated these statements, and stated that they handle most of the matters pertaining to the children and the home.

This theme was also noted in conversations with the other participants as well, for example D1 discussed that she was also typically responsible for the majority of the household duties, but indicated that this has lessened as her children age. Other participants spoke about the division of work, inside and outside of the home. For example, F1 spoke at length about how she
and her partner divide all responsibilities pertaining to their family. Alternatively, as noted in the autoethnography, my partner was responsible for the majority of the responsibilities pertaining to the home and the children; however, this decision was based on income primarily. It appears that earning potential may have also been a factor for the participants, for example A1 and A2 spoke about how they are currently financially comfortable, but when further explored did not note any fluctuations in financial stability based on whether A2 was able to take hours within her casual position or not.

Although the division of responsibilities differed throughout families, in this particular group of participants the female managing the majority of the household responsibilities appeared predominant. However, this sample is limited, and further exploration would likely be beneficial to gain a thorough understanding of this conceptually for families. What became evident was that the division of all responsibilities may be more pronounced in response to having a child with long-term medical needs and complexities, as the needs of the child must be factored into the responsibilities of the home (such as tube feeding and administering of medications).

**Mothers Reducing Working Hours as Opposed to Fathers**

This point transitions into the third and final theme indicated within this category, mothers reducing working hours as opposed to fathers. Participants A2, B2, and D1 reported that they reduced their working hours or stopped working completely in order to take care of their children, and that this circumstance was compounded by their child’s health (including the transplant and resulting immunosuppression). A1 stated in regards to A2 taking care of the children and not working currently: “…and so she was home, and so from that perspective we will probably always be a single income family because of that…so for myself, it’s hard, I mean
I am still at work, it’s hard to really maybe say that you are fully dedicated to your job at that point.” He identified that although he is physically out of the home and at work, it is hard for him to be present and concentrate while working because he is often worried about his child’s health, as well as his family at home.

In regards to his spouse B2 not working currently in order to care for their medically complex child, B1 discussed how the ability to find appropriate childcare for their child due to his medical needs has proven to be extremely difficult. B1 stated: “…and that is something that wouldn’t be easily passed along to a babysitter from down the street, and that is why…(B2) is not going back to work right now, she’s taking care of him, so that’s going to be a big adjustment when he goes to school.” In stating that this could not be easily passed along to a babysitter, he is referencing the fact that their child has complex health needs that require relatively complex tasks for a babysitter to be responsible for. Thus, this babysitter could not be just anyone, because they would have to be able to perform the medical tasks required (such as tube feeding and medication administration). The family would have to feel as though they trust this person with their child, and both B1 and B2 stated that they have not found anyone outside of their family that they would trust at this time.

D1 was also not working in order to take care of her child; however, at the time of the interview she was transitioning back into the workforce, which had been difficult for her. She stated: “…like over the past few years it has always been an off and on stay at home mom kind of thing, because of how healthy or sick he has been, or what procedures may or may not be coming up…so that’s definitely impacted my working ability. But since he has been healthy for the past few years now, I am just trying to get back into fulltime work and that so it’s been rough that way.”
In response to a question about employment, A2 described the situation as being “forced” to stay home with the children. She stated: “well I’m more like forced to stay home, but I do work in the evening, now I just went back about a year and a half ago. I just work a couple of evenings per week.” As A2 appeared to be somewhat stressed when discussing this matter, the matter was not explored further in order to avoid causing additional undue stress. She did not discuss the reason for her staying home with the children as opposed to her partner, A1.

Both E1 and F1 stated that they divided the responsibilities of the household equally with their partners, as well as the required reduction of working hours. In regards to working and the division of labour and leave, E1 reported: “my husband didn’t work, because we were based in (name of location) at the time, and you know, I was collecting my maternity benefits…” She states that her husband took time off work (during the time of medical travel) while she was on maternity leave, and they have both since returned back to work, as E1’s mother has fortunately offered to take care of their child fulltime. Additionally, in regards to working and the division of responsibilities, F1 identified that she divides the responsibilities with not only her ex-husband but also her fiancée. She stated: “I am fortunate that during my four days on she is with my ex-husband, so I am able to come home and shower.” F1 and her ex-husband share custody of their children 50/50. Within the essence of this narrative, F1 identified that her ex-husband and her fiancée are both incredibly supportive, and they all have a positive relationship.

In regards to the observed differences based on gender, A2 appeared to be the most reactive, as she described that she felt “forced” to stay home with the children while her husband is working. The reasons for this decision were not unpacked, as causing undue marital discord was something that was actively avoided throughout the interviews. The other two female participants who disclosed that they were not working outside of the home but their male spouses
were did not present as outwardly upset with the situation. D1 explained that she and her husband have supported each other with all decisions pertaining to the family, and in regards to work she stated: “you go from working the odd part-time job and then being at home, and then the odd part-time job and then back at home, um and so trying to get back into work on a fulltime basis has been stressful.”

B2 identified that she and B1 made this decision together based on what they felt was best for their child. She stated: “yeah, I haven’t gone back. Because he is tube fed and his medications are so sensitive, I don’t trust anybody at this point. And the whole vaccination thing and respecting that, and if anybody is sick, so yeah for us, we just… it’s just, it’s what we have decided is best for us right now.” Although B2 stated that this decision was made mutually, she did discuss her need for a break and self-care periodically, and appeared to be notably insightful regarding her needs. She stated: “I know when I am starting to feel like I need a break, and I’ll just, like my mom and sisters are fantastic, like they will come over and watch (child’s name).” None of the participants elaborated as to why the female of the family was chosen to stay home to provide care and to be responsible for the majority of the household responsibilities, as opposed to the male of the family.

It was noted in the interviews that all of the participants who identified that they are now working less, or not working outside of the home, were working previously before having children. Although it is not clear whether or not this would have been altered if all of their children were born without medical complexities, what did become evident is that having a child with medical complexities does often impact the ability to work outside of the home. As noted in subsequent themes within this study, the availability of resources can be negatively impacted by the need for more specific options. For example, the need for safe, hygiene, and at times highly
specialized childcare limits the potential options for childcare, and thus decreases the ability for
the family to work outside of the home, as they must provide the majority of childcare within the
home in response to the lack of feasible options.

**Biology and Genetic Endowment**

The five themes that were indicated under the superordinate theme of managing the
medical aspect within the biology and genetic endowment category of the social determinants of
health were: being born sick, co-occurring disorders, this is our normal, chronic medical
condition, and illnesses are longer and/or more severe. The two themes that were indicated under
the superordinate theme of the medical aspect manifesting in life were: illnesses causing a
disruption to life post-transplant and experiences on the waiting list for an organ transplant. All
of the eight participants reported themes related to biology and genetic endowment.

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<th>Biology and Genetic Endowment (100%)</th>
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<td>• Being born sick.</td>
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<td><strong>The Medical Aspect Manifesting in Life</strong></td>
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<td>• Illnesses causing a disruption to life post-transplant.</td>
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<td>• Experiences on the waiting list for an organ transplant.</td>
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**Being Born Sick**

The first theme, being born sick, appeared to be part of the story-telling process for each
participant. Understandably, they likely wanted to give some context to the situation and to share
how their families came to be where they are now. For example, in regards to their child being
born sick, A1 stated: “...it was kind of like, okay we still don’t know what happened... I’m not so concerned with that really right now; it is what it is.” He described that although previously they were concerned about obtaining a specific diagnosis because they were seeking specific treatment that would be tailored to the diagnosis, they have now stopped focusing on this aspect, and they are still without a diagnosis. They are maintaining their primary focus on managing symptoms and maintaining their child’s wellness, as opposed to searching for answers, because they feel as though the care that their child is receiving is adequate and their child has fortunately been medical stable for some time.

F1 explained that she knew immediately that something was different about her new baby when her child with additional medical needs was born. She stated: “...she was only about twelve hours old, actually when she came out I knew something was wrong with her right away, just because, she had little dysmorphic features, she had one ear higher than the other, I know this sounds silly, but her nostrils, everyone has one nostril bigger than the other, but her nostrils were perfectly round and the exact same size. They are mild, like she doesn’t look like anything is wrong, but as a mom you go over every inch of your baby...” Within the essence of this narrative, F1 described that her motherly instincts made her aware of her baby’s medical concerns as soon as she was born. She then went on to explain that initially the medical professionals caring for her and her baby thought that she was being “paranoid” when she voiced her concerns, however she was ultimately correct, and her baby needed intensive medical intervention shortly afterwards.

It was noted within this theme, throughout the conversations with all of the participants, that there appeared to be a type of grieving that became evident within the storytelling process. For example: grieving their child’s health, their child’s potential ability to live a life free of
medical difficulties, their preconceived notions of their birth story and parenting their newborn baby, and their immediate future as they must now address the medical concerns (such as traveling out of province for emergent surgeries, and subsequent surgeries). This was in addition to the apparent fear for the prognosis of their child, and ongoing fears related to prognosis. As noted in the autoethnography, I can indisputably relate to this grieving process and these fears, and can attest that in my experiences, this is a feeling truly unique to having a child with serious medical concerns.

**Co-Occurring Disorders**

The second theme, co-occurring disorders, was observed as the participants spoke about the additional medical concerns that their children are experiencing. Every child in the study was reported to have some form of a co-occurring disorder, including both physical and mental health concerns. For example, a child who also has a diagnosis of asthma might be more susceptible to acquiring a disease because they are immunosuppressed, but any acquired chest infections may be even more severe and difficult to manage because of the co-occurring disorders. The co-occurring disorders were reported by participants to impact various aspects of their lives, from the family’s ability to see friends and other family members, to their child’s coping at school.

This theme was observed in F1’s explanation of how due to various co-occurring diagnoses, her child’s extensive and complicated required medication regimen impacts their ability to leave the home for social engagements with loved ones, as their child requires several medications at very strict times. Additionally, these medications need to be administered in a routine fashion (such as mixed into yoghurt), as their child has been diagnosed with autism and struggles with disruptions to her routine.
Another example of this theme transpired within A2’s discussions of their child’s co-occurring disorders. He stated: “…just to be clear, our situation, we were just talking about this, like, it’s almost divided into two parts. It’s the physical transplant and then there’s what happened. Like, she suffered a brain injury because of the transplant or something afterwards. So, like, for us, like, it’s almost two separate…” A1 agreed with her statements, and elaborated: “it’s hard to divide the, you know, the immunosuppression part from the rest, right, from the recovery from the brain injury…” They explained that although they are impacted by the immunosuppression, they are also continually impacted by the other medical concerns.

The difficulties discussed by participants in relation to managing not only their child’s immunosuppression, but also their co-occurring disorders, appeared to be significant in all participant families. As noted in the autoethnography, my child typically becomes extremely ill very quickly, as she also has severe asthma, and this has been a constant stressor and cause for concern, concurrently with the condition of immunosuppression. It was evident as the conversations with the participant families evolved throughout the interviews how intertwined the co-occurring medical conditions are, but also that all of the participant families consider immunosuppression to be a condition, as opposed to a side effect resulting from the transplantation.

This is our Normal

The third theme, this is our normal, is linked to the first theme but listed separately, as this theme was observed when the participants normalized their circumstances and spoke about not knowing anything other than their current reality, and consequently had nothing to compare it to. D1 explained that they were already experiencing medical concerns for their child’s entire life leading up to the transplant, so coping and functioning post-transplant was not overly
difficult for them. She stated: “...yeah he’s been good with it, because it was nothing new for us...” She described that because their child required so many invasive tests and surgeries leading up to transplant, that they were always careful and mindful of his medical needs as a family, so the transition to living with the recommendations associated with immunosuppression was not difficult for the family. For example, many of the recommendations, such as cleanliness and screening for illnesses, were already well ingrained within their routines.

B1 and B2 explained that they knew their child was going to be born with additional medical needs while the child was still in utero. B2 stated: “...he was 4 months old when it happened, so we don’t know anything different. I feel because he was born like this and always on medications, it was never different, pre-transplant to post-transplant.” Throughout the conversation, B1 agreed with these statements, and corroborated the essence of the narrative as well. B2 went on to explain that she knows other families who she believes likely struggle more than they do, because their second child was born with an illness, and so they do have another child to compare the situation to. She stated: “…it’s our normal, and we don’t have any other kids, so it’s not different...we don’t know normal.”

B1 and B2 noted that they believe that it may be more difficult to have a child born with medical complexities after having a child born without medical complexities, as then the family would have a less difficult birth to compare to. However, this was not echoed by the other participants, including myself within my lived experiences, that having a child born with medical complexities following a child who was not born with medical complexities made the situation inherently more difficult to address. From my own lived experiences, you do what you need to, and I was just happy to have my child any way I could get her, and so the differences were not forefront in my mind. What was also evident throughout the conversations with participants was
how they felt as though others who have not experienced this could not possibly relate to the 
stress and pain of having a child born with medical complexities. There is merit to this sentiment, 
and this also likely contributed to my ability to typically gain rapport quickly with the 
participants, as they could identify strongly with my lived experiences.

A Chronic Medical Condition

The fourth theme, this is a chronic medical condition, arose as the participants spoke 
about how the condition of immunosuppression should be taken seriously as a condition, as 
opposed to a side effect of the transplant procedure. This theme was strong and evident both 
directly and indirectly throughout many of the conversations had with the participant families.

For example, E1 explained that the considerations that come with having an 
immunosuppressed child are often overlooked or minimized in her experience. She stated: 
“…she’s been immunosuppressed since she was a baby, so that makes things fairly complicated 
in terms of childcare, and what we deem to be a necessary risk, so it seems like what the health 
professionals say isn’t necessarily what we deem to be a necessary risk...” She identified that the 
state of immunosuppression creates additional risks for her child, and she gives the example of 
worrying about putting her child into standard childcare, due to the additional possible risk of 
exposure to potentially harmful pathogens within typical childcare settings. She explained that 
the medical professionals she was speaking to classified this as a “necessary risk” for her child, 
whereas she disagreed and was not comfortable with this level of risk. She did not place her child 
into standard childcare, and instead a family member was now providing fulltime childcare so 
that their child would not be exposed to the same amount of potential illnesses as she likely 
would within a childcare setting.
C1 described that integrating her child’s immunosuppression into their lives was not difficult for them, as she has always viewed immunosuppression as an additional medical condition. She has prioritized measures to keep him safe, such as screening for illnesses and also ensuring that everyone is up-to-date on vaccinations, including the annual flu shot. In regards to immunosuppression, she explained: “…it’s a life-long chronic medical condition. Um, and a lot of people think that transplant is an immediate emergency thing and that once you get over the surgery you are fine. Yeah, it’s not the case; it’s a lifelong chronic condition.” She stressed that immunosuppression should not be considered exclusively as a side effect of a transplant procedure, but rather that it needs to be regarded as a lifelong medical condition. Throughout the interview she indicated that this has been very difficult for her, as at times others can undermine the experience by suggesting that a transplant is a means to an end to obtaining perfect health, as opposed to a necessary procedure to survive that also includes the acquisition of a new medical condition: the state of immunosuppression.

It was observed within conversations with the participants that the lack of a “cure” for this condition is extremely stressful, and at times difficult to manage, as it remains that currently this is a lifelong condition. All expressed hopes for medical advancements, in order to cease the need for long-term immunosuppression for transplant recipients.

**Acquired Illnesses of Increased Duration and/or Severity**

The fifth theme in this category was that the illnesses are longer and/or more severe for the children due to the impact of the condition of immunosuppression. This specific theme was highly prevalent throughout the interviews, and was spoken about at length by all eight participants. For example, D1 identified that her child had one significant and prolonged illness following the transplant, but has been otherwise healthy and medically stable. She reported that
the illness did require a lengthy hospitalization, which may not have been the outcome if their child was not immunosuppressed. She described that the resulting hospital admission impacted the family as a whole, from functioning to bonding as a family, in addition to the disruption to their daily lives and routines. She stated: “…we’ve been really lucky, in that we haven’t had to worry about him getting sick too often or anything like that. I think we are like on the lower end of that, because I know a lot of people deal with a lot…” She described that she feels as though their family is an anomaly, in that their child has not experienced numerous illnesses following the transplant, because she knows that this can occur often for immunosuppressed children.

F1 described a medical crisis which occurred post-transplant, and stated that this incident was nearly fatal for her immunosuppressed child. F1 explained: “…I went straight to emergency with her and we went from totally healthy to critically, life-threateningly sick, within hours… so the common cold could have killed her, and so she had to stay in hospital in isolation…between my ex-husband and I, we all had to take time off for sure, but knock on wood, she’s been on the same dose for years now, and managing well…” F1 identified that the medical incident resulted in a lengthy hospitalization, which required both F1 and her now ex-husband to take off work in order to be with their immunosuppressed child in hospital, and also to care for their other children at home (they also attended the hospital for a length of time). Although F1 stated that their child is now medically stable, the medical instability that they experienced lasted for over two years, which also included multiple additional admissions to hospital, and thus this was an extremely difficult time for their child, as well as for the entire family.

Regarding the fear of contracting prolonged and severe illnesses post-transplant, A1 explained: “…and every time she gets a little cold you start to spiral and the negative of, that it’s not just a cold, it becomes so much more with her kind of thing, and so um, so yeah, that’s kind
of been like the struggling side of things with that you know.” He discussed that when his child begins to show signs of any illness he becomes worried, because he is concerned that the illness will escalate and become critical, as this has happened in the past. He described past illnesses that have resulted in lengthy hospitalizations, which was difficult for the family to manage. A2 agreed; however, she also explains that she does not believe that their child becomes ill more frequently than their other children, but when she does the illness is typically more severe with an increased duration, as compared to others who may have the same illness, such as their other children. For example, A1 and A2 both discussed that their child has been hospitalized for illnesses that did not impact their other children to the same extent, and they believe that the condition of immunosuppression is the reason for this outcome. Due to the potential for increased duration and severity of illnesses, and concern regarding undesirable outcomes including admission to hospital, both A1 and A2 reported that the ongoing fear of their immunosuppressed child contracting an illness, and the resulting chronic stress, is significant for them.

B1 and B2 both described an acute and nearly fatal medical incident that occurred shortly before the transplant, which was traumatic for the family, and continues to contribute to their fears regarding their child’s health potentially declining. B2 explained: “…when (child’s name) went into cardiac arrest here at home, what happened was that we were at home for almost two weeks, we were just settling into life… and I changed him, and he let out this really weird cry, not the norm, I picked him up, then his head went into my head, and I looked at him, and like you are grey, no contact, and I was like (B1) call 911, call 911.” Fortunately, they were able to get their child medical attention and he survived this very serious incident. They both elaborated that although their child is more medically stable now following the transplant, this incident
continues to impact them. B2 explained: “…now when (child’s name) rolls his eyes back when he’s really tired, that’s a trigger for me. And, it’s a trigger for (B1). It’s huge, but we know he’s okay.”

C1 also discussed that illnesses impact her immunosuppressed child more than her other children, although he is on quite a low dose of immunosuppressant medication, which she indicates lessens his risk. She explained that her child is on a lower dose of immunosuppressant medication because his donor was a very close biological match to him, which subsequently lowers his risk of rejecting the organ. She stated: “…when he does get sick it takes him a long time to get well…” She also reported that illnesses have resulted in frequent trips to hospital emergency rooms for urgent care, and that she believes that the increased severity and duration of the illnesses is a direct result of the condition of immunosuppression.

E1 also reported that her child struggles with illnesses, but explained that it is the consequences and longevity of the illnesses that are difficult typically, as opposed to the severity. She stated: “…it’s the bacterial infections that causes grief, and the medications that she is on, I think that’s been the biggest hurdle in the last three years. It has been, you know, when she gets an infection or anything and she is put on an antibiotic, which then causes diarrhea, which then causes bad Tacro (Tacrolimus: immunosuppressant medication) levels…” Within the essence of this narrative, she identified that her child’s medication levels are impacted by the diarrhea she experiences as a result of taking the antibiotics, which can take months to resolve, and this in turn causes the need for blood tests every few days in order to check the levels. She went on to explain that the blood tests are difficult for her child, because they occur so frequently, which causes additional stress for the child and the family. E1 also identified that illnesses are a concern for other immunosuppressed families that she knows, especially around the transition to
school. This likely contributed to E1’s previously reported concerns regarding sending her child to standard childcare, and the potential for increased exposure to pathogens in this environment that could cause serious illness.

As noted within the conversations with the participants, the risk of illness is a constant stressor and cause for worry for the families. This appears to fluctuate based on the levels of immunosuppression and the age of the child, but does not appear to completely dissipate at any time, for any of the participant families. This was observed in addition to the ongoing fears for prognosis for their child with immunosuppression, which was noted in conversations with all of the participants to varying degrees.

**Illness Causing a Disruption to Life Post-Transplant**

The next theme in this category was the illnesses causing a disruption to life post-transplant for the child and the family, which in turn caused stress and duress for the entire family. This theme is linked to the other themes within this category, as the participant families spoke at length throughout the interviews about the ongoing impacts to daily life and functioning. For example, D1 indicated that the required hospital admission resulting from a significant illness disrupted their family, including the bond shared by their two children. She describes her children as very close, and so the physical and emotional distance was difficult for them to cope with. D1 stated: “…so when they were really little…and (child’s name) would have his surgery, right, we would be gone from home for a while, right, and I mean we always took his brother with us, um, when we could, right, until, but he still missed him, he couldn’t get out of bed and play with him when he wanted to…you know they couldn’t rough house like they had previously until he was more healed…so he really did miss him…” She identified that although they typically went to every appointment and procedure together, in this instance they were
separated as a family for about six weeks, which was extremely difficult for them, as both their children were quite young at the time, and they are so strongly bonded. She also explained that they missed their youngest child’s birthday during this time, which caused further disruption and feelings of guilt as per her account within the essence of the narrative.

Another example of the theme was observed as A2 described the stress and upset for the family resulting from their immunosuppressed child contracting an illness. She stated: “…probably like the greatest stress is when she does get the illnesses, just I mean to suddenly shift my day or my week around to accommodate having her home, or take her to the doctor, or things for the other kids, this often can be taxing…” A2 described stress and disruptions to routines resulting from the illness and subsequent hospitalizations, but also that this has impacted her ability to work and ultimately function outside of the family home. As identified in the gender section, A2 appeared to be responsible for the majority of the childcare, as opposed to her spouse A1 who works fulltime outside of the home.

As evident in the conversations with the participants, the duration and severity of the acquired illnesses impacts all levels of functioning, based on the outcomes of the illness (such as need for hospitalization and/or for the child to miss a substantial amount of school). This also appeared to have positive outcomes; as noted by the participants, the ongoing cause for concern and subsequently missing their sibling (such as during surgeries and hospital admissions) has appeared to strengthen the sibling bonds within the families with more than one child. As per the autoethnography, I have also noted this strengthened bond within my own children.

**Experience on the Waiting List for an Organ Transplantation**

The final theme in the category of biology and genetic endowment is the experience on the waiting list for an organ transplant. Many of the participants disclosed struggles with the
lengthy wait times associated with the transplants due to low organ availability, and that it was considerably stressful and fear-inducing, because their children were typically very ill and struggling to survive throughout the wait. There were no living organ donor participant families within the study, and all of the children received cadaveric organs for transplantation.

This theme was observed as F1 explained the frustration and pain they experienced while waiting on the list for an organ transplant, as they watched their child suffer from illness and felt helpless to ease the pain or help her in any way. She stated: “…that was a hard decision, because we were in a position where we do, we do have two other healthy children, and we also have this daughter who is dying.” She identified that while they waited for an organ to become available that could be matched to their child, they contemplated leaving Canada to pay privately for a transplant, but were warned by their doctor at the time that this would likely cost a significant amount of money, which would negatively impact the family and their ability to provide for themselves and their children. F1 went on to explain: “…with kidney and renal failure you have dialysis, with liver there’s nothing, you can only watch your kid suffer and die, it’s just, it was so difficult to get through, we were fortunate in the end.”

A2 explained that there were positive and negative aspects to waiting on the list. She states: “…we actually waited down there for six weeks before we actually got the call. It was kind of nice because it was a like a vacation. She did have to be on dialysis but down there they only do dialysis three times a week…so we had more days off, it was a lot easier for her…and then after that it kind of went downhill.” She stated that she felt as though they were on vacation at times, because of the decrease in dialysis and that they were waiting outside of their province of origin while on the organ transplant list, in an area with a much warmer climate than that of their province of origin. However, she also stated that as her child became sicker the waiting
process became increasingly difficult, because despite the initial decrease in dialysis being easier for her, her health began to deteriorate rapidly. The medical facility was able to find a suitable organ for their child notably quickly, which the family does attribute in part to waiting in a more heavily populated area, as compared to their province of origin.

B2 described that they feel very lucky that they received a transplant, as there were not many organs available in Canada, due to low rates of organ donation. She stated: “…we were one of the six who got heart transplants in (year). We are lucky. One of six, so that’s not very many, there were only 22 hearts. That’s not a lot, especially for paediatrics.” As per her report, it appears that their child did not have a significantly lengthy wait for an organ, which was likely due to his significantly deteriorating health pre-transplant. The transplant lists are essentially triaged, where the sickest individuals are placed at the top of the list in their region. For example, in our family’s experience our child was at the top of the paediatric transplant waiting list for a liver in our region for several weeks before our scheduled living donor surgery.

From the accounts of the participants it is clear that illnesses are a major concern for families with children who are immunosuppressed following transplantation. The ever-looming threat of illness is something that is not far from the mind of these families at any given time, and rightfully so based on the experiences reported. Three of the participants spoke at length about medical incidents so severe they almost lost their children. This ongoing stress impacts families, and is a part of the everyday reality for families with a child who is immunosuppressed. For example, this was observed as a participant disclosed how even now when their child rolls his eyes she and her spouse are triggered back to previous trauma regarding a significant medical event that occurred, where they almost lost their son. The constant considerations and
implications resulting from immunosuppression further highlight why it is important to consider immunosuppression as a condition, as opposed to merely an unavoidable side effect.

Within conversations occurring around these themes, four of the eight participants stated that there needs to be more and better access to counselling for families. For example, B2 stated: “…I think it’s just something that should be looked at as a whole, and developmentally we see all these other people because he was born so sick, but I think they missed the mental health aspect.” Additionally, also in support of this point D1 stated: “I think definitely having a counsellor involved from the very beginning would help…for the parents, for the child, as they grow.”

All participants spoke about waiting for an organ, and indicated varying levels of stress and emotional turmoil throughout the process, based on the circumstances and impacted by the length of time waiting on the organ transplant list. Beyond myself and my own lived experiences, there were no other living organ donors within this study. Several of the participants identified that having more support while waiting on the list, such as counsellors and/or social workers readily accessible, would assist in stress management, coping, and the maintenance of the overall wellness of the child and family throughout this situation, as well as throughout the entirety of the process.

**Healthy Behaviours**

The six themes that were identified under the superordinate theme of the long-term management of immunosuppression within the healthy behaviours category of the social determinants of health were: protecting the children and maintaining health, cleaning, hygiene, medications, diet, and routine medical testing. All of the eight participants reported themes related to healthy behaviours. Healthy behaviours were defined within this study as behaviours
that are engaged in intentionally, as an effort to maintain good health (a lack of, or decrease in, illness and/or symptoms of illness).

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**Protecting the Children and the Maintenance of Health**

The first theme, protecting the children and maintaining health, was a strong theme and was present to some extent throughout the majority of the conversations. For each family the focus of their efforts to protect their children were slightly different, based on their child’s needs and other medical conditions. This theme was observed as B1 discussed that the medications, routine blood tests, and an underlying fear that his child’s body will reject the organ transplant are his primary concerns in protecting his child and maintaining his child’s health. B1 explained: “…his [medication] levels fluctuate, and you want to know what they are at all the time, and so that’s the hardest thing for myself, knowing his levels and you know, when we go once per month for blood work, I know they fluctuate throughout the month, and so is the level one week going to be as high as it is when he gets his blood work done, and then rejection sets in, type of thing. That’s the most stressful part, not knowing if rejection is going to set in or not.” He stressed that the potential for organ rejection is a serious concern for them, and although the child’s levels are monitored closely, the possibility of rejection is never far from their minds.
In regards to maintaining the health of their immunosuppressed child, A2 explained that they are constantly planning their lives around the strict timing that is required for their child’s medical needs. She states: “…you know it’s the constant, like watching the clock for fluid intake, or you know, it’s time for meds… but it’s constantly on your mind. Like, we are going to go out tonight, so you have to make sure that you take the meds with us, or are we going to be home by eight, so we can give her the meds, so we don’t have to bring them with us…” Both A1 and A2 discussed that monitoring the times that their child requires care, such as the administration of medications or fluids, is an integral part of their routine as a family, but is also notably disruptive to their ability to plan social gatherings or act spontaneously.

Another intervention that came up quite frequently in regards to the protection of the children and the maintenance of health was the flu shot specifically, although vaccinations in general were also discussed by all eight participants. As per the recommendations of the Canadian Paediatric Society: “beyond ensuring that immunocompromised individuals receive all routine immunizations that are not contraindicated by their condition (such as live vaccines), health care providers and caregivers should make sure their own immunizations are complete and up-to-date to establish a protective environment” (Canadian Paediatric Society, 2019).

In regards to the importance of the flu shot to protect immunosuppressed individuals, D1 stated: “we still get our flu shots and adamantly wash our hands and stuff, but he has been really good about not getting sick.” She explained that her family prioritizes their flu shots, but also that their family and her child’s friends have consistently made sure that they have their flu shots in order to help protect him. Similarly, C1 stressed the importance of flu shots to their family as well. She works with medically complex children, so she ensures that everyone associated with this work is respecting this recommendation. She stated: “we instituted making everybody get flu
shots in the fall, if you are going to work, live, or visit here you will have a flu shot.” B2 explained that her opinion of flu shots changed after they had their child, and she now understands the importance of the flu shot to protect others who are medically vulnerable. She stated: “[the doctors] were like you should get your flu shot to protect the baby, and I was like I am healthy I am fine, and she was like it’s not about you, and then when (child’s name) was born, I was like wow, kids are sick and dying, you know, so I definitely am pro-flu shot now.”

E1 discussed the importance of providing people with accurate information about the flu shot, as well as about vaccines. She stated that she knows some people who cannot differentiate between the flu and other ailments, and so they assumed that they caught the flu after receiving the flu shot. She explained: “I think that they are making a big push for flu shots but I don’t see the push for other vaccines…I think that there is a lot of that misinformation.” She explained that she believes more standardized education should be provided to people regarding the flu and the importance of the flu shot, and also that healthcare practitioners should be expected to provide medically validated and correct information, in order to avoid confusion that may lead people to make decisions not based on facts, such as becoming apprehensive towards the flu shot because they believe that it caused them to contract the flu.

Unease regarding risks within the community, from risk of infection as a result of vaccine apprehension, to the potential risk of contracting an illness from community spread, was evident throughout the conversations with the participants. This fear appeared relatively consistent, but also noted was that the fear seemed lessened at times by actively engaging in the clinical recommendations to maintain health and wellness, such as increased hygiene and receiving routine vaccinations. In addition to the benefits of following the recommendations that are encouraged by practitioners, it is of interest that these recommendations may also possibly bring
a sense of autonomy and control to families. Instead of potentially feeling helpless and
victimized by invisible threats and the actions of others, they may feel as though they have the
recommendations to utilize as a means of protecting their children and their families.

**Cleaning and Cleanliness**

This is one of the five themes related to the management of the condition of
immunosuppression. In order to provide insight into what this experience is like for families on
a daily basis, each theme looks at a specific aspect of what is required for management based on
recommendations from medical professionals for immunosuppressed individuals.

Sick Kids Hospital in Toronto suggests the following to parents and caregivers of
children who are immunosuppressed in regards to keeping their home clean and safe: “dust and
vacuum your house weekly, wash your child's bed linens, bathroom towels, and pajamas at least
once a week, wash all dishes and utensils in hot water or in the dishwasher, wash surfaces in
common areas such as the bathroom, kitchen, and living room with a disinfectant, pay particular
attention to surfaces that are touched frequently such as handles on doors, the refrigerator, the
oven, cupboards, sink taps, toilet handles and seat, telephones, and computers (clean these
surfaces regularly), clean toys before your child touches them, and do not use humidifiers unless
you clean them daily” (Sick Kids Hospital, 2012).

When asked about keeping the home clean, D1 stated: “…the cleaning thing I am like, I
keep it clean but I know I could probably do better than I do (laughter).” E1 identified that she
found it easier to maintain the cleanliness of the home before she returned to working outside of
the home, but still does not find it overly cumbersome. She stated: “I took two years and then
went back to work, and it definitely got harder, with the return to work and housekeeping, and
then you have the kid destroying everything and making messes (laughter)…we certainly try, we
have definitely learned what to focus on and what not to focus on. We don’t have to tidy all the
time as long as there is nothing dangerous lying around.” F1 shares custody of her children with
her now ex-husband, and she stated that she and her fiancée ensure that the environment is clean
before the children return. F1 explained: “…we are pretty, well more my fiancée, he is anal-
retentive with cleaning and stuff, he’s like (child’s name) is coming, and so he washes all the
floors, and he washes the TV down, and her iPad.”

E1 also stated that although they keep their own house clean to protect their child, their
family members needed to be told and reminded initially that this is something that is required to
keep their child safe, especially since her child is still in the oral-phase. She explained: “…it’s
not too bad, but it’s always in our mind, right, and even going to other people’s homes, we have
had discussions with my in-laws and we have said you really have to clean up more, like this
actually needs to be a clean environment…” She identified that these conversations were
fortunately well received, she stated: “yeah, it took a few reminders, but yeah (laughter). They
understand, it’s just different, they have to be a bit more aware, what’s around and, you know,
the age, the age is such a problem because she’s (age) and she’s still putting things in her mouth,
and so we are still wandering with hand sanitizer and wipes everywhere.”

F1 explained that they too experienced a similar situation, but it does not appear that their
concerns were as well received and addressed in their situation as compared to the experiences of
E1. F1 stated: “…it was very difficult to go anywhere with her, and it’s a little bit about the
immunosuppression because I worry about if it’s clean, like I have a, well she’s an ex-spouse
now of my brother, like their house was disgusting, I didn’t want to go there, like they had a dog
and puppies running around, so there is some issue with that.”
Ensuring cleanliness while away from the home and out in the community can be difficult for immunosuppressed families. For example, B1 stated: “…we’re more cognizant of who is around…but we still go out to eat quite a bit. We just make sure the table is clean, and if someone appears to have symptoms of illness while we are out we kind of turn way, stay clear.” He explained that they try to limit their child’s contact with others while in the community, in order to decrease his risk of contracting an illness from others. B2 agreed, and also elaborated: “…when we are in public it’s much different. We sanitize everything, high chairs, stuff like that.” She identified that they are much more hyper-vigilant about their cleaning practices when they are out in community, as opposed to when they are at home, because the risks of contracting an illness are much higher.

A1 discussed the concerns he has regarding travelling with their immunosuppressed child, and specifically concerns about the cleanliness of hotel rooms. A1 explained: “I don’t consider hotel rooms to be the cleanest places. It’s kind of like, we go in, and I want do to my cleaning of everything…it’s kind of uh, always in your head, all the work that I will have to do just to go somewhere…it becomes kind of a hindrance for us.” A1 and A2 also moved with their family recently, and they made sure that their new home was very clean before they moved in to ensure that their child would be protected against any potential lingering germs. A1 stated: “…I am a little more on the hyper-vigilant side of things…like I said, always buying the sanitary wet wipes and that kind of stuff, so that’s been hard for us.” A1 elaborated that the costs of cleaning supplies, such as the disinfectant wipes that the family uses regularly to ensure the cleanliness of surfaces at home and within the community, can be quite significant, as they are cumulative. He stated that initially he did not think about the financial impact, but when he considered the costs long-term, this became more of a concern for them, and they believe that immunosuppressed
individuals and families should receive compensation and/or cleaning and medical supplies provided to them to offset these costs.

Within the conversations with the participants, it was observed that although none took issue or disagreed with the required increase in cleanliness, as noted within the clinical recommendations. However, what was stressed was the resources (time, money, supplies, etc.) that it takes to maintain these practices, and how this impacts families within various areas of functioning, such as having less income for other things and having less time to spend engaging in preferred activities.

**Hygiene**

The next theme is hygiene, which was another theme that was prevalent, as this was spoken about often throughout the interviews by the participants. Aside from hand washing, an additional point that was discussed in the interviews was dental hygiene. The recommendations for hand washing for immunosuppressed individuals as per the Canadian Paediatric Society include: “before eating or preparing food, after urinating or defecating, after touching body fluids or excretions or items that might have had contact with human or animal feces (e.g., clothing, bedding, toilets), after touching plants or soil, after collecting or depositing garbage, after being in any environment outside the home or visiting a public place, and after touching animals” (Canadian Paediatric Society, 2019).

An example of this theme was evident in D1’s discussion, as she stated that hand washing is a critical aspect of illness prevention for their family. However, D1 also identified that when her child was younger he did not like to wash his hands as much as he needed to, but now as he has gotten older he understands why it is necessary and has accepted it as part of his daily routine. D1 stated: “…he doesn’t mind it, it’s just second nature to him now…” Similarly, in
regards to hand washing, A1 stated: “...the thing is, you come to our house you wash your hands. The first thing you do is wash your hands.” C1 also explained that hand washing is very high-priority in her home, she stated: “...we adopted his immunosuppression as part of our family. Um, so, we have just been using hand sanitizer and hand washing, and that kind of stuff.”

All participant families narrated that hygiene is imperative to protecting their children who are immunosuppressed, and also that ensuring others respect and cooperate with their needs can be a stressor at times. D1 discussed that in their experience friends and family were not initially overly cooperative with hand washing and other aspects of preventative health measures that are recommended, which was difficult for them. She stated: “...because a lot of them wouldn’t want to get their flu shots, or they wouldn’t um, like, wash their hands as often as I would have liked...as we got more into this whole journey they understood more and more about why we did what we did, so, everybody is kind of onboard now, and they get their flu shots, you know, all that kind of stuff so, it has been kind of nice to have everybody, kind of adapt to, you know, being safe around him.”

The participant families frequently discussed the importance of hand hygiene while they are out in the community, such as in restaurants or stores. This can be a significant stressor for families, as the risks of potential infection exposure are increased while in the community, due to the significant amount of other people and points of contact. For example, F1 stated that they prioritize hand hygiene when out in the community, she explained: “I wanted to go out and I wanted to enjoy life, not that we got out much now but we still go out and take her and she’s healthy, and as long as she’s healthy, but we’re obviously careful, we wash our hands lots and wash her hands lots...”
B1 also discussed the importance of hand hygiene in the community, and ensuring that individuals in the community maintain social distancing around their child. B1 stated: “…you don’t let a grandmother touch him in the shopping mall because he’s a cute baby, kind of thing. Like, sorry, your hands, we don’t know where they have been…” Additionally, B1 stressed the importance of hand hygiene in cold and flu season. He stated: “…in the winter we seem to be more, because it is flu season, making sure you wash your hands 100%, and every day when I come home I make sure I wash my hands before I come play with him, and it’s just something we adapted to.” B2 agreed with the aforementioned points, and expanded to further explain their diligence around hand hygiene immediately post-transplant, as it was a significant concern for them at this time, because their child was considerably medically vulnerable.

As their child is still in the oral phase, in addition to using wipes and hand sanitizer on objects at home, E1 reported that they are even more vigilant when they are out in the community. E1 stated: “…we take her everywhere, she goes everywhere that any other kid goes…if it is incredibly crowded we will avoid things with lots of kids, adults aren’t a big issue…but we still avoid places that are incredibly congested with toddlers, right, things like that, or if we do we stay really, like we take her to the museum and stuff, but we just stay close and wash our hands a lot.”

C1 also discussed her experiences, and stressed the importance of hand hygiene in the schools. C1 explained: “…the preschool he went to, all the kids washed their hands in a basin before lunch, and so we had to stop that. You will have to go to the bathroom, take these kids to the bathroom to wash their hands. And, we also instituted using hand sanitizer every time you walk into the room…And they were good in the classroom with wiping down tables and chairs with bleach-wipes and stuff, so he made it through preschool without a lot of problems.”
Additionally, C1 stated that having supports within the school to ensure that appropriate hand washing is occurring is important, especially when the children are young.

C1 elaborated further on hygiene, and discussed the importance of dental hygiene for her child who is immunosuppressed. She stated that she had to advocate initially, in order to obtain extra coverage for the required additional dental care, but she ultimately successful. C1 explained: “…a dirty mouth is the worst kind of infection. So, we do every three months a dental cleaning, and at some point he will need veneers on his front teeth, because the bilirubin in his system coloured his teeth. And his baby teeth were basically green, his adult teeth have come in with a very yellow tinge to them. So, no matter how much he brushes they never look clean.”

The importance of maintaining hygiene, such as hand hygiene, in order to decrease the risk of contracting a transferable illness was noted by all participants within this study. As was noted within the findings pertaining to the requirement of increased cleanliness, none took issue with the requirement for increased hygiene, and all identified that they agreed strongly with the benefits. What was again noted was the time and effort that this requires to maintain, and the anxiety that can be provoked at times when it is perceived that adequate hygiene has not been completed, such as people in the community trying to touch one of the children (no handwashing, unclear risks for transfer of illness).

**Medications**

The next theme is medications, and there was a substantial amount of discussion regarding medications throughout the interviews. This theme focused on the prescribed medication regime, and how the children and families manage this aspect of care. As per the Children’s Hospital of Pittsburgh, the advice given to parents and caregivers of children who are immunosuppressed following solid organ transplantation about medications includes: “it is
critical that patients on immunosuppressive drugs take their medications directly as prescribed each day - changes in the way they take the medication could trigger an immune response. Over time, doctors may adjust or change the type of medication your child takes” (Children's Hospital of Pittsburgh, 2020).

This theme was observed in B1’s discussion of the importance of the medication regimen and ensuring that the medications are administered at the right time. He described that planning their lives around their child’s medication and other required needs schedule (such as tube feeding) can be notably difficult and taxing at times. F1 discussed similar concerns, but reports that as of recently her older children have been able to help her administer her immunosuppressed child’s medications. D1 discussed the importance of involving older immunosuppressed children in their own medication administration, and explaining to them what the medications are for, in order to engage them as stakeholders in their own care when they are younger, so they can continue to be actively involved and maintain their own health as they age and become more independent. She stated: “…he has known, even when he had his transplant and in the beginning and he was on those thirteen medications or whatever they come home on, so he was only seven, he knew the names of all of them, and mostly what they were all for. So we have really integrated that into part of his routine and his life because we tell him we are not going to be around all the time, you need to learn how to do these things, you need to make sure that they are done, because if you don’t you are going to potentially die, you know, it’s harsh but it is reality, that is where it would lead to if he didn’t.”

In regards to prescribed medications and the maintenance of the physical health of his immunosuppressed child, A1 explained that ideally he would prefer that she was not on immunosuppressant medications. He stated: “…I feel like that would be a huge difference, but
maybe it wouldn’t be, I don’t know, um, you know other than that really nothing constantly, it’s just like her overall health right, it’s taxing, but then any parent with a sick child has that same kind of thing.” He identified that he is concerned about the impacts and side effects of the medication specifically (such as a higher susceptibility to illnesses).

B2 narrated that in her experiences the transition to home from hospital was initially difficult, and this was compounded by the extensive medication regimen that their child was discharged on. She explained: “I don’t even know how I functioned, I just did it, I guess I was just happy to be home, and we were so grateful. He was on sixteen medications and Q3 feeds and like, six or seven times per day, and (B1) drove home from (name of location) so I was home alone, and between meds and feeds I was up every hour. And I was like, how did I do that, but you just do it, I mean, you don’t have an option. I just did it, and I knew it would change, because I saw other transplant parents and knew that at some point we wouldn’t be this, and it did become that way, and so there was hope.” She went on to elaborate that their child’s care needs have since changed and become much more manageable, including his medication regimen. However, she stressed frequently that more support for families transitioning back to home from hospital would likely be beneficial. She reported that the support that she received from other immunosuppressed families during this process was imperative, and absolutely beneficial to her coping and adapting to the transitions.

Regarding the ongoing effectiveness of the medications and risk for subsequent organ rejection, B1 explained that the fear of the medications no longer working for his child is often on his mind. He stated: “…I know it’s something we can’t really control either, and that as far as medications for immunosuppression go and what not, he’s going to be on it for life…and I always think about what if the time comes where I don’t have another moment with him type of
thing, but I kind of try to push that away as much as I can, because you can’t go around living like that…you can just fear that he will pass away because something might fail, and we know where the organ came from, and how we got to this place now with the transplant, and every moment for me is another moment with him.” Although it is a painful concept, it is all too possible of an outcome for medically fragile children, and so it is a difficult but important perspective to include.

It was observed throughout the conversations with the participants that medications can be a source of stress and worry for parents of children living with immunosuppression. For example, the strict medication schedules can be difficult to maintain and to balance with other aspects of life (such as outings and other plans outside of the home, like attending sports games or piano lessons). The immunosuppressant medication, although necessary to maintain wellness and decrease the risk of rejection, can also cause stress and alternative risks, as it increases the medical vulnerability of the child in other regards (such as the ability to recover from acquired illness).

Diet

The next theme is diet, with a focus on special considerations for children who are immunosuppressed, including both food and water consumption. As per the Canadian Paediatric Society, the recommendations for food safety for immunosuppressed individuals include: “all milk, fruit and vegetable juices should be pasteurized, avoid cheeses produced from raw or unpasteurized milk, especially soft and semi-soft varieties (e.g., brie, camembert, and blue-veined cheeses), avoid raw meats, seafood and eggs, lettuce and all other raw vegetables should be washed thoroughly, even when they are labelled as prewashed, and avoid cross-contamination when preparing foods, keep cooked and raw foods separate and use different cutting boards or
surfaces for raw and cooked foods” (Canadian Paediatric Society, 2019). The recommendations for safe water consumption for immunosuppressed individuals include: “not drinking tap water in Canada when ‘boil water’ advisories are in effect, drinking only bottled or boiled water when travelling to regions with suboptimal sanitation, not drinking well water unless the source is properly screened and monitored by health authorities, and not drinking water directly from rivers, streams, lakes and ponds” (Canadian Paediatric Society, 2019).

D1 discussed that the increased water intake that is required for the prevention of potential kidney damage due to the prescribed immunosuppressant medications can be difficult to manage at times. E1 also explained that ensuring that her child intakes enough water is difficult, and elaborates that her child experiences diaper rash and difficulties with toilet training (due to increased urination) as a result. As per the experiences of the participant families, not only does ensuring the children intake an adequate amount of water to prevent kidney damage cause stress for the children and the family, but this also impacts the child’s progress and development (such as toilet training).

E1 also reported that they changed their eating habits as a family immediately to accommodate the needs of their immunosuppressed child. She explained: “…we won’t let her eat the same way as other kids eat, and sometimes that’s a problem when we are visiting friends and stuff, um, because we stick to a specific diet with her, and with how we eat now, you know, we just changed as soon as she was listed for transplant, you know we were told from the dietician, like day one or something, because of her increased risk of kidney failure we need to restrict sodium…” She elaborated that although it is not difficult for them to manage her diet at home, it does sometimes become difficult when they visit friends for a meal, because they may serve
something processed with high sodium, which is not a healthy meal option for their child due to the immunosuppressant medications.

Immunosuppressed individuals are also not advised to eat raw fish (or any raw foods) due to the risk of contamination, and cannot eat or drink anything with grapefruit in it because grapefruit has been shown to block the immunosuppressant medication from being effective. D1 identified that initially it was difficult to keep her child from trying new foods that are considered to be restricted, but as he got older he was able to understand, and he was also able to consult his doctors himself about why he needs to avoid these foods. D1 stated: “...I feel bad but I know he will never be able to try, well his big thing is sushi, he wants to try sushi but he can’t eat raw fish after his transplant.” She also identified that she worries about her child potentially consuming a beverage with grapefruit at an event like a birthday party, such as Fresca, as many drinks do not necessarily make it obvious that they contain grapefruit.

In regards to safe water consumption, A1 and A2 both stated that they worry about the potential for contamination from tap water, and so they only give their child bottled distilled water. However, they also explain that this additional measure to protect their child is also very expensive. B1 and B2 also discussed the importance of safe water for their child, and also elaborated that they always make sure to have water with them at all times. Although it is imperative that all children have access to water as required, based on the experiences of the participants, it appears that families with immunosuppressed children focus much more on water as compared to other families, both in terms of water accessibility and safety, but also the need to ensure daily increased water consumption. One participant described that she feels as though forcing her child to consume the required amount of water daily is taking away his autonomy,
which causes her to consequently feel guilty, and she wonders how this will impact her child in the future.

As noted within the observations from conversations with the participants within the theme of medications, diet can also be a source of stress and anxiety for parents of children living with immunosuppression. Some children are required to have tube feeding, and this presented challenges in the provision of this nutrition (such as staying home for the tube feeds, to avoid having to bring everything with them if they were to try to go out). There are numerous recommendations for individuals living with immunosuppression in regards to diet as a result of the medications, such as ensuring that they do not intake an excessive amount of sodium and that they remain very well hydrated, to protect other vital organs (such as kidneys) from any damage resulting from the required medications. Participants noted that it could be extremely challenging at times to ensure that their child was drinking enough water, which also increased stress levels and was difficult for the child. No participant disagreed with the benefits of maintaining these, or any of the other, clinical recommendations. However, what was noted again was the time and resources, and also the stress, resulting from the ongoing maintenance of the recommendations.

**Routine Medical Testing**

The final theme in the category of healthy behaviours is the routine medical testing that is required for the children to monitor their health on an ongoing basis. The participants spoke about blood tests exclusively, as “regular testing is often needed to monitor the effectiveness of the drugs,” although other medical tests can be required for immunosuppressed individuals, such as routine urine/stool sampling and organ biopsies if required (Children's Hospital of Pittsburgh, 2020).
An example of this theme was observed in C1’s discussion about her experiences, she stated that because her child has to endure the medical tests so frequently the tests became part of their normal routine, and subsequently he now tolerates the tests well for the most part. She explained: “…yeah he has done really good with that, up until about eleven years of age he wanted to sit on my lap but that’s okay (laughter). He graduated to me just standing beside him, and now he just goes in on his own.”

D1 also identified that although the tests were hard when their child was younger, as he grew older he was able to tolerate the testing better and it has become routine for them as well. She stated: “…he just takes it like a champ now because over the years he has gotten used to it, and they have gotten less frequent, so he doesn’t need to worry about it as much…” E1 similarly reported that initially her child was highly reactive to the blood tests, and would experience symptoms of panic, but as she has gotten older she does not react as strongly. E1 stated: “But it’s certainly getting better as time goes on, but it’s a lot, these kids have to go through a lot.” F1 believes that her child has become stronger for having gone through such significant medical challenges. She also stated that even though her child has poor vascular access she rarely cries during blood testing. F1 explained: “…I swear to God it made her stronger, because it takes a lot of pain to make her cry, a lot, so, but I don’t know about a negative way.”

Alternatively, one participant family identified a great deal of stress associated with the ongoing required medical tests, both for themselves as parents as well as for their child. B2 described that the routine blood tests have been very difficult for her child, which has in turn impacted she and her spouse, as they worry about their child’s wellbeing long-term and if this stress might have longstanding impacts on him. B2 stated: “…our Tacrolimus levels have been stable now, so we now do monthly blood work for transplant in addition to Tacrolimus level, and that is 10
MLs of blood and we do a scalp poke, because he is a hard draw, well that we know if, we haven’t tried it since because it’s not really worth it when our kid is kicking and screaming and we are holding him down. So literally when we get off at the third floor of children’s hospital now to go to for blood work, he just starts crying instantly, and it’s horrible.” B2 stated that she is worried about her child developing post-traumatic stress disorder (PTSD) from the extensive medical procedures and testing that he has undergone thus far, and that she believes that the regular blood testing may be a trigger for him.

As was also found in the existing literature, the participants noted stress resulting from their child undergoing painful medical testing (such as regular blood tests). The stress appeared to be more pronounced for families in times of medical instability, as this typically resulted in a significant increase in required medical testing. What was also noted, was that as children age they appear to become better able to tolerate the tests, but typically as the children age they also require less frequent testing (decreases with time following the transplant). One participant also stated that she believed that her child was much stronger as a result of what she has endured, including the routine medical testing.

Based on the accounts of the participant families, it is clear that the maintenance that is required for immunosuppressed individuals, based on the recommendations to maintain health from healthcare professionals, is stressful, extensive, and can be notably difficult for their children. These practices become part of the daily lives of immunosuppressed individuals and their families, and life without these measures may prove dangerous for immunosuppressed individuals, due to medical fragility and the vulnerability to risks associated with a lack of cleanliness and high-risk social interactions (such as not maintaining social distancing when someone has a communicable illness). These points further highlight the importance of the
consideration of immunosuppression as a condition, due to the long-term and multifaceted impacts of the condition on the lives of individuals and their families.

**Physical Environments**

The two themes that were indicated under the superordinate theme of leaving the physical environment of the home within the physical environments category of the social determinants of health were: admissions as a necessity and a disruption of life at home and difficulties in leaving for leisure (travel). The five themes that were reported under the superordinate theme of feeling secure, protected, and validated within the community were: safety in schools and in the community, community health and hygiene, the identity of family within the community, vaccinations - concerns regarding vaccine hesitancy and the anti-vaccination movement (community health concern), and the organ donation registry - concerns regarding a lack of an opt-out system (community health concern). All of the eight participants reported themes related to physical environments.

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Hospital Admissions as a Necessity and also a Disruption to Life at Home

The first theme, hospital admissions as a necessity and a disruption to life at home, came up several times throughout the interviews, as the participants spoke about the struggles associated with the lengthy hospital admissions that were required for their children. These admissions disrupted the routine of the families, and also took the families out of their primary physical environment and source of comfort, their homes. All the participants had to leave their province of origin to have the transplant procedure, as Manitoba and Saskatchewan are unable to facilitate these transplants at this time.

Families spoke about their experiences with hospital admissions frequently throughout the interviews. For example, D1 described that a lengthy admission away from home post-transplant was difficult for them to manage, because they could not bring their younger child with them, and they were away from him for several weeks. She stated: “…that was really hard, that time because we never left him any other time, when we had gone we would always take him with us, so that one was really hard.” She identified that this was the longest that they were ever apart as a family, and this admission resulted in them being away from their younger child for his birthday, which caused a significant amount of stress for the family.

Similarly, E1 stated that the lengthy admission was difficult for her family, however she also explained that although being away from home and their natural supports was challenging for them, they knew they were in the right place and that their child needed this care, and so this made it easier for them to process and cope with being away from home. E1 stated: “…it was
difficult but we knew we were in the best place, so it was fine. The thing is that, that was where we needed to be, we were there for six months. But I think when you have got a kid who is really sick, and she was really sick waiting for the organ, I think you just accept it as better to be here even if it is a pain.”

Hospital admissions can occur frequently for immunosuppressed individuals, for a multitude of reasons. F1 explained that her child was admitted intermittently for the better part of the first two years of her life, which was extremely difficult for their family, as they also had two older children. F1 also explained that she never left her child’s side when she was admitted, and that someone from their family was always with her. However, this also impacted her ability to care for herself and to ensure that her own basic needs were met. She stated: “…because I didn’t like leaving her, having to call somebody, hey I am freaking starving, can you bring me food or a coffee or whatever.” F1 also stated that her family was fortunate, in that her sister attended lengthy hospitalizations with her family in order to bring her other two children, so that the family was never apart for long. She identified that as a result of this cohesiveness, she has not noted any negative impacts to her relationship with her children, and has seen a stronger bond between herself and her children.

In regards to juggling existing responsibilities during admissions, A1 described the experience as significantly challenging. He stated: “…when she’s in the hospital I am usually the one that stays with her overnight, so, um, (A2) will, you know, now it’s like get ready in the morning and take (child’s name) to school, and then come, and so she doesn’t get there until nine or nine fifteen, and I’ve spent the night there so, I am going to work, after going home and showering, and I am not at my job until ten or ten fifteen… And so yes, it’s a struggle specifically when she’s in the hospital, and then yeah, when she’s sick we’ve always said my
wife can’t work, because she gets sick, she needs to be home.” A1 identified that as the sole income earner for the family, he struggles to maintain work life balance when their child is admitted to hospital. A2 agreed, and also described stress and upset to the family balance during their experiences with hospital admissions, such as difficulties in balancing the needs of their other three children. She stated: “…it was even more difficult because you know we were juggling picking them up, and they had activities, and taking them here or there, you know, so all that had to be juggled as well. Or it had to be like sorry guys, you know, we can’t do this, we have to cancel this, so I think that really affected them.” A1 and A2 explained that the hospital admissions impacted the entire family exponentially, in all areas of functioning. A1 also reported that the illness and subsequent admissions has caused stress and strain in their marriage at times.

B1 reported that having to be away from home for extensive periods of time during the admissions was very difficult experience for them, and disrupted the balance of their lives substantially. B1 stated: “…it was definitely very stressful. Not being in your normal location, for work life balance, for that many months, well, what do I do… but I mean I come back here while he’s in the hospital and, you know, you never want to think about it, but if he would have passed while in the hospital and I wasn’t there, could I ever live with myself if I had to come back? Would the financial hit have been worth it for me? You know, in that sense, yeah. So that’s what was really stressful about it, do I come home, or do I go back there, what do I have to do? But, you do what you have to do, and it worked out.” B2 agreed that the admissions were a difficult experience, and further elaborated that the disruption to the mutual bonding process with their child was very hard for them, and continues to impact their family. B2 states: “…in hindsight, (A1) should not have gone back to work the week we got home, because it was like wait, way too fast, not just for me but for him, because he didn’t have time to be with (child’s
name) alone, and it wasn’t fair, but whatever, hindsight is 20/20…” B2 went on to discuss that in addition to B1 returning to work too early that it impacted his bonding with their child, because she is the one providing the majority of the direct childcare, that this is prolonging the disparities in their individual relationships with their child.

Based on the responses from the participants, it is clear that hospital admissions represented a significantly stressful period for families. This is due to the apparent stress associated with the child’s health becoming unstable and the potential for negative outcomes, as well as more insidious stress due to the disruption to life, decreased time with other children, decreased time with a spouse, decreased time together as a family, and increased difficulty maintaining other existing obligations (such as employment and school).

**Difficulties in Leaving the Primary Physical Environment for Leisure**

The next theme in this category is difficulties in leaving the primary physical environment (home) for leisure (such as travel). As per the Canadian Paediatric Society, recommendations regarding travel for children who are immunosuppressed are as follows: “immunocompromised children and youth should be individually evaluated for destination-specific travel risks, if possible by a travel clinic. Special attention to protective vaccines, and to hand hygiene in airplanes or areas of public transit, is essential. Immunocompromised individuals should travel with a personalized ‘health passport’ that lists their medications and immunizations, describes their condition, and provides their health provider’s contact information” (Canadian Paediatric Society, 2019).

A1 and A2 indicated that their ability to travel as a family had been impacted by the complex health concerns of their child, and also impacted by the additional financial expenses associated with the medical supplies that are required but not covered or subsidized. These
additional expenses cut into their disposable income, making it harder for them to budget for, and to justify, travel for leisure. A1 stated: “…specifically traveling, traveling is hard. We don’t go on vacations, really, just because, you know, it is based on immunosuppression, but it is the big picture as well. She’s a little bit different. If it was just immunosuppression we could probably, there are ways that we could get through, but there are obviously other things that make it a struggle for us to go away.” A2 agreed, and elaborated: “…it’s like we can’t afford to go on vacation because we have to pay all of these other out of pocket expenses, and so you know we can’t afford things that we might want to afford because we have all these others expenses.” They both went on to discuss that the cleanliness of hotel rooms is also a deterrent for travel, as they do not trust that the rooms have been cleaned to the standards that are required to keep their child safe, and so they spend a substantial amount of time cleaning the hotel room when traveling.

Although engaging in leisure activities may not appear to be absolutely necessary to sustaining life, it is an important means by which to increase coping and engage in self-care. Decreased abilities to participate in leisure activities can further increase stress and decrease coping.

Safety in the Schools and Community

The next theme is safety in the schools and in the community, and several of the participants identified that they rely on the staff at the schools to help keep their children safe. This is important because outside of homeschooling as an option, schools are a physical environment that all children will have to spend a considerable amount of time in throughout their lives.
For example, A1 and A2 offer differing descriptions of their experiences as a family within the school system. A1 explained: “…she was in the public school system, and they were pretty good with that kind of thing, um, she’s at (school name) in her second year now, they’re not as, um, they don’t kind of participate in that as much, but you know what, I found that the public school system did a really good job of just enquiring about a lot more and being a little more cognizant of her needs…And I just feel like (school name) isn’t so much in that regard…they don’t acknowledge the fact that if there are kids who are sick maybe stay away from them.” A2 disagreed to some extent, as she identified that both schools have been supportive. A2 stated: “…but yeah they’ve both been pretty good, and even her school now will call me during the day and touch base with whatever is happening, or you know, can we do this or that, and so you know they’ve both been really good, you know supporting that.”

A2 further elaborated that she feels as though her child’s educational assistant (EA) is helpful in protecting her at school. She stated: “she has a one-to-one EA with her, because of her other disabilities, and so I feel like the EA kind of protects her from other kids that may be sick.” C1 also explained that EAs are necessary for children in the school systems who are immunosuppressed, because they help to keep them safe. She stated: “he needs an EA to make sure that, if the kid beside him coughs all over him, she takes him to wash his hands immediately.” C1 stated that her child’s school was especially supportive and receptive to her immunosuppressed child’s needs. C1 explained: “…because they have been quite upfront with families about the fact that they have an immunosuppressed child in the school, and an unvaccinated child would be a risk to him. And if you do not choose to vaccinate your child we would be more than happy to help you find another school in our system and help you to arrange bussing for your child.” None of the other participants reported that any other school addressed
the issue of potential vaccination hesitancy within the school, or offered any support on this matter specifically.

As children spend a significant amount of time in school, the participants reported that the risks associated with school were a considerable stressor for them. These risks included exposure to communicable diseases and the child not independently maintaining the required recommendations while in school and away from the parents. This was also noted as a strong anxiety for those families within the study who have children who are not yet within the school system, as they are anticipating these stressors and difficulties, in response to their own fears and perceptions as well as previous experiences, and stories of experiences from others.

Community Health and Hygiene

This theme transitions into the next theme in the category of physical environments, community health and hygiene, with a focus on the school system. Cleanliness is an important part of keeping children who are immunosuppressed safe by minimizing the risk of contracting illnesses, and considering they spend so much time within the physical environment of school, the cleaning practices of the school may become a concern for parents. The extent to which an individual is immunosuppressed varies based on the dose of immunosuppressant medication that is currently prescribed.

Sick Kids Hospital recommends several interventions to decrease risk for children who are significantly immunosuppressed in community, but identifies that all children who are immunosuppressed should consult with their doctor about how to limit the contact with those who have an infection. The recommendations as per Sick Kids Hospital include: “keep your child away from crowds, try to avoid stores, markets, parties, etc., keep your child out of daycare and group play activities during the treatment period, avoid communal play areas such as play
parks, sandboxes, and public swimming pools, limit sharing of household items such as toys, towels, drinking glasses, and eating utensils, all visitors should be screened for illness - they should not visit if they are sick or have recently been directly exposed to someone who is sick (in the event that this cannot be avoided, the sick family member should wash their hands thoroughly before coming in direct contact with your child), if you must be in a public place, use a plastic cover on the stroller and choose times when there is less likely to be crowds (an older child may wear a mask), and when at a clinic, doctor's office or medical lab, advise them of your child's lowered immune system and request to be put in a room right away or ask for an appointment at the beginning or end of the day (avoid waiting rooms as much as possible)” (Sick Kids Hospital, 2012).

An example of this theme was observed as C1 explained that she had to advocate for better cleaning measures within the school once her child entered a new school, but after facing initial opposition she was ultimately successful and the school implemented enhanced cleaning measures in order to protect her immunosuppressed child. C1 stated: “…so they had hand sanitizer in the classrooms, and explained the situation to the school managers, and they agreed to use bleach wipes on the desks every night. Stuff that was needed for him.”

In regards to the schools helping to prevent illnesses for the children who are immunosuppressed by using communication effectively to inform parents of concerns, C1 described that the school has been quite helpful and has communicated concerns promptly in her experience. She explained: “…we had a little scare when one of the kids that he chummed with the most got chicken pox, and that involved having to get a special vaccine flown in for him, but other than that, and he didn’t get the chicken pox, it was just like oh that kid beside him has it. They let me know the minute they had a diagnosis…” D1 also narrated that the schools were
helpful in communicating any issues about illnesses that might harm her immunosuppressed child in her experience, she stated: “they have been good, because there was one, a couple of years ago I think, there was chicken pox going around at his school, and they told me right away. So I just kept him home from school for the rest of that week, and part of the next week, and it was okay, he didn’t get anything, and they have been really good if there has been an outbreak or if anything serious happens.”

As noted by participants, potentially insufficient hygiene and cleaning practices within the community, such as schools, is also of significant concern. As discussed by the three participants with experience working with young children, this is of particular concern within the younger years, as these children typically do not have a firm grasp of adequate hygiene practices (such as covering coughs) and it induces stress that sufficient cleaning may not be taking place, in response to these considerations. It is important for all parents to feel that school is a safe place for their children. Just as some children may require a wheelchair ramp, immunosuppressed children require additional attention paid to aspects of cleanliness and hygiene to keep them safe. However, this is not always the case as noted by participants, and additional advocacy and subsequent policy changes may be beneficial to ensure that these requirements are being addressed adequately within the school systems.

**Family Identity within the Community**

This point transitions into the fifth theme indicated in this category, how the family identifies within the community. Voicing concerns regarding their child’s wellbeing and safety within the community may make parents feel as though they are not like the others parents, and only perceived by other parents as associated with this aspect of their lives. A1 stated: “I think it’s kind of, like our identity, is kind of like you’re (child’s name) dad…”
This can also lead to the children and their families becoming better known within the school. D1 described that following a school fundraiser everyone knew about her child’s medical concerns and upcoming surgery, but she also explained that this did not seem to bother her child. She stated: “…when he had his transplant his school did a fundraiser for us. Yeah, it was really awesome of them, um, and everybody kind of knew him after that, because they had his picture plastered all over the hallways, and that kind of stuff, um, that was okay, I think he didn’t mind though because he liked the attention (laughter). Yeah, so and now everybody just kind of knows about his heart, and he has never hidden his scar or anything like that.”

Although this theme was not reported on strongly throughout the interviews with the participants, it is of note that having a child with medical complexities may alter sense of self and individual autonomy, especially within community settings. For example, within my own lived experiences, I feel that we often receive sympathy from other parents when I explain what is required to keep my child safe (such as screening for illness and increased hygiene and cleanliness) when required (such as arranging playdates). Although it does not impact me chronically, I do perceive that I am different than these parents in this regard, and this can be challenging at times (such as when forging new bonds and friendships with other parents).

**Vaccinations and Vaccine Hesitancy**

The next theme is focused on vaccinations and concerns about vaccine hesitancy and the anti-vaccination movement. This is a community health concern and something that needs to be considered within several of the physical spaces of the community, such as within the school and within extracurricular activities. This theme is one of the strongest within the study, and was discussed by all eight of the participants, as they all expressed concerns about vaccine hesitancy in the community to varying degrees. In regards to the importance of vaccines to protect children
who are immunosuppressed, Sick Kids Hospital states: “immunizations reduce the risk of many serious infections. Family members you live with should update their immunizations. This includes having annual flu vaccines. Immunizations make it less likely they will get sick and expose your child to one of these serious infections” (Sick Kids Hospital, 2012).

An example of this theme was observed as C1 discussed that she is concerned about vaccine hesitancy and unvaccinated children, especially considering her child was far too young to receive any vaccinations before he was transplanted. C1 stated: “well there are some things I worry about yes, because at the time that he was transplanted, he went on the transplant list a week before his first birthday, and at that time you could not get the measles mumps and rubella until you were a year old, we knew he was going to be put on the transplant list, but because of Public Health protocols we could not get him vaccinated early…so he has never had that, and now with measles popping up all over the place, that is a concern.”

Similarly, D1 stated that she is also concerned about the anti-vaccination movement, and explained that their natural supports have been quite helpful and cooperative with ensuring that they are vaccinated in order to protect their immunosuppressed child. D1 stated: “I don’t like anti-vaxxers (laughter). Yeah, both of us, and my kids, have all gotten the vaccines that we are able to get, ever. I know (child’s name) now, he can’t get live vaccines, so we have taught him that he can only get dead vaccines, and so this time when we got the flu shot he asked the pharmacist himself, is it a dead vaccine, and so we try to make him as independent as possible with stuff like that…” D1 often discussed the importance of fostering independence within her immunosuppressed child, as she identified that children with medical complexities should have additional autonomy and responsibility to maintain their health while they are young, so that they
will continue these behaviours as they become older, to ensure that they will be lifelong active participants in their own health care and wellness.

E1 reported that although she disagrees with the anti-vaccination movement, she does not believe that it is becoming more prevalent necessarily, but that the Internet is potentially giving people more of a voice, and also making it easier to recruit possibly vulnerable people into the movement. E1 stated: “…I don’t think it is growing as much as people think it is…It’s just that people are voicing that now, but um, it drives me crazy to see those boneheads right now (laughter). That they just have no validity at all, no real world understanding, no scientific backing at all, it drives me crazy, and it makes me laugh more than anything, and just feel bad for their families.” She went on to elaborate that they encountered a concern within their immediate family regarding vaccination hesitancy, which they addressed directly with the family member, and this resulted in the family member changing their views and subsequently vaccinating their children.

F1 works within the clinical healthcare field, and so the anti-vaccination movement has been particularly difficult for her, as she has encountered others who cannot interpret and/or misinterpret the science to her that she can understand, in order to make inaccurate arguments about their perceptions of risks regarding vaccines. F1 explained: “…the most stressful, now that she is (age), is going to a public school. And because she can’t be vaccinated with most vaccines, she is exposed to children who are unvaccinated, and being immunosuppressed, that’s frustrating. I have had little rants, and everybody weighs in, and I think that everybody is entitled to their opinion, like there is a common poster on Facebook, if I can’t send my kid to school with peanuts or peanut butter, you shouldn’t be able to send your kids to school unvaccinated.”
In regards to vaccinations and the impacts of vaccine hesitancy, both A1 and A2 agree that they are important; however A1 appears to be notably more concerned than A2. A1 stated: “…the whole sentiment is that if you don’t do it for yourself, do it for whom ever, and it’s true, it’s you know, um, she’s susceptible to some of these things, and just because you don’t, you know just because you don’t feel that it’s necessary…” On the contrary, A2 appeared to have shown lower levels of concern as compared to other participants, and stated that because her child was old enough at the time of the transplant to be able to be vaccinated she is not as concerned about the anti-vaccination movement, but still disagrees with it and is worried about the safety of other people’s children. A2 explained: “…with regards to the vaccinations, like um, (child’s name) was fully vaccinated before the transplant, they made sure that she had every single vaccination under the sun, that she could get, and so, I kind of feel like, the people who aren’t vaccinating for normal childhood illness, I feel like those people are, they’re putting their own children at risk, not so much my child…” As many children who require a transplantation surgery are often too young to receive all the required vaccinations before the procedure, and cannot receive live vaccinations following the procedure, it would be interesting to know how A2’s beliefs may differ if her child was unable to receive all of the vaccinations beforehand.

B1 also appeared to show lower levels of concern as compared to the other participants, and he identified that this is partly because he feels as though they control everything about their child’s environment currently and thus he is safe. B1 stated: “…for me, I don’t think I can control other people. You know, their body their choice, if they want to vax, great, it helps him out a lot, if they don’t want to vax, it’s their choice. For us we manage how often he goes out, where he goes, that type of thing, and the kind of people he’s around.” Their child is quite young, the youngest immunosuppressed child in the study, and so it would be interesting to follow up
with B1 as his child ages to see how his perception may change as his child gains more autonomy.

B2 expressed significantly more concern regarding unvaccinated children as opposed to B1, and discusses several times throughout the interview that this is a considerable stressor for her, and one of her primary concerns about her child transitioning into the school system. B2 stated: “…we actually had a scare last year, we had a family friend’s daughter who is not vaccinated, because her mom is whatever, I get her decision but my rule is that your decision effects how we interact, and when there is a potential measles exposure, you know, you can’t see us for a few weeks until we know that you are not affected, and all that, and our decisions to protect our child are your consequences for not vaccinating, right? That is just how it works…I know your daughter is not vaccinated, whereas most of the population is going to be, to be honest.”

In regards to whether the government should be doing more to protect and to support immunosuppressed individuals and families, five out of the eight participants stated that they would like to see vaccinations become mandatory, and especially for children who are attending public schools. For example, B2 stated: “…I don’t feel that people are educated enough to see the actual consequences for these kids who cannot get vaccinated. And that is where I create awareness, because I know that if (child’s name) gets exposed to measles, we have a 36-hour window where we can potentially not kill him. But, 36 hours is not a lot of time, and you would have to know that your kid has been exposed to measles. Like, so, I always share that on Facebook, and people are always like that’s scary, that petrifying, and it is scary to think about putting him into school and having someone unvaccinated affect him.”
Additionally, four out of the eight participants expressed notable concern regarding the misinformation associated with the anti-vaccination movement. For example, F1 stated: “I understand that there is a very small percentage that have reactions, but I get that, but I would rather see that small percentage not be vaccinated than anybody who, you know, says I don’t want to be vaccinated because this could happen, and my two older children who are up-to-date with vaccines, they are not autistic, (child’s name), who has pretty much no vaccinations other than the flu shot, is severely autistic. So, it’s frustrating.”

On the spectrum of concern expressed by parents, it appeared that A1, B2, and F1 expressed the most concern about vaccine hesitancy and the anti-vaccination movement, while A2 and B1 appeared to show less concern as compared to the other participants. Interestingly, both married couples within this study showed notably differing levels of concern in regards to vaccinations and vaccine hesitancy, while the other participants who identified as married indicated that the views that they expressed were views shared by their spouses.

Based on the experiences and concerns expressed by the participant families, it is evident that vaccine hesitancy substantially impacts the reality of those who are living with the condition of immunosuppression, and creates considerable fear and uncertainty for immunosuppressed individuals and their families. Although the right to freedom of choice is a common argument of those who support the anti-vaccination movement (as per their social media pages), freedom of choice should require further analysis if it causes a detrimental impact to the lives of others who are not privileged to be able to make this choice for themselves. Additionally, this contributes to health inequity for immunosuppressed individuals, as well as other individuals who may be medically vulnerable, as the protection of their health in the community is not being prioritized, which can leave these individuals disadvantaged and at risk for infections and illnesses that have
the potential to be fatal. The stress and fear of this possibility also negatively impacts the psychological safety of immunosuppressed (and/or otherwise medically vulnerable) individuals and their families within the community.

**Organ Registry System**

The final theme in the category of physical environments is focused on the organ registry system in Canada, and whether it should change from an opt-in system to an opt-out system. Currently, organ donors must go online to express their intent to donate organs post-mortem. This change would require those who do not want to be considered for organ donation to complete this process, and all others would be assumed organ donors. This was a strong theme, and was also discussed by all eight of the participants. Additionally, this theme is a community health concern, and also something that needs to be considered because it impacts how long individuals are waiting for organs, and consequently how long individuals remain sick while waiting, which then increases the amount of time that the individuals would be significantly medically vulnerable and unable to live their lives.

Some of the participants narrated that they were admitted to hospital while waiting for the transplant, so they could not even leave the physical environment of the hospital during this time, which then decreased their quality of life and subsequently increased stress. For example, A2 explained that they had to leave their province of origin to await the call within the area that the transplant would be facilitated for six weeks before they received the call for the transplant. During this time they had to pay for accommodations, and they were away from their natural support system. Another example of this concern was evident in F1’s discussion of how the wait times for an organ impacted her child medically, she stated: “I can’t put into words, like she was literally less than a week away from dying when she got her liver.”
All eight of the participants expressed significant support for a change to the current organ registry system to make it an automatic opt-in system. A2 reported that she is very much in support of the organ donation opt-out system, as opposed to the current opt-in system that is in place in Canada. A2 was the first participant to mention this theme; and subsequently all eight participants reported that they would also advocate for and support a potential change to an automatic opt-in organ registry system. A2 stated: “I do understand the system now, you can sign your donor card if you want, but if your family says no, it’s no. I don’t feel like it should be the family’s ultimate decision, I feel that it should be up to the person, and if they’re no, like with the opt-out system they didn’t opt-out so, that means that they want their organs donated…there would be a lot more organs available if that was the system….” A1 agreed with A2’s concerns, and elaborated that having an automatic opt-in organ donation registry would not only save lives, but also save costs to the medical system for long-term routine maintenance medical procedures, such as dialysis.

D1 stated that she would support this change to the current organ registry system, and also made an interesting point resulting from a recent conversation she had with her spouse. She stated: “I would like to see that across Canada, and not because my son had a transplant, but you don’t need them when you die, um, my husband gave me a scenario the other night, if you had a million dollars, would you rather give it to starving children, or would you rather burn it? Well, that’s kind of a no-brainer right? So I mean, we kind of look at it the same way, do you need your organs when you are buried six feet underground, well no, so why not give them to somebody who can use them.”

B2 also agreed that changing to an automatic opt-in system would save lives, and she identifies herself as an enthusiastic advocate to support this change. She requested that her
friends and family sign-up to become donors as a result of her child’s transplant. She stated: “…I am like I need you guys to sign up to be donors, and I had about twenty people say I did it because of (child’s name). And that was my biggest gift. Last year after his transplant I did a live video of myself just bawling, and I had said that nobody has a child thinking that they will be an organ donor, nobody does, and the reality is, someone watching this will have the decision to make one day, for your child to donate… And so I always create awareness, because in times of stress, you might say no, because you’ve never had that conversation, and you just can’t.”

Based on the experiences of the participants, as well as the enthusiasm and passion that the participants displayed in advocating for this change to the current organ registry system in Canada, it is clear that it would likely be beneficial for individuals requiring organ transplantation and their families if their concerns were addressed, and the change was ideally implemented as a result. Negative impacts of the current system that were identified by participants included: long wait times for organs, suitable organ shortages, medical deterioration as a result of waiting for an organ, and high costs to the medical system due to increased medical needs (such as lengthy hospital admissions), as well as routine medical procedures what would no longer be required following a transplantation surgery (such as dialysis).

**Employment and Working Conditions**

The two themes that were reported under the superordinate theme of quality employment as a support within the employment and working conditions category of the social determinants of health were: a supportive employer as a resource and the reduction of work-related stress. Six of the eight participants reported themes related to employment and working conditions. The two themes are very closely intertwined, but are presented as two separate themes, as one participant
did report an increase in stress upon returning back to her employment after her leave that she
took during the crisis period was completed (extended maternity leave).

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<tr>
<th>Employment and Working Conditions (75%)</th>
<th>Quality Employment as a Support</th>
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<tr>
<td></td>
<td>• Supportive employer as a resource.</td>
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<td></td>
<td>• Reduction of work-related stress.</td>
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**Supportive Employment as a Resource**

The first theme, a supportive employer as a resource, was mentioned by several
participants as being crucial to enduring the stress while within the acute periods of crisis. For
example, F1 explained that she and her now ex-spouse both had supportive employers during the
crisis period. F1 stated: “(name of ex-spouse) was on sick leave, and holidays, work was
fantastic, we have a different executive now, but the executive at the time basically said while
you are gone don’t worry about work…” F1 went on to elaborate that their employers offered
them many options for their leaves from work (such as using sick time and/or holiday time
before exploring other options), with the intent of having them both off of work, but also being
paid during that time, which is quite supportive and notably flexible to their needs during the
crisis period. She also explained that they were able to get some of her ex-spouse’s time
reimbursed by an agency, which decreased their stress and increased their resources in regards to
additional time that could be taken moving forward to address subsequent illnesses and other
stressors that occurred.

Another example of this theme was evident in A1’s description of his current
employment. A1 stated: “I have a really um, an incredible employer that kind of respects that,
but the times that she’s in the hospital, it’s hard…” He described that his employer was
incredibly supportive throughout the process, which helped their family navigate the situation, as
employment was not something he had to worry about during this time. He did state though that concentrating on work was difficult during this period, due to the stress of their child being admitted. A1 was the sole income earner in the household at the time, as A2 was not working in order to be able to take care of the children. A2 has since returned to working part-time with an employer that she has worked for intermittently for many years. She stated: “…my employer is supportive, so the times that I haven’t been able to work, I just say you know what my daughter is in the hospital so I can’t work any shifts this week, and so she’s been fine with that…” She identified that her employment is flexible when needed, and so this does not contribute to the stress, but rather alleviates it, because the employment is an additional income for the family as well as supportive when required.

Additionally, B1 and B2 both explained that B1’s employer has been very supportive throughout the process. B1 is currently the sole income earner for the family, as B2 is staying home to take care of their child. They also elaborated that they receive a comprehensive healthcare benefits package that reduces their stress, because they do not have to pay much out of pocket for medications each month, and they have access to counselling (free of additional charges) as required. B1 stated: “…my employer was really good about it, when he was born, and I had six months off work at full pay, so I mean, his meds are, they do cost quite a bit, and they will only be going up, Tacro especially, but um, my plan is really good through work, so we haven’t noticed it much for ourselves.” B1 stated that this employer gave him six months off of work at full pay in order for him to be with his family during the crisis period, which helped their family substantially financially and emotionally during this time. B2 described that because of this, finances were not a stressor for them throughout the process, and they both stated that they did not incur any unmanageable debt during the crisis period. B2 describes their family as lucky,
because they were able to be together as opposed to other families that they met who had to be apart for employment purposes during the crisis period.

Although gainful employment with comfortable pay and adequate benefits is often the focus of what is required to ensure that employment is supportive and a positive fit for employees, what was also strongly noted by the participants within this study was the importance of employment flexibility in times of stress. Having a child with medical complexities typically means more appointments and sick time, which results in an overall decrease in the ability for a caregiver to leave the home regularly on a set schedule to attend work. Working from home, as well as flexible start/stop times, were noted as easing this stress and increasing the overall satisfaction with employment for the families within this study.

**Impact of Work Related Stress**

The second theme is the reduction of work-related stress. Although this theme was present throughout the first theme in that having a supportive employer decreased stress for the families, one participant reported that returning to work disrupted the equilibrium that was established while she was on leave during the crisis period. E1 stated: “…when I stayed home it was a lot easier. Um, I stayed home for two years, with her because that was probably as long as we could take before we lose our jobs, um, so I took two years and then went back to work, and it definitely got harder, with the return to work and housekeeping, and then you have the kid destroying everything and making messes (laughter). Um, so yeah, we certainly try, we have definitely learned what to focus on and what not to focus on.” She identified that continuing to maintain all that is necessary for her immunosuppressed child, such as daily housework to ensure the cleanliness of the home, is much more difficult to manage since she returned to work following the acute crisis period.
Although none of the participants reported that they had an unsupportive employer, based on the identified importance of a supportive employer reported by six out of the eight participants, having an unsupportive employer would likely be very difficult for immunosuppressed families. An unsupportive and inflexible employment environment may add to the individual and family stress, as well as cause the crisis period to be more difficult for various reasons (such as worrying about the potential for the loss of finances and being unable to get time off work). Characteristics of supportive employment that were identified by participants as being valuable were: flexibility in working hours or shifts, understanding regarding absences, paid leave, and options for other types of leave as required (such as paid sick leave, paid family sick leave, paid vacation hours, and statutory holiday banked hours).

**Income and Social Status**

The three themes that were indicated under the superordinate theme of decreased income and financial impacts to the family within the income and social status category of the social determinants of health were: not being able to work and/or cutting back on working hours to accommodate the child’s illness, decreased income, and expenses directly related to the illness. The two themes of not being able to work and/or cutting back on working hours to accommodate the child’s illness and decreased income are interrelated, but are presented as two separate themes in order to explore the participants’ experiences related to being unable to work due to family constraints, and also the financial impact of the situation to the family. All eight of the participants reported themes related to income and social status.

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<th>Income and Social Status (100%)</th>
<th>Decreased Income and Financial Impacts to the Family</th>
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<td>• Not being able to work and/or cutting back on working hours to accommodate illness.</td>
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Unable to Work and/or Reducing Employment

The first theme, not being able to work and/or cutting back on working hours to accommodate the child’s illness, was reported by several of the participants to be occurring both during the crisis period and beyond. As identified in the gender section, some of the female participants indicated that they ceased working and/or cut back their working hours, as opposed to the male participants. Additionally, the reduction and/or ceasing of employment was noted as contributing negatively to financial stress by several of the participants.

An example of this theme was evident in A1 and A2’s discussion regarding why they were a single income family for many years and how this has impacted their family. A1 stated: “…it’s a struggle specifically when she’s in the hospital, and then yeah, when she’s sick we’ve always said my wife can’t work, because she gets sick, she needs to be home…” He described A2 not being able to work outside of the home because the responsibilities and the uncertainties that they face on a daily basis, due to their child’s medical complexities. A2 agreed, and elaborated: “…I can’t really have a fulltime job, at least not at this point in time, because then at least if she does get sick…and we’re in hospital for two or three weeks, the first time in a year there goes my vacation time, and then what? And subsequent times, then what do I do? It feels like it would be a futile effort to work…” The reasons for A1 and A2 deciding that A1 would work fulltime outside of the home as opposed to A2 were not discussed. However, A1 and A2 stated that currently they are not facing any financial stress, and they have not incurred any unmanageable debt throughout the process, and so finances may have contributed to this choice for the family.
Similarly, in regards to not being able to work and/or cutting back on working hours to accommodate the child’s illness, B1 discussed that he is the sole income earner within the family currently, and that the medical complexities for their child prevent B2 from working. B2 confirms this statement, and she indicated that because their child’s health needs are so complex they do not trust just anyone to provide care to him, but they have explained that some close family members have learned what is required in order to provide some care periodically for short periods of time. The reasons for B1 and B2 deciding that B1 would work fulltime outside of the home as opposed to B2 were also not discussed, but currently they too stated that they do not have any financial stress, and that they have not incurred any unmanageable debt throughout the process as well, and so finances may have also been a factor in their decision.

D1 explained that her child’s illness also impacted her ability to work outside of the home, due to the uncertainties of his illness and numerous planned appointments and procedures. She went on to elaborate that she is now transitioning back into the workforce but indicated that this has been stressful. She stated that although she has considered returning to school to pursue additional post-secondary education, she fears that they cannot afford this currently, and this appears to be limiting her potential options in terms of available employment. The reasons for D1 ceasing employment as opposed to her spouse were not discussed, however she did not report being in acute crisis at any time during the interview.

Although this theme is intrinsically linked to employment/working conditions, as well as difficulties accessing childcare, what was noted in this particular aspect of the phenomenon captured within this theme was the helplessness that was detected at times throughout the conversations with the participants. For example, for those who decreased their employment outside of the home, they identified that they had no other choice. Although this was not the case
for the single parents within this study (one worked from home, and the other worked shift work
and shared 50/50 custody), it appears that this could be difficult and challenging for someone
caring for their child outside of a pairing to manage. Without assistance from a partner, and/or
other natural supports, and limited access to appropriate childcare (as also noted by participants
within this study) it is not clear how this situation might be mitigated for a single parent within
these circumstances. Further research that is specific to focus on a sample of single parents may
be beneficial in gaining a thorough understanding of the experiences for those who may have
decreased or limited assistance via outside resources.

**Decreased Income**

The second theme, decreased income as a result of the crisis period, was reported in
conjunction with, but also in absence of, the previous theme. For example, C1 works with
children who are medically complex. She explained that because her son is immunosuppressed
this has impacted the children she is able to work with, as she cannot provide care to anyone with
a communicable disease. This has subsequently negatively impacted her income, as she does not
receive payment unless she is providing care. C1 stated: “…yeah I became a little more careful
about the children that I accepted, because we have some kids coming from the northern part of
the province testing positive for tuberculosis, and so those children don’t come to my home.
Basically kids that carry viral things, don’t come into my home now.”

E1 reported that she and her spouse were both on leave during the acute period of crisis; her husband was on a paid leave and she was on maternity leave. As they both had a reduced
income at this time, she explained that this caused them to go into debt. She extended her
maternity leave due to her child’s medical needs, which prolonged the period in which she had a
reduced income. E1 stated: “…I know most families end up going into some debt while they are
away, so yeah, that certainly creates a whole other level.” However, she and her spouse have since returned to work, and she is currently working part-time by choice. She stated that they are not currently experiencing any acute financial stress and that they do currently have access to full-time childcare via family. F1 also reported that her family went into a substantial amount of debt following the crisis period; however, she too indicated that they have recovered financially, and that they are not currently experiencing any acute financial stressors.

The financial stress and hardship that can be incurred as a result of having a child born with medical complexities was extensively noted by participants, and is an important aspect of the phenomenon to investigate. This financial stress can further negatively impact families by adding to the existing stress resulting from the situation, as well as leave families financially disadvantaged, as compared to their prior financial functioning, for a significant length of time. The financial implications also leave less income to address other needs, such as specialized nutritional requirements, high-quality childcare, medical equipment, and required medications that are often not completely covered as compensated medical expenses (or not covered at all).

**Expenses as a Result of the Illness**

The third theme within the category of income and social status was expenses directly related to the illness. The primary source of the additional expenses reported by participants was associated with the costs of the required medications for their children. Other significant financial impacts that were reported were the result of the travel that was necessary for the transplant procedures (accommodation, transportation, and food expenses were reported as only partially covered, or not covered at all, depending on province of origin).

For example, A1 stated: “…dealing with the different things to ensure that her health is maintained, and yeah, and the medications, the immunosuppression drugs are not cheap.” He
also reported additional uncompensated expenses; he explained: “another thing that we kind of glazed over is the amount of time we spend at the hospital. I mean, you go to the casino and you can get free parking at the casino, but you know, you’re at the hospital for like… Yeah, and not only are you dealing with your sick child, and eating out a lot because you’re not at home, and buying hospital food, and then paying upwards of twenty-six dollars a day for parking, which is ludicrous right, so there was a period of time where we were at the hospital every single day, well six days a week, we had Sundays off, when she was on dialysis, but it adds up. It’s always been a little bit of a point that I feel has been overlooked, and obviously being immunocompromised we spend more time at the hospital, it’s definitely been an issue, and I’ve always thought there should be a change on that.”

Regarding medications and coverage, B1 and B2 stated that they have excellent benefits via B1’s employment that cover the majority of the costs for the required medications. They also report that Pharmacare has not been helpful for them, B1 stated: “we are never going to hit Pharmacare, and that is one thing I wish (name of location) would change, is the deductible, even do it like Saskatchewan, like twenty-five bucks or something…” It appears that although Pharmacare is helpful for some families, it does not appear helpful for families who are not within a low socioeconomic status, leading to families feeling that they are without help despite being negatively impacted by significant medication costs.

Both A1 and A2 discussed that they feel as though the medications required for children should be completely covered. A2 indicates that although they are aware that programs like Pharmacare exist to help families offset the costs of medications by assigning each family a deductible based on their income, that this does not help them as their deductible is too high (this was a complaint made several times throughout the interviews by the participants). A2 stated:
“…most of the medication, is more expensive, you know, and because we are not destitute, you know like, we are comfortable so we don’t qualify. Like Pharmacare, we are all registered but we have a huge deductible for Pharmacare, and sometimes we meet it and sometimes we don’t, but we are paying a lot out of pocket every month for medications, and so to have something like that fully covered would be amazing.” They also elaborated on additional costs that they have incurred that are not covered, including: the feeding pump (for tube feeding), the bags required for the tube feeds, the wheelchair, diapers, and distilled water (due to a concern regarding waterborne illnesses).

Residents of provinces with government medication coverage within the study stated that they did not feel any stress caused by the costs of their medications. For example, it was disclosed by participants that in Saskatchewan no medication prescribed to a minor will ever cost more than twenty-five dollars, and even this cost is covered by most employment benefits packages. Based on the stress reported by the participants residing in provinces without comprehensive government coverage, it would likely be beneficial for provincial governments not providing this coverage, such as in Manitoba, to address these concerns, and perhaps consider adopting a system similar to that in provinces with comprehensive coverage, such as in Saskatchewan.

Participants reported that more funding would be beneficial to cover travel expenses, as the transplant procedures were not able to be completed in the province of origin, and so they had no choice but to leave the province on medical referral to have the procedures completed elsewhere (typically Alberta or Ontario). E1 stated: “…so if we are sent out of province, like we were sent to (name of location), and you get nothing, you can apply to (name of program) and you get like a hundred bucks a month or something, but, yeah, there’s really nothing, well not
provincially, transplant families have it a little bit lucky, we have access to David Foster and stuff, but in terms of the province there is absolutely nothing.” F1 also reported financial stress and expenses related to travel, she stated: “…everybody thinks that Ronald McDonald House is free, but when you are paying that on top of a mortgage, and we had a pretty hefty mortgage, um, and I was getting 55% of my salary, and flying back and forth, (name of government program) is brutal for what they cover, um, yeah, we went into debt for sure.”

All of the participant families identified that agencies like the David Foster Foundation, the Ronald McDonald House, and the Canadian Transplant Association were overall supportive and very helpful, however they identified that more government monetary assistance for families would be beneficial. Considering families have no choice but to leave the provinces of Manitoba and Saskatchewan to procure the required transplant procedure, the collective governments of both Manitoba and Saskatchewan could consider re-evaluating the funding allotted to these families to cover travel costs, in order to alleviate additional financial stress and lasting debt incurred by families in these circumstances.

**Social Supports and Coping Skills**

The three themes that were indicated under the superordinate theme of decreased contact with natural supports as a result of the illness within the social supports and coping skills category of the social determinants of health were: impacts to the ability to see friends and family (having to cancel plans), screening for illness, and lost friendships. The three themes that were reported under the superordinate theme of stress and impacts to the family within this category were: impacts to the relationship with the other children, impacts on relationships among spouses (family discord), and expanding the family after having a sick child. The four themes that were identified under the superordinate theme of the importance of external supports
outside of the immediate family were: the importance of natural supports, importance of support groups as a means of coping and support (online (social media) and in-person), difficulties accessing childcare due to special considerations to protect the immunosuppressed child, and having to cancel childcare. The final theme within the category of social supports and coping skills under the superordinate theme of individual management of stress was coping and self-care. All of the eight participants reported themes related to social supports and coping skills.

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<th>Social Supports and Coping Skills (100%)</th>
<th>Decreased Contact with Natural Supports</th>
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<td>• Impacts to the ability to see friends and family (having to cancel plans).</td>
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<td>• Screening for illness.</td>
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<td>• Lost friendships.</td>
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<td>Stress and Impacts to the Family</td>
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<td>• Impacts to the relationship with the other children.</td>
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<td>• Impacts on relationships among spouses (family discord).</td>
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<td>• Expanding the family after having a sick child.</td>
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<td>Importance of External Supports outside of the Immediate Family</td>
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<td></td>
<td>• The importance of natural supports.</td>
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<td></td>
<td>• Importance of support groups as a means of coping and support, online (social media) and in-person.</td>
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<td></td>
<td>• Difficulties accessing childcare due to special considerations to protect the immunosuppressed child when making decisions regarding childcare.</td>
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<td>• Having to cancel childcare.</td>
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<td>Individual Management of Stress</td>
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<td>• Coping and self-care.</td>
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Impacts to the Ability to see Friends and Family

The first theme, impacts to the ability to see friends and family (having to cancel plans), was brought up by participants in the context of not being able to see loved ones due to illness. For example, if the immunosuppressed child is ill the family would have to cancel plans in order to care for the child. Alternatively, if the loved ones who they are supposed to see are ill, the family must cancel plans in order to protect the immunosuppressed child from the illness.

E1 stated that her friends and family are used to them cancelling plans, but remain supportive as they understand what is required to keep their immunosuppressed child healthy and well. She explained: “…they call us and, we cancel, I mean our friends are used to us cancelling plans. Like when someone gets sick or, it’s good because our friends will be the ones who cancel the plans, which takes a lot of stress off of us, so if their kids get sick they will call us and say don’t come over because my kids have whatever, which is really nice not to have to constantly be saying well I can’t come over because your kids are sick.” Similarly, F1 also described their friends and family as supportive, as they have also had to cancel many family dinners and other engagements due to illnesses. She stated: “…we didn’t allow anybody in who had cold or flu-like symptoms, um, so yeah we have had to cancel family dinners at our house, and we have said you guys have to go somewhere else.”

A2 also explained that this has been a concern for their family in their experience, she stated: “…if people are sick we don’t get to see our friends, right, and so plans get cancelled, and if she’s not feeling well we stay home from church. Stuff like that is a constant consideration, like how she is feeling, you know, is someone else sick, it is a constant consideration, and always at the back of your mind.” Both A1 and A2 often stressed the importance of their natural supports, as well as their religious community, and so missing these engagements is notably
difficult for them. B2 also reported that illness has impacted their ability to see family and friends. She stated: “…with our cousins, they had the flu, so we cancel. No major holidays have been cancelled yet…” She goes on to elaborate that one of the children in her extended family attends daycare regularly, and so she worries about this child infecting her child with an illness, as this child is likely exposed to many pathogens within the daycare environment. She also discussed that she prefers to have some idea about who their child caught an illness from, so that they may have some information about the duration and the severity of the illness, as opposed to not knowing.

Natural support systems, such as family and friends, are important to coping and overall wellness. As discussed by the participants, the condition of immunosuppression can decrease the ability to see natural supports, due to the potential for illness and risk for contracting communicable diseases. This may further increase stress and decrease coping, as well as negatively impact the children’s (the immunosuppressed child and any siblings) opportunities for socialization with peers.

**Screening for Illness**

The next theme, screening for illness, was intertwined with the previous theme and came up throughout the interviews in regards to families having to ensure that the individuals who will be around their immunosuppressed children are healthy, and thus will not pose a risk to the child in terms of infecting them with a communicable illness. Recommendations to minimize the risk of contracting infections include: “avoid contact with individuals known to have a respiratory illness, especially when they are symptomatic, notify the child or youth’s treating physician at the first signs of respiratory illness during influenza season (some patients require testing and treatment or prophylaxis with neuraminidase inhibitors), inform the child or youth’s medical
team when there is influenza illness within the household, minimize exposure to crowded environments, such as shopping malls, during influenza/respiratory virus season, avoid primary or secondary exposure to tobacco smoke, [and] avoid risk of exposure to fungal pathogens by: minimizing exposures to construction, excavation and renovations sites, where fungal spores (e.g., Aspergillus) can thrive, minimizing inhalation of fungal spores from plants and animals (i.e. in farms, barns or pigeon coops, or from mulching, turning compost piles or cave exploration), [and] not smoking marijuana” (Canadian Paediatric Society, 2019).

This theme was notably strong, and was discussed by several participants throughout the interviews. For example, screening individuals is something that both A1 and A2 have become quite familiar with in their experiences as an immunosuppressed family. A1 explained: “…our family all knows, they come in and they go, but just our friends, you know, it’s always like is anyone sick, has anyone been sick? We’ve cancelled a lot of play dates.” A2 agreed, and elaborated: “…if someone has a cold, and we’re not going to expose her to that, you know, we protect her in that way, and it seems as though a lot of play dates get cancelled because of that reason or just, having another family come over or friends come over and one of them is sick, so we always confirm the day before or the morning of that everyone is healthy….so it’s just become a fact of life, that’s how life is with the transplant.”

Constant engagement with risk assessment, such as that involved with screening for illnesses, can be difficult to manage and may lead to increased hypervigilance and stress. Although the participants reported ongoing impacts to their social engagements and relationships with natural supports, none disclosed that they were actively isolating themselves, and all described ongoing contact with supports.
Lost Friendships and Relationships

The third theme in the category of social supports and coping skills is lost friendships and relationships, which was reported by participants as a result of the changes that they made in their lives to accommodate their child’s health needs. For example, C1 stated: “a lot of my friends have fallen off over the years, I can’t blame that totally on the transplant, but some of it had to do with that, yes. Um, one of my friends is, was, she used to be my friend, is of a religion that is very against transplant. Um, so she didn’t hang around very long. And a family member that followed the same religion withdrew from our lives as well.” D1 also reports impacts to friendships, she stated: “…I know like friendships especially they really got put to the test, and not all of them lasted, so, I mean it’s either they need to learn how to support us or we don’t need them.” They both explained that although they have lost relationships with friends and family along the way, ultimately prioritizing their child’s wellness is worth far more than anything they have lost in the process.

Losing relationships with friends and family can be extremely difficult, and can lead to increased stress and social isolation. In my own lived experience, our family has lost friendships with individuals who are against vaccinations as noted in the autoethnography. This has also impacted our children’s friendships, as they cannot invite children over who are not vaccinated as per the guidelines provided by our child’s medical professionals (we ask parents directly if their children are vaccinated). These interactions can be uncomfortable at times, and can decrease the feelings of comradery with other parents.

Impacts to the Relationship with Siblings

The next theme, impacts to the relationship with the other children (siblings), was discussed by several of the participants throughout the interviews. All of the participants with
multiple children narrated that the situation did impact their other children to some extent, both negatively and positively.

D1 explained that the illness impacted their other child negatively significantly, as they ended up having to spend a considerable amount of time apart as a family due to the medical needs of their child with immunosuppression. D1 stated: “…the year after his transplant when (child’s name) got sick, I mean the first few months we ended up in (name of location) again, because we weren’t sure if it was part of rejection or, that kind of thing, and, um, we ended up missing his (age) birthday, and that was the first time we had ever missed any special occasion, or anything like that, so that was really hard for myself.” She went on to elaborate that they had to be apart for six weeks when their immunosuppressed child was admitted, and so this also impacted the bond that her children share, because they are very close in age and share a strong emotional connection. She also explained that they had to miss their child’s birthday because their child with immunosuppression was admitted to hospital, which was extremely difficult for them. She indicated that they felt guilty and tried to make it up to their other child afterwards with extra attention and special outings. She stated: “I know that I have always spent more time with our sick kid right, so I always try to make it extra special when, you know, there is one-on-one time or whatever, something just for him, so when I missed that it was really hard to take that.” She also explained that her other child often worries about the wellbeing of their immunosuppressed child, and is scared that he might get sick again, which causes ongoing stress for their child.

Both A1 and A2 reported that they believe that their children have been negatively impacted by the outcomes of the illness and admissions that have been required for their child with immunosuppression. A1 stated: “…if I can speak from their perspective I think that they felt
neglected, because a lot of the attention has been on (child’s name) and her needs, and um so, um, so yeah, it has caused stress in our relationship in that respect. Um, you know, it’s stressful when she’s in the hospital.” A2 agreed, and elaborated: “…the older kids always mention every time she is in the hospital, or you know we always have to cancel things or we don’t get to do things, not so much now that they are older but, they a little bit more understand…” She stated that her other children had to miss out on social engagements and other activities because their immunosuppressed child was ill and/or admitted, and this has made them feel guilty at times because their other children were disappointed, and so similarly to D1 they also tried to make up for it to them afterwards in other ways, such as special outings and spending more time with them.

F1 identified that the medical challenges they experienced impacted her other children positively, as it strengthened the bond between her children, and an additional positive outcome was that her other children responded by becoming caretakers for the immunosuppressed child. F1 explained: “…they have never ever ever said anything negative, like this is because of (child’s name) or all this is because of (child’ name), they are nothing but second moms, they traveled to (name of location) actually, my oldest went to (hospital name) and finished there, which is kind of neat. They traveled with us, and they stuck with us until (child’s name) got critically sick after the transplant…” She described that their family was able to remain together, and rarely had to be apart despite being within an acute medical crisis intermittently for the majority of a two-year period. She stated that her two other older children continue to support and care for their sibling who is immunosuppressed, and describes them as second mothers to the child. She elaborated: “…they never resented it or, and as far as I know they have zero
resentment, and they both babysit her independently, (child’s name) and we can totally trust them, we can go out for a few hours and leave her meds, and they can give her a bath…”

As noted by the participants, lengthy hospitalizations and constant worry can increase stress throughout the family, and result in the family needing to be separated for varying lengths of time, which may cause risk for further stress and potential for negative impacts to family bonding. However, fortunately what was identified throughout the participant discussions of relationships, were the strengthened bonds that the participants now experience as a result of what they have endured as a family.

**Impacts on Relationships among Spouses**

The next theme, impacts on relationships among spouses (or family discord), was reported in regards to the impacts of the crisis period on the marriages of the participants, which resulted in discord on varying levels of severity, from an increase in arguments resulting in family tensions and discord, to divorce.

D1 identified that although things were difficult for them at times, she and her spouse have always supported each other, and she states that there has not been any lasting damage to the marriage. D1 explained: “…we supported each other when the other needed it, um, yeah and mostly, you know, we were always open about it and how it was effecting us personally, and as a couple, I think I took it a lot more harder than he did, for anything, um, and so for me it was a lot more grieving process I guess, because I always figured that it was my fault. Yeah, so um, but, it’s worked out, like, it worked out. It wasn’t anything that we couldn’t support each other through.” She stated that she had felt guilt and grief in the past as she blamed herself for her child being born ill, she also identified that she has since addressed these intrusive negative
thoughts with a counsellor and reports that she is now doing well. These thoughts were not explored further to avoid any potential risk of re-traumatization.

A1 and A2 explained that they have experienced an intermittent increase in marital and family discord from the crisis period, but further elaborated that the discord was not anything unmanageable for them, and that their marriage and family remained strong throughout the crisis period and beyond. A1 stated: “…it’s hard, and I’m going to work and all you’re trying to do is just function, just trying to function, and, um, so yeah, it, you’re not really focusing on your relationships that you have in your life, with your spouse and your kids, and it just starts to show fractures here and there.” A2 agreed, and explained: “…it has put a strain on our relationship at times, you know, we, you’re tired and you’re cranky, and you just need some sleep, and you’re sleeping on those chairs, and so, or I am at the hospital all day with her, and so it affects our relationship too. It affects all aspects of the family relationships.” Both A1 and A2 stated that they are not experiencing any acute family discord currently, and describe their marriage as supportive and positive.

F1 reported that her marriage ultimately did not sustain the crisis period, as she and her spouse did eventually get a divorce. F1 stated: “I think that the term having a sick kid makes or breaks a marriage, um, and I think if you don’t have a good solid foundation, which now in retrospect I recognize, it’s going to fall apart, and my ex-husband, as you know, in order to be a donor your liver has to be under ten percent fat or something… but in five months he lost fifty-four pounds, cold turkey, he quit drinking, and he was, he looked great, he was in perfect health, he quit drinking, and probably at that time our marriage was the strongest. Um, however after everything crumbled, after we found out he couldn’t donate, he just kind of fell apart.” She went on to elaborate that after her ex-spouse was informed that the living donor procedure could not
be performed her marriage suffered, and eventually ended in divorce. She stated that they
separated amicably and still have a very supportive relationship. It appears that based on the
experiences reported by F1, she and her family did trend towards mal-adaptation temporarily.
She explained that although leaving her marriage was difficult, they have since stabilized and
have been co-parenting and co-existing successfully. Thusly, even though they did move towards
the mal-adaptation state they utilized their resources (separation, divorce, two separate
households, ability to co-parent, natural supports, etc.) to regain the family equilibrium and to
create a new normal for the family successfully.

Each family is unique in how the stress impacted the bonds between spouses. Although
many participants spoke of strengthened bonds throughout the family overall and in regards to
the children, strengthened marital bonds specifically were only disclosed by one participant.
Many participants reported no change to the marriage, or intermittent increases in discord. One
participant explained that the stress was the initial catalyst, and ultimately her marriage did not
survive. Throughout my lived experiences, I noted no immediate significant changes to my
relationship with my spouse specifically, but very prominent increases in the bonding with my
children and an overall increase in satisfaction in my family life. As time goes on and my
marriage continues to evolve, we have struggled with a decrease in attention paid to our
relationship, which has become problematic. As noted also by the participants, living as an
immunosuppressed family comes with an increase in demands on resources (such as time), and
in hindsight this may have impacted my marriage more than I initially anticipated. It would
likely be beneficial to explore this phenomenon in further detail, specific to marital functioning
across time, to better understand ongoing impacts to marital bonds.
Expanding the Family

The next theme is expanding the family after having a sick child, which was identified by three of the participants in regards to having a child after their previous child was born with a serious illness. A1 and A2 had a child after their child was born with medical complexities, and they reported that although they were worried they received additional medical monitoring throughout the pregnancy, which along with reassurance from their team of medical professionals helped to alleviate their stress. A2 stated: “we were worried for the first while…we were very reassured the whole way through that everything was going fine, and so you can enjoy things more.”

B1 and B2 also decided to have another child but worry about how the situation might transpire, as B2 was pregnant at the time of the interview. B2 stated: “…it took lots of decision making, and months of talking, and thinking about if this is the right time, but will there ever be a perfect time, because this is just what happens when you have a complicated child. We haven’t told very many people yet, because we don’t have our first appointment until December. It’s new and exciting, but it’s also nerve wracking, we know what can happen now, our knowledge is almost too large, because kids are born sick.” She identified that they are also consulting with their medical teams frequently and plan on taking all possible precautions to avoid any potential medical concerns for their baby. However, they understand that some things cannot be avoided, and they have accepted this risk, as it is part of their reality.

E1 also reported that she is pregnant at the time of the interview, and although she and her spouse waited longer than they necessarily would have to have another child, this is mostly due to the fact that they wanted to ensure that their immunosuppressed child was medically stable before they decided to expand. E1 explained: “I am pregnant right now so we are having
our second. We probably wouldn’t have waited three years, had we had a healthy, quote-end-quote normal child, um, we probably wouldn’t have waited that long, but it’s impossible to say really, but our plan was to have them closer. Um, but otherwise, you know, I know a lot of people get really concerned about having more kids, we didn’t have that concern at all…” E1 identified that they do not worry about managing both children, as their immunosuppressed child is now medically stable. She stated that they are not overly concerned that their second baby will also be born with a medical condition, and she explains that they will handle anything that happens as it comes.

As there does not appear to an abundance of readily accessible research about the expansion of a family after having a child with complex medical needs, additional in-depth research on this phenomenon would likely be beneficial to enhance the understanding of this experience. Based on the experiences disclosed by the participants, it appears that close monitoring by teams of medical professionals is a resource that has helped them to cope with the stress associated with the situation. Family counselling may also be a resource that would be helpful in this situation to further mitigate stress and encourage coping.

**The Importance of Natural Supports**

The next theme, the importance of natural supports, was reported throughout the interviews. Natural supports are considered within this study as supports that are not provided by professionals, for instance family members and friends. For example, in regards to the importance of natural supports, F1 spoke at length about how supportive her family and friends are, including her fiancée and her ex-spouse, and how helpful this has been for her throughout the process. She also reported that her sister came with them when they had to travel out-of-province for medical care, in order to help them care for their other children. A2 explained that
although they do not live near her family, they do live near A1’s family. She stated that A1’s family has been tremendously supportive, and she has forged a strong bond with them throughout the process. She further explained that his family helped her and their family in terms of emotional support, in additional to assistance with childcare.

B2 also stressed the importance of natural supports. She stated: “…our immediate family is good, and they understand, because they saw him at his worst. They knew how lucky we are, and it opened everyone’s eyes, like kids get sick, and not in terms of flu and cold, that’s not sick, but spending months in the hospital is totally different. So yeah, definitely, my family is my go to…” She also identified that her family is helpful in offering childcare when she needs assistance, she explained: “I know when I am starting to feel like I need a break, and I’ll just, like my mom and sisters are fantastic, like they will come over and watch (child’s name), and they are confident with (child’s name).” Both B1 and B2 discussed the stress associated with finding appropriate childcare for their child, as he has significant and frequent medical needs, and so they must ensure that anyone who may take care of him will be responsible enough to do so safely. B2 identified that she feels confident in leaving her child with her family (mother and sister), and that her family feels confident that they can handle any medical needs that may be required.

E1 stated that her family and friends are incredibly helpful; her mother changed her plans significantly to be able to care for their child fulltime after E1 went back to work, in order to avoid placing their child in a daycare environment, as this would increase her risk of being exposed to illnesses. E1 explained: “…it makes all the difference. I know a lot of families who are about the same kind of situation as us, about three years out kind of thing, and they still haven’t returned to work, because they don’t know what to do about the whole childcare
situation.” She also identified that her friends and family are supportive, and respect what is required to keep their child healthy and safe.

Similarly, C1 identified that her natural support network was helpful, especially in the period following the transplant where C1 felt as though they were not receiving adequate care after being discharged from hospital. C1 stated: “…outside of my own family, there was none (referring to her family as supports, and stating that the medical team in her province of origin was not helpful). I just used family. Um, and I think I supported them as much as they supported me, because everyone was super attached to this child.”

Based on the experiences of the participant families, it is evident that having a supportive and helpful network of natural supports (friends and family) is a resource that is crucial to transcending through the crisis period, to ensure that coping and overall wellness is maintained for both the immunosuppressed individual and their family. All eight of the participants spoke about the importance of natural supports, making this a significantly strong theme throughout the study.

The Importance of Support Groups

The next theme is the importance of support groups as a means of coping and support. Support groups included both online (social media) and in-person groups, and this was something that was indicated by several of the participants as being helpful to them during the crisis period and beyond. Interestingly, the male participants did not indicate that support groups were helpful for them in any capacity, while four of the six female participants did identify that support groups were helpful.

F1 explained that she received support from people that she connected with who had children with the same diagnosis as her child, but wishes that there was a standardized process
for families to connect and to seek support. F1 stated: “I wish there was some sort of registry where X amount of people put their names on the list and when someone is diagnosed with biliary atresia, or any kind of autoimmune, or a kid who needs a liver transplant period, because I love talking to people about it, because I got so much… and it gave us hope, it gave us strength, through everything that we went through…” F1 stated that she prefers in-person supports as opposed to online support groups, but believes that both are helpful and beneficial for fostering connections with others.

C1 not only identified that support groups are helpful (both in-person and online), but also that she runs an online support group for families with children who are immunosuppressed. She stated: “…we have right now, because it’s still fairly new, ten or twelve people. It’s an online support group. We have ten or twelve people, in the province. But we are also hosted on a number of other websites, for people whose children may require transplant or have required transplants …” She went on to elaborate that although she is involved with some other support groups online, she typically gives more support than she receives in her own group, because her child is the oldest child of all the parents and caregivers in the group, and so they often come to her for advice and guidance regarding what to expect for their children.

A2 identified that she prefers online support groups, as compared to in-person support groups. She reported that she uses online groups often for support and resources, she stated: “I am totally for Facebook groups. I feel like Facebook and that is the easiest. Honestly if it was a face-to-face group where you had to meet up, you know with sick kids, time constraints, I don’t think I would be interested in something like that. But if it’s a public or a secret Facebook group, I would be way more interested in that, I would join that, because it’s something that you can do at two in the morning…yeah, more accessible.”
B2 identified that she finds online groups supportive, and prefers this means of support as opposed to in-person groups, although she also states that she has made friends with other families in the online groups and they do get together in-person with their children periodically. B2 stated: “…online, I use social media a lot for my own wellbeing, and that was my own doing, and even after he got the transplant I had connected with a couple of people…that’s when friends on Facebook start adding you, and you start messaging.”

However, B2 also reported that social media use can have a negative impact on wellbeing, and at times those boundaries can be exhausting to maintain. She explained: “…so there was a really hard balance, and it got to the point where there was this one person who would never comment on my stuff, she would message me, and it got to the point where I didn’t have the energy to respond to messages, and I wouldn’t even respond to people commenting, I would just read it and that would fill my bucket, as I would call it. When you are sending me messages I have to open it and read it, and you can tell that I have read it, and then she would ask if things are okay because I read the message and haven’t responded. Well, I don’t have the energy to respond to your first message; I am not going to have the energy to respond to your second message.” She identified that although she received emotional support online that was valuable to her coping, some online relationships were not worthwhile to maintain and were not necessarily appropriate, as the people reaching out were acquaintances that were then asking to meet her critically ill child. She also describes feeling pressured at times to respond to messages and maintain communication with individuals online, when she felt as though she did not have the energy to do so.

As explained by the participants, online and in-person support groups can be extremely beneficial to coping and stress management. These groups can be a place to meet new people, a
place to talk to people with similar life experiences, and a place to share tips and tricks to managing the requirements of the condition(s). However, as was reported by one participant, it is also important to note that these groups can also contribute negatively to coping, if the interactions become excessive, taxing, and no longer helpful.

**Difficulties Accessing Childcare**

The next theme is difficulties accessing childcare due to special considerations required to protect the immunosuppressed child, and taking this into consideration when making decisions regarding childcare.

An example of this theme was observed as F1 discussed her experiences with finding appropriate childcare, as she stated that they have struggled to find childcare due to their child’s complex medical needs. She did report that between herself, her ex-spouse, her older children (teenagers), and her fiancée they are able to handle the majority of her care internally within the family. F1 explained: “…there were very few people that we trusted, and of the few people who did babysit, when we absolutely needed it, they were petrified, but yeah…So, I have a few people who I am comfortable leaving with her…”

E1 reported that she and her spouse were very stressed regarding the potential of placing their child in a standard daycare service. Consequently, her mother made changes in order to be able to take care of their child fulltime, so that they know she is being cared for appropriately, and not being put at risk for illness. E1 stated: “…yeah we were very lucky, so she did that because she knew that it was in (child’s name) best interest not to go to daycare.” She identified that because she and her spouse work with young children they are very aware of the risks for contracting illnesses associated with childcare settings.
A1 and A2 reported that they regularly have difficulties accessing safe and appropriate care for their child, as their child is medically complex and has additional support and care needs. A2 stated: “…in the summer, it’s horrible, it’s constant like looking after these two and, you know, the other kids are older. But it’s just like yeah, constant… Yeah, because again, it’s hard to find a babysitter, and we can only use (A1)’s family so much, before they don’t want to babysit for us anymore… You have to be very intentional to try to find the time to get out, yeah. We can’t just call up teenager X, Y, or Z, or use our teenagers, you now, we need someone who is responsible and trained, so it’s hard, really tough.” A1 agreed, that stated: “…somebody who isn’t scared about giving meds, and dealing with tube feeds, and that kind of stuff, and the whole ASL thing, and that kind of stuff, and so yeah, it has definitely impacted things.”

B1 and B2 also reported that they are having difficulty finding appropriate care for their child, based on their child’s medical needs. As they have not identified any feasible long-term options, B2 is currently not working in order to stay home to take care of their child. B1 stated: “…there is definitely a trust level with people taking care of your kid, because I mean on top of his meds that he needs, and making sure he gets the right dose, and you are trained in hospital to do that…” B1 and B2 also both described not being able to trust just anyone, such as a neighbourhood teenager, in taking care of their child due to his additional medical needs, and so this impacts the amount of childcare that they have access to regularly.

D1 discussed that the cost of daycare and/or additional childcare outside of school hours is the main hindrance to their family accessing these types of services. She stated: “…see and that’s mostly part of the other reason why I have only been working part-time these past years, not only necessarily because of the immunosuppression but because it is so damn expensive.” She stated that if she worked fulltime basically all of her wage would be going towards covering
daycare costs, which would be counterproductive, as finding employment would then not benefit the family financially.

Based on the experiences reported by the participants, it appears that finding safe and appropriate care for their medically complex children can be extremely challenging. One participant also reported that the care that they required was not accessible due to the high costs associated with the available childcare. Other outcomes regarding the difficulties associated with finding appropriate childcare that were reported by the participants included: decreased time for socialization alone with their partners (or date nights), decreased ability to work outside of the home, and subsequently decreased income.

**Having to Cancel Childcare due to Illness**

This theme, having to cancel childcare, is related to the previous theme, but is focused on having to cancel arranged childcare specifically because of illness. This came up for only one participant, but would likely be something that could impact families periodically based on their reported experiences in cancelling social engagements.

In regards to cancelling childcare due to illness, A1 stated: “oh yeah, if like someone was not feeling well, or you know, even with my family it’s kind of like someone is going to babysit and it’s like I have a bit of a scratchy throat, and so they don’t come kind of thing. So yes, there’s that.” The result of cancelling childcare for the family could range from having to cancel social plans to being unable to attend work, as per A1’s description of their experiences.

As per the accounts of this participant, in addition to the lack of access to appropriate high-quality childcare to address their children’s needs, they often had to cancel childcare they had found (much of the time via family or friends) due to illness. This further negatively
impacted the ability for the family to engage in activities outside of the home such as work, or independent parental socialization with peers.

**Coping and Self-Care**

The final theme of the eleven themes within the category of social supports and coping skills is coping and self-care. The participants were asked to what degree they participate in self-care and other activities to facilitate coping, and their responses varied from none to seeing a counsellor regularly as a means of maintaining their mental health. No acute crisis and/or inability to cope was noted, or reported by any participant, throughout the entirety of the interviews.

An example of this theme was observed as B1 discussed that he does not require much to maintain his wellbeing typically, but has accessed the counselling they have available to them via his employment benefits when he has required additional assistance with his mental health and wellness. B1 stated: “…I make sure my TV shows are caught up on, and I make sure my games are caught up on, like I do online gaming so, I make sure those are caught up on, but usually when he’s in bed because I don’t want to deter my time with him either.” Similarly, B2 stated that she is very self-aware and knows when she needs to take a step back momentarily to work on her own mental health and wellness. B2 stated that her self-care activities include: shopping, therapeutic floats (via a float spa), and going out to run errands or to do the shopping by herself. She did explain that at times it is difficult to prioritize her relationship with B1 in regards to coping and self-care, such as getting out together to spend time alone. She stated: “…but it took us a long time to go out on a date night, so we got home in March last year, and it wasn’t until like July that we went out. Ten months almost, but when we were in hospital we did make time for ourselves.”
B2 also described that she and B1 handle stress and cope very differently as people, and she stresses the need for readily accessible family counselling in order to prevent family discord. She stated: “…but I think in hindsight if they push for the counselling, and I know they can’t but I do believe that it could have made a big difference. Our social worker was really good, (B1) really connected with her, which was awesome, and I just did a lot of talking, I am really self-aware.” B2 appeared to be very insightful, and she tried to regulate her parenting journey with their child as best she could in times of acute illness by engaging in normalizing activities, such as clothing their child, and thus became upset when she could not do this. She advocates for counselling to be more available to families, as well as encouraged by the medical teams, and so families would not have to seek their own support or attempt to normalize accessing these resources to other family members who might be apprehensive but require assistance.

C1 stated that she was offered some support while her child was admitted to assist her with her mental health and wellness, but that it was not a good fit, as this person was much younger than her and could not relate to her life experience. C1 explained: “…this lovely young social worker came along and wanted to chat with me about how things were, and how I was feeling, she was fresh out of social work school, and didn’t have a clue about real life, and when I said well it’s not easy sitting here with him when I have several other kids at home having to be babysat by other people, and she was like oh. No, she wasn’t married, she didn’t have kids, she didn’t have a clue what the mother instinct is.” C1 also identified that she feels as though families who do not appear to be acutely in crisis or in dire need of help do not get offered resources, and so this is a missed opportunity to provide support based on assumptions and without any formal assessment of needs. She stated: “…if you appear to be competent, they assume that you have everything under control, and that there are no problems. The squeaky
wheel gets the grease.” She indicated several times throughout the interview that she did not feel as though they were well supported by their medical team after returning to their province of origin following the transplant, and that this contributed to her creating a support group in her area for caregivers of paediatric transplant recipients.

In regards to self-care, A1 denies that he actively engages in anything specifically, and stated that it is the expense associated with anything he might be interested in that is often a deterrent. A1 stated: “…all the impacts of, you know, I think it’s really hard for us to even measure the financial impact, the true financial impact, right. I mean, the golf thing it’s not hard to spend seventy or eighty dollars, and you kind of go, that’s a lot of money, and so in the back of your mind, you can kind of make that decision that it is for my family, but that’s also a lot of money that I don’t want to spend, and so yeah.” Both A1 and A2 reported that the additional expenses associated with the illness that are not covered or compensated decreases their disposable income, and thus this impacts their ability to engage in travel and/or activities that they enjoy.

E1 explained that she and her spouse coped adequately within the crisis period and beyond, as they are mindful of their stress levels consistently as a baseline, and so transferring this practice to times of crisis minimized the impact to them as a family. She also described that spending time with their friends and family has been very beneficial for maintaining their wellness as a family. By her account, E1 appeared to be quite secure in her coping, despite the medical hardships she and her family have faced. She stated: “…we do pretty well, we manage to stay low stress when things are good, and we do our best when things aren’t so good.”

D1 identified that she and her spouse do attempt to go on date nights as a means of self-care and to maintain their relationship, but that it is hard to facilitate because they have two
children. D1 stated: “…we were good for a few months, or we would have one once a week kind of thing, but that has fallen by the wayside now…” She went on to discuss other impacts to her self-care and coping, such as a traumatic incident that occurred, and struggling with anxiety and depression. She stated: “…my anxiety and depression has really been a big factor in all of this also, and also with our health concerns with our child and all that kind of stuff, it definitely just piled onto it, and I never dealt with what happened all those years ago ever before, so now like twenty years later it’s getting worse and worse, so I myself just started seeing a counsellor, I am sure that we will work through like everything, you know, with what’s happened in the last ten years and what has happened in my childhood, so, I think that has put the most stress on our family because I was so good at hiding everything my husband didn’t know that I was dealing all of this until last year.” The trauma history that was disclosed was not further discussed or unpacked in order to avoid re-traumatization, which can be dangerous outside of a clinical trauma-oriented environment. D1 indicated that she is not within an acute crisis currently, and also identifies that there are no immediate concerns regarding her mental health and wellness.

D1 also discussed the importance of having access to counselling, and states that she is addressing these concerns with a counsellor currently, and that her mental health and overall wellness have since been improving. She and her spouse are also attending counselling together, which she identifies as helpful. Although she is facing mental health concerns currently, it appears that she is insightful and resourceful, and is addressing the situation in a healthy and proactive manner. D1 explained: “I think that we are on the right path to having everything dealt with and more open and communicative, because we don’t want it to end, we don’t want to throw in the towel, we want to work and fight for this because, you know, that’s why we got married in the first place.” In addition to individual counselling and couple’s counselling, D1
also indicated that having access to family counselling facilitated for families throughout the process would be helpful. D1 identified that her child has struggled with mental health concerns as well, and that she feels as though these symptoms would have been mitigated had they have had access to counselling throughout the process. She indicated that as families grow and change, having this support continuously would not only help any immediate problems, but also assist in the prevention of any future concerns.

F1 explained that she and her ex-spouse were not compatible in how they managed stress during the crisis period, which caused further discord and breakdown. She stated that the more time that passed following the transplant and the initial crisis period, the more different she and her ex-spouse became. F1 explained: “…it became well we have an immunosuppressed kid, a sick kid, lets bunker down and we’re going to stay home, and we’re not going to go anywhere…he became more introverted and I became more extroverted, and um, I got the, after the transplant I got this whole kind of zest for life, like she can do this and she can make it through so we are going to enjoy every minute…and so we did not see eye-to-eye on that, when I think um, that was probably the beginning of the end for us. It ended in a positive way, if I can say that.” F1 appears to be very insightful, and identifies that the changes in their relationship and their differences that were becoming more pronounced signalled to her that this was the beginning of the end of their marriage. She maintains that their relationship remains positive and that they ended the marriage amicably, which is a better outcome to protect the long-term wellness of the children, as compared to a marriage that might end on volatile terms. She states that she continues to access counselling as needed and prioritizes her mental health.

Based on the experiences shared by the participants, it is clear that mental health and wellness needs to be prioritized throughout the crisis period and beyond, to ensure complete
individual and family health. All of the participants within the study discussed self-care and coping to some extent, and although three of the participants identified that they are currently engaging in self-care minimally or not at all, they also identified that this is something that they were actively addressing within their lives as well.

**Access to Health Services**

The three themes that were indicated under the superordinate theme of the family experiences within the healthcare system in the access to health services category of the social determinants of health were: effectiveness of health services in the province of origin, effectiveness of health services in the province that the transplant occurred, and the transition from paediatric to adult care. All of the eight participants reported themes related to access to health services.

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<th>Access to Health Services (100%)</th>
<th>Family Experiences within the Healthcare System</th>
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<td>• Effectiveness of health services in province of origin.</td>
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<td>• Effectiveness of health services in province that the transplant occurred.</td>
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<td>• Transition from paediatric to adult care.</td>
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**Effectiveness of Health Services within the Province of Origin**

The first theme in the category, the perceived effectiveness of health services in the province of origin, was noted by several of the participants in regards to their experiences with the healthcare services within their home province. Several of the participants identified that they felt as though the care that they received in the province where the transplant procedure was facilitated was better, as compared to the care they received once returning home to their province of origin.
For example, A1 stated that his impression overall of the healthcare system in his home province was favourable, but he thinks that possibly if they resided in America the access to services may have been faster. A2 had a similar opinion, in that she also found the care in her home province to be effective. She identified that they have an adequate number of medical supports (such as social workers and counsellors), more than they require in fact, and that the team is also very supportive and accessible to them. She did reiterate that the medications are a concern for them, as despite having additional insurance they continue to have to pay out of pocket for the medications, which are quite expensive.

In regards to what aspects of the medical travel and subsequent care associated with the transplant surgery were covered by their home province, A2 identified that she did find this coverage to be adequate. However, A2 stated that although she found the coverage to be good, they still had to pay out of pocket for numerous expenses, such as accommodations. Fortunately, they were able to fundraise and were gifted money by family to help cover the expenses, and so for them it was not as stressful or as difficult as it could have been otherwise. Additionally, although A1 stated previously that he thought that perhaps the healthcare in America would have been expedited, A2 disagreed with this statement, and explained that she could not imagine if this happened to them in America, because she believes that there would have been essentially no way for them to be able to pay the required costs.

D1 stated that she did find the care that they received to be exemplary, and explained that although they did not agree with one medical professional, after they expressed their concerns this person was no longer involved in their care. D1 stated: “…we’ve been kind of lucky where everything has been good, and everyone has been really supportive, and thoroughly explaining what is happening and what is expected and that kind of stuff.” She reported that the continuity
of care in their home province has been excellent, as there is very little staff turnover, and so they have seen the same professionals for many years.

E1 explained that she has found the care they received in their province of origin to be incredibly thorough, and that they have expedited access to specialists, which otherwise might typically involve referrals and lengthy waiting lists. Additionally, she elaborated that when they need to attend a hospital ER for a concern, that are prioritized and seen right away, as opposed to having to wait for long periods of time within the waiting room, as this could cause more risk for exposure to other contagious diseases. E1 also did state that initially when they returned to their province of origin the inpatient care that they received was not adequate in their experience, but this ended when they were discharged and moved into the outpatient care system. E1 discussed that as per their experiences, it is clear to her that the healthcare system in her province is making positive changes, she explained: “…so there are ways that the healthcare system is trying to make it better, and there are ways that it is not quite working out, but you can see ways that there are attempts being made to reduce the stress anyways.”

Based on their experiences, B1’s primary recommendation to improve the care that they received in their province of origin is to change the policy on life-saving medications for children, so that these medications would be either completely covered or heavily subsidized. He stated: “…and that’s life saving meds, you know, and lifesaving meds shouldn’t be anything to do with your Pharmacare deductible, you know, you pay whatever amount, or Trillium it’s free in Ontario, or whatever. Trillium is Ontario, and Alberta is free as well, and in a lot of provinces they are considered lifesaving meds, which they are, and they should be free.”

B2 stated that although she found the care in her province of origin to be mostly sufficient, she found that there were not enough resources available. B2 explained: “…the other
transition that I could change is having the social worker follow-up after you’re home, because there is a difference from living in hospital, and there is a difference from living at home…” She indicated that the supports that they had in the hospital that they traveled to for the transplant were more attentive and accessible, and that more support when returning to the province of origin would likely be beneficial to help ease any potential difficulties during this transition.

C1 identified that she felt as though they were lost during the transition back to their home province, and states that they did not receive adequate follow-up care once returning. She explained: “…the most stressful part was immediately post-transplant, when we came back home, and there was no follow-up from the transplant community. He was probably five years post-transplant before we even talked to the transplant people here. We had several staff changes and they kind of lost us, which is one reason that I started a support group.” She also indicated that even now since making contact with the medical team in their province of origin, in their experience the team has not been present or accessible for them when they require assistance.

Although some participants noted that the care within their province of origin was adequate, many also noted that they felt there was a notable decrease in care when they returned to their province of origin. A decrease in care can lead to negative health outcomes for the children, as well as increased family stress. Transitioning between health teams can be difficult, and this may have also contributed to these negative experiences.

**Effectiveness of Health Services within the Province that Conducted the Transplant**

The second theme in the category, the perceived effectiveness of health services in province where the transplant occurred, was noted by several of the participants throughout the interviews. The overall experiences associated with this care were reported as highly favourable, as compared to the care received in the province of origin.
An example of this theme was observed as F1 narrated that in her experience the care that they received within the facility that conducted the transplant was more effective than the care they received once returning to their province of origin. F1 stated: “...our system here it is very broken, and they are so, the morale is down here and they are short staffed often, I just don’t think they have the ability...I wish it was better here, but I think they spent a lot of their time, and resources, and money just trying to keep the wards functioning.” She went on to elaborate that her province of origin has limited resources and an abundance of individuals seeking care within the hospitals, and so existing resources are stretched thin and do not adequately provide enough care and support for all who require it.

D1 reported that the care they received in the province that they traveled to for the transplant was outstanding, and that this team is also still accessible to them in terms of resources and support. Similarly, E1 reported that they found the care in the province that conducted the transplant procedure to be exemplary as well. Furthermore, although C1 narrated several concerns related to the quality of the care that they received once returning to their province of origin, she had nothing negative to report regarding the medical team in the province where the transplant was conducted, and described the care as being “wonderful.”

A2 stated that the care they received in the hospital that conducted the transplant was better than they had initially expected it would be. Additionally, A2 explained that their wait on the transplant list was not unmanageable based on their location at that time, which she identified is a highly populated area and so this likely decreased the waiting time (more access to available organs). She also stated that once her child was able to accept a larger sized organ they moved up the list fairly quickly, but that the information and support that they received while waiting on the list in this location was sufficient, which decreased their stress during the waiting period.
B2 reported that the care that they received in the province that they had to travel to in order to have the transplant facilitated was better in her experience than the care that they received in their province of origin. B2 explained: “…and another transition that we had that was hard was that the (name of hospital) team, I don’t know how the transplant team is here, but the transplant team in (name of hospital), like we have a major attachment to that hospital, we feel like we are home…” She indicated that the change in the quality of care they received once returning home contributed to the difficulty and stress with the transition out of inpatient services. For this reason, B1 and B2 reported that they were initially considering moving closer to the hospital where the transplant occurred. However, they ultimately decided to stay in their home province for the time being, but they have not ruled out the possibility of moving eventually, should their child require more care than they feel that their province of origin can provide.

The general consensus from the participants was that the care that they received within the province that they travelled to for the required medical care, was outstanding and better than care received prior to and/or post transplant. A confounding factor that may have impacted these experiences could have been the increase of available resources (such as doctors, specialists, and specialized allied health) within the province in which they travelled to, as compared to their province of origin, as the specialized resources are likely focused to where the procedure occurs.

**Transitioning from Paediatric to Adult Care**

The third and final theme in the category is concerns regarding the transition from paediatric to adult care for the children who are immunosuppressed. This theme was only identified by one of the participants, as her child is the oldest of the children in the study and is currently a teenager. C1 stated: “we are looking at, he’s (age), and [soon] he will be turning
eighteen, and he will be moving out of the paediatric sphere, and so we now have to start looking for adult doctors who can manage and deal with everything…” She stated that although the specialists in their province of origin have been inaccessible and not overly involved in their care, their primary care providers have been excellent and will likely assist them with the transition into adult care. She stated: “…if I am not happy with what is happening I will tell his paediatrician and she will pop in. But she did her residency here and she has known him before transplant, since he was four months old. I mean, we’ve been lucky, other than the change in GI, that we have had consistency all the way through, which you don’t always get.”

Based on the experiences reported by the participants within the theme of accessing health services, it is evident that they showed a significant preference for the care experiences within the province in which the transplant was conducted, as opposed to the care experiences within their provinces of origin. Another concern that was raised was the difficulty in transition points in care, as observed in the experiences of transitioning from a lengthy hospital admission to home, as well as transitioning from the youth care system to the adult system. More support during transitions in care would likely be beneficial in easing this stressful period for individuals and families.

**Culture**

The category of culture produced one theme exclusively, spirituality and coping, which was placed under the superordinate theme of spirituality, but also includes the absence of spirituality. Information about the cultural and/or racial backgrounds of the participants was not collected in this study. Five out of the eight participants reported experiences related to culture, in the context of spirituality and coping.
Spirituality and Coping

Participants identified with spirituality to varying degrees, from organized religion to less structured and more personalized forms of spirituality. For example, C1 identified that she is a spiritual person, but has not found that she has required organized religion to be a part of her life. She stated: “I guess I am spiritual; I don’t belong to an organized religion. I have pretty solid beliefs, but I have never found the need for an organized religion.”

F1 also identified that she is a spiritual person, but similarly does not identify with an organized religion. In regards to her experiences with spirituality, F1 explained: “…it was a good five years of what I want to say was hell, and it just felt like, I really just questioned any kind of faith that I did have.” She went on to elaborate that in times of crisis she questioned her faith, and has not drawn upon it heavily since as a means of coping. This suggests that although spirituality may have been a part of her ability to process and cope previously, during this specific period of crisis it does not appear that spirituality was necessarily an important or helpful part of her coping at that time. At the time of the interview she appeared fairly neutral regarding spirituality as an influence in her life presently.

B2 stated that although she does not identify as a person within an organized or labelled religion specifically, that she is a very spiritual person, and this has helped her to cope throughout the process. B2 stated: “…it’s my spiritual beliefs, I don’t want to say God, maybe the Creator, somebody or some person up there, um, just, the biggest thing that impacted me, and my intuition, it’s always right… I needed something to believe in, whether it was right or wrong, and I just need something to help. And that four-letter word, hope, gave me so much hope.” B2
went on to elaborate that she sees signs that remind her of the transplant, which typically occurs for her around the anniversary date of the surgery. She stated: “I can’t make it up, I have taken pictures of it, it’s the weirdest thing, but I have had water spill into a heart, weirdest things, and I firmly believe that it is our angel saying hi...”

B2 also described that she feels as though she receives signs from her child’s deceased organ donor, and that this individual is watching over them. She explained that these beliefs kept her going because they gave her hope during the crisis period, and beyond, which has likely helped her to avoid trending into a state of mal-adaptation. Alternatively, B1 stated that spirituality was not a significant factor in his life, and he also appeared to be coping and functioning adequately.

Both A1 and A2 stated that they identify as religious people; they attend church weekly and find that organized religion is very important and supportive in their lives. A1 stated: “…our church has been super supportive as well, supporting us big time when we were in the (name of location), and just on going that they have been a big support for us.” A2 agreed, and went on to elaborate that it is difficult for them when they have to miss attending their church weekly as a result of their immunosuppressed child’s health and susceptibility to illness. A2 explained: “…if she’s not feeling well we stay home from church. Stuff like that is a constant consideration, like how she is feeling, you know, is someone else sick, it is a constant consideration, and always at the back of your mind.” A1 and A2 were the only participants within the study that reported that they participated in organized religion regularly, as they identify as Christian and attend church weekly as able.

As per the experiences reported by the participant families, it appears that for some spirituality can be a positive factor for coping, as well as a support in times of crisis. Although
five of the participants did identify with spirituality, three of the participants did not identify with any form of spirituality. These three participants appeared to be functioning and coping as adequately as the other participants based on their descriptions of their experiences. Thusly, spirituality appeared to enhance coping for some, but the absence of spirituality did not appear to hinder coping for others.

**Education and Literacy**

The five themes that were indicated under the superordinate theme of family experiences within the school system in the education and literacy category of the social determinants of health were: concerns regarding the transition to the school system, the children who are immunosuppressed within the school system, missing school, difficulties at school, and illness hindering the parent’s ability to return to school. Seven of the eight participants reported themes related to education and literacy.

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<th>Education and Literacy (87.5%)</th>
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<td>• Concerns regarding the transition to the school system.</td>
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<td>• Illness hindering the parent’s ability to return to school.</td>
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**Transitioning into the School System**

The first theme, concerns regarding the transition of the immunosuppressed child into the school system, was reported by the participants in regards to worrying about their young children attending school when they are older. For example, B1 has a child who is young and not in
school as of yet, and in reference to the transition to the school system, B1 states: “I think the school system transition is going to be a tough one, when it comes down to that.”

E1 and her spouse both work with young children, and so she explained that based on what they have seen in terms of the spreading of germs and contraction of illnesses, they are very concerned about their young child’s transition to the school system when it occurs, and thus they are considering placing their child within a private school to mitigate this risk. E1 stated: “…we are both (job titles), we have been sneezed on a lot and coughed on, we have seen what school really looks like, especially in those younger years. Um, so yeah, we have looked into alternatives, which I would have never considered if we didn’t have an immunosuppressed kid…”

Another example of this theme arose as C1 discussed the importance of advocating for your child’s safety within the school system, as her child is older and has been within the school system for many years. She states that she gives advice to other parents with immunosuppressed children who fear this transition within the context of the support group that she manages. C1 explained: “I have talked to a mom recently who was afraid to let her child go to school, because they had, what they call the non-compatible transplant, and it’s tougher, and she was definitely afraid that he would pick up germs and stuff.” She went on to elaborate that one of the recommendations that she advocated for was that her son should not share his school supplies with the other children, in order to minimize the risk of contracting an illness from the shared supplies. Additionally, she advocated for enhanced cleaning practices within the school in order to keep her child safe, as this would ideally also reduce his risk of contracting a communicable illness.
As noted throughout this study, and throughout many aspects of life, transitions can be difficult. Transitioning into the school system is considerably difficult for children living with immunosuppression and their families, based on the potential risks to health, as well as the stress and anxieties experienced by parents throughout this transition in regards to ensuring that their children are receiving the care and attention that they require to remain safe within this new environment.

**Immunosuppressed Children within the School System**

The following theme is regarding the children who are immunosuppressed within the school system, and the concerns that have been identified about maintaining health and wellness within the school system on a day-to-day basis.

For example, C1 stated that her child did struggle with the transition, and that it has taken consistent advocacy and reminders to help keep everyone on task, including her immunosuppressed child and the staff at the school. C1 explained: “…so much of what I have learned with the liver transplant, translates into any transplant. The issues around immunosuppression, and how to get your kid into the school system, and how to advocate for their safety, I don’t know about (name of province) but here in (name of province), if you have a child that has had a transplant, you can get a one-on-one EA for health reasons.” She stressed the importance of an EA for immunosuppressed children, as she states that an EA is imperative to keeping children safe within the school system; especially when they are younger and do not necessarily engage in all the required health and hygiene practices. For example, an EA can remind children to wash their hands regularly, whereas a teacher may not have time to focus on ensuring that this is completed.
B2’s child is not yet within the school system, but she states that she has discussed her concerns and what to expect with her friends who also have children who are immunosuppressed. B2 stated: “…I asked them how they dealt with the school transition, and the one mom was like I don’t tell them they have to be vaccinated, because you can’t change someone’s mindset, but I write them a letter about how they can help her daughter be healthy, and that includes being vaccinated, washing your hands, and being mindful. And she goes, the first year she was harping on everyone to be vaccinated, and she goes it’s only going to make people mad, and doing it in a way that will help her daughter, people have been more responsive. She always includes her phone number and email because people might have lots more questions.” B2 explained that her concerns about her child’s eventual transition into the school system do encompass what she has discussed with her friends, which also included: unvaccinated children, contact with ill children, increased illnesses, not engaging in hygiene practices (such as hand washing), and not drinking enough water while in school (to prevent kidney damage). She states that her friends with older immunosuppressed children recommended that she get the school staff involved early, that she advocate for what is required to keep her child safe, and even that she should come by the school periodically to check on her child to ensure that her child is following the required hygiene and care practices. However, this periodic checking on a child might have the potential to negatively impact the trust and the overall relationship between a parent and a child, based on the age of a child and the amount of autonomy that a child is seeking.

Stress and concern regarding immunosuppressed children within the school system was not only observed within the interviews with parents who have school-aged children, but also with the parents who have children that are too young to be in school as of yet, as they reported
anticipating significant challenges within the school system. This may be exceptionally difficult for these parents currently, as they (or family) are typically caring for their children fulltime at this point, and transitioning the responsibility of caring for a medically complex child to an institution filled with unknown people is likely incredibly difficult to fathom for them at this point in time. This also appears to be compounded by stories of difficulties experienced by others.

School Absences

The next theme is regarding the immunosuppressed child missing school while within the school system, and what factors contribute to the absences. As children who are immunosuppressed typically have follow-up appointments with their professional supports, and are more susceptible to illnesses, this can ultimately result in an increase in school absences. For example, A2 identified that her child has missed more school than her other children when sick with the same illness, which is hard for her child as she really enjoys school. She stated: “…that’s how it is with (child’s name), he’s like the normalizer of our family, he’s sick for a day, he might have a running nose for a day, but she’s sick for a week. It’s just seeing the difference there; it’s in your face.”

E1 identified that by working with children, and also through the people she has met who have children who are immunosuppressed, she has learned that children who are immunosuppressed miss a substantial amount of school, which is especially significant in the first years. She stated: “…that kindergarten year can be really rough, I know a lot of families who have said that their kid maybe went half the time that year.”

Increased school absences can lead to children falling behind in their studies, as well as missing important socialization with their peers. As per the experiences of the participants,
school absences are a significant concern for families with immunosuppressed children. As many of the absences can be caused by illness and/or required follow-up appointments with medical professionals, it is unlikely that it would be a simple concern to address and remedy, but perhaps the recent move towards including a virtual component to children’s education may be of some assistance.

**Difficulties at School**

The subsequent theme, difficulties at school, was reported by one of the participants in regards to her child’s experiences in regulating his emotions while at school. D1 stated: “…when he started kindergarten, he had a lot of tantrums about going to school, when he missed school it made it hard to go back, and um just a lot of like anger issues that we have gone through, and even up until last year, this year has been really great since he started school, but even up until last year I would get phone calls from the school where I would have to go pick him up because he was running around the halls, or throwing things, or being really aggressive, so I think having a counsellor from the very beginning would definitely help as they grow older, and teaching them these skills from the beginning, because it definitely makes it harder the older they are to change their ways, and learn, even to get them to want to go is difficult sometimes.” D1 stressed throughout the interview that if her child would have had access to counselling she believes that these concerns would have been mitigated, and as a result she strongly advocates for access to counselling for all families with children who have complex medical needs. She also stated that her child is not experiencing such significant symptoms at the time of the interview, and that the symptoms appeared to have lessened as he aged.

Difficulties at school experienced by immunosuppressed children can present unique and distinct challenges to the child and to the family, as these difficulties are often also compounded
by an increase in absences (due to illness, appointments, and/or required tests and procedures),
an increase in risk for illness and potential for feeling unwell more often than others, and the
cumulative absences throughout the school years causing an increase in missed lessons and time
interacting with teachers and peers.

**Illness Hindering Caregiver’s Ability to Return to School**

The final theme in the category of education and literacy, illness hindering the parent’s
ability to return to school, was reported by one participant in regards to her difficulties pursuing
additional post-secondary education at the time of the interview. She identified that she and her
spouse decided that she would stay home to provide childcare throughout the process. She
reported that she is transitioning back into the workforce, which has been difficult for her. She
stated that she has considered returning to school but is concerned that they cannot sustain the
student loans financially at this time, as they have been a single-income family for a number of
years. D1 stated: “I keep looking at it now because I never did go when I was younger, um, but
now I almost feel like I am too old, or we can’t afford the student loans after, or you know, like it
always seems like there is something that is hindering it. I am not sure how that is going to go.”

Based on the conversations with the participant, it is evident that the condition of
immunosuppression can impact various aspects of acquiring education and literacy, both for the
children and the caregivers.

**Childhood Experiences**

The three themes that were indicated under the superordinate theme of the impacts to
development and experiences from childhood to adulthood within the childhood experiences
category of the social determinants of health were: worries about the long-term impact to the
child and concern for potential childhood medical trauma, worries about potential childhood
mortality, and concerns regarding implications in adulthood. Three of the eight participants reported themes related to childhood experiences.

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**Concerns Regarding Potential for Medical Trauma**

The first theme, worries about the long-term impact to the child and concern for potential childhood medical trauma, was identified by one of the participants as being a significant concern for her. Medical trauma was defined within this study as a difficult medical experience causing psychological trauma. None of the other participants reported that they were concerned about their children experiencing medical trauma when asked.

B2 explained that she believes that her child has been incurring medical trauma throughout the entirety of the process, beginning from the first procedure that occurred when her child was an infant. B2 stated: “…that is one thing I would change going back would be, you know, the doctors, the medications, he’s doing well, but what about the mental health of the child? I know people say he doesn’t remember but I don’t care, he remembers, and there is long-term damage for sure.”

Although she stated that medical professionals have told her that her child could not possibly remember the procedures that occurred when he was an infant, she identifies that she absolutely disagrees. B2 stated: “…I will never forget the ICU doctor telling me that (child’s
(child’s name) is so young that he will never remember any of this, but now that I can do my own research, and I know it’s only Google and there are only so many things out there, but studies show that around five or six weeks of a child’s brain development, that they start realizing what they want to do and what they do not, well (child’s name) didn’t have that option.”

B2 also reported that her child is triggered periodically back to memories of the previous medically-oriented trauma, which causes him duress. B2 explained: “…sometimes at night he wakes up screaming, and I have no idea why, and usually I can console him quite easily, but one day I figured it out, I asked him, told him actually, (child’s name) you are not in the hospital anymore you are safe in mommy’s arms, and that was it. It’s huge. He hears those words he’s like yeah okay I am, I am safe.” She indicates that she has spoken to their medical team about her concerns, and they are discussing potential options.

B2 identified that she believes that her child has PTSD from medical trauma, and thus she is currently in the process of seeking professional help for him, in order to address the current concerns and also to prevent possible further decompensation. She stated that in addition to the first procedure potentially causing trauma, subsequent blood tests continue to cause trauma and she is worried about the long-term impacts of these medical interventions to her child’s wellbeing. Throughout the interview, she stressed the importance of having counselling available to immunosuppressed children and their families, and she identified that not enough attention is paid to the mental health of the children, which can have detrimental impacts to their overall wellness.

Although this theme was not strongly reported upon by the participants, it was included because it is important to note this concern, as it is a considerable stressor for this participant within the study. The anxiety regarding potential lasting psychological impacts to her child
resulting from the procedures and tests associated with her child’s medical complexities have further negatively contributed to the overall stress for this participant, and would likely have the potential to significantly decrease coping if not mitigated.

**Concerns Regarding Potential for Child Mortality**

The second theme, worries about potential child mortality, was strongly reported by two of the participants during the interview process. However, all participants identified fears regarding prognosis to some extent throughout the interviews.

B1 and B2 discussed that although they of course hope that their child is happy and healthy, potential concerns for his mortality have unfortunately been a significant worry for them throughout the process, especially in acute periods of crisis. B1 stated: “I always think about what if the time comes where I don’t have another moment with him type of thing, but I kind of try to push that away as much as I can, because you can’t go around living like that, I don’t feel anyways, you can just fear that he will pass away because something might fail, and we know where the organ came from, and how we got to this place now with the transplant, and every moment for me is another moment with him, right? So we spend as much time with him as we can while he is still here, and if he grows to outlive us, excellent, and we will help him through whatever he needs.” B2 also identified that the potential for her child’s mortality has been a continuous concern for her, but states that it was a more significant concern during the acute crisis period as opposed to currently, whereas B1 identified that he continues to worry about the potential for childhood mortality currently. B2 stated: “…there has been people who I thought would want to be seeing him, but I get too brutally honest about our journey, and the highs and the lows, I have actually said please pray for (child’s name) because he is dying. No questions asked.”
Both B1 and B2 appeared to be very much impacted by the crisis period and the prospect of potentially losing their child. No other participants in the study brought up the fear of their child dying during the interviews to this extent. B2 identified that mental health intervention and family counselling would be beneficial to reduce concerns throughout the process, and by their account it appears that this intervention would also be beneficial in managing these fears. These persistent fears may also likely contribute to the risk of trending back towards a crisis state and mal-adaptation, as it may be difficult to focus on coping and managing stress while continuing to experience negative intrusive thoughts of this nature. However, both B1 and B2 appeared to be within a bon-adaptation state at the time of the interview, and there was no evidence of acute crisis, and so it appears that despite this affliction they have been managing to stay within the bon-adaptation state of coping. Both had identified that counselling was a regular component of their ongoing self-care and coping.

Although all participants touched on worries regarding potential prognosis for their children, it appears that the level of which this impacts families varies and fluctuates. For example, B1 and B2 reported that this concern is at the forefront of their minds very often, which was more significant than reported by other participants when asked about their thoughts and potential fears regarding prognosis. Their child is quite young (the youngest child within the study), and only recently had the transplant procedure. Similarly, based on my own lived experiences, I was much more consumed with thoughts of prognosis during the initial crisis period, as compared to years later. Thusly, as evidenced within this study, it appears that the level of perseveration on prognosis may fluctuate based on time from the transplant, as well as the more apparent overall stability of health.
Concerns Regarding Implications in Adulthood

The third and final theme in the category of childhood experiences is concerns regarding implications of the disease impacting the children in adulthood. The participant who identified this theme was the individual with the oldest immunosuppressed child within the study. C1 stated: “…because it is a life-long medical condition. And it will impact their ability as an adult to make a living. Yeah, and there are some things that you just can’t do. As a transplanted adult, to work as a waitress, would be deadly…” C1 explained that she worries about how the condition of long-term immunosuppression will continue to impact her child and his options for employment as an adult, because some professions will not be safe for him, and he will also likely have to take more sick time than the average employee because he is more susceptible to illness.

As per the experiences disclosed by the participant families, it appears that the immediate and ongoing impacts to the children’s mental health, in addition to the impacts to their physical health, are significant concerns for families. Other concerns include how the condition of immunosuppression will impact the children as adults, such as their ability to work. These concerns further demonstrate that immunosuppression should be viewed as a condition, as the state of immunosuppression is permanent, impacts individuals significantly throughout their lives, impacts functioning, and decreases potential options (such as employment) for individuals.

Race/Racism

As information about the race and/or cultural backgrounds of the participants was not collected, limited data about race/racism was generated. This information was not collected as it was determined at the time of the ethics proposal that race and ethnicity would not be the focus of the study, and thus this information would not be used fully, and hence not collected. Later,
with the establishment of the use of the social determinants of health within the study, race and ethnicity as concepts may have been beneficial, but the decision was made to only utilize this information as it emerged within the participant interview discussions. Further research regarding race and ethnicity, and how this may interact with the condition of immunosuppression, may be beneficial. Also of note, as I conducted many of the interviews and follow-up conversations over the phone, I have never actually seen many of the participants, and so I have no information (not even visual cue) as to what race or ethnicity they may be.

There was one theme under the superordinate theme of race within this category that was reported by one participant, race impacting the ability to find a suitable match for transplant.

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**Race Impacting the Ability to Find a Suitable Match for Transplant**

C1 stated that because her child comes from a rich racial background, it was difficult to find him a suitable donor. She explained: “…it’s very difficult if your children are of mixed blood to get a good match, he is of the First Nations, but he is Saulteaux and there is very few of them in this province. Actually not a lot of them any place in Canada, and he is from a Saulteaux group, that when they moved from the East many years ago…and so in his genetics is some African American, it’s pretty far back, but it complicates the matching process.” She identified that this likely increased their time spent on the waiting list for a transplant, and thus potentially their time within an acute period of crisis. However, fortunately they were ultimately able to find a very suitable match for her son, and the transplant has been successfully thus far.
Autoethnography

In 2013 my child was born, she was not diagnosed with any medical concerns while in utero, and I thought that I was going to be having a healthy baby. Shortly after her birth, our midwife expressed concerns that our baby was jaundiced, likely too jaundiced to be considered within the spectrum of normalcy for a newborn, and we were then referred to the Children’s Hospital. There we spent many hours in the ER as the doctors conducted numerous tests. I remember crying as I watched helplessly as my baby had countless painful blood tests. Eventually they informed us that she had biliary atresia, and we were admitted to hospital. My husband left to be with our older child, who was being babysat by grandparents so that we could be together at the hospital. I stayed with our baby, someone was always there, as several of the participants have also explained. We never left her side.

We were admitted for the better part of the first year of our child’s life, between Winnipeg and Toronto. I remember this time being very difficult and lonely, as we were together as a family of four very infrequently. I was nursing our baby so it was typically me who was in the hospital with her, and my husband was with our older child. I missed them both desperately, but I was happy to be able to spend the time with our baby. I watched over her constantly, I barely slept, and as she slept I remember that I would watch her breathing, so scared that it would stop. It’s difficult to know how we functioned then, but it’s almost like being in survival mode all the time. Not thriving, just surviving.

The initial tests were only the beginning, and what followed were months and months of watching our baby undergo countless painful procedures and medical tests. Additionally, our child was getting thinner and thinner by the day, and we could not do anything to help. It was the worst feeling in the world; I did not know it was possible to cry so much or to feel as sad as I did
then. I just had to keep reminding myself that we were going to do all we could to help. When I started the medical workup to become her living liver donor I finally felt as though after months of struggling we were finally getting somewhere.

Our stories are similar but different, and I absolutely feel that being a researcher with lived experience was beneficial in conducting this research. Families tended to open up to me quickly, and looked relieved when I informed them that we are also an immunosuppressed family. This seemed to alleviate any stress for them as to why I might be doing this research, and I did not have to explain to them that I wanted to contribute to this field, because they already understood. They too wanted to contribute, and unprovoked all of the participants enthusiastically offered tangible advice to any family who may find themselves in this circumstance. This advice ranged from where to find the cheapest medical supplies to how to navigate the school transition. It amazed me that every participant did this, and this was perhaps the most beautiful part of the study, as it really gave me a sense of community and wholeness. At the end of the process I wondered if the reason that I was drawn to this subject of study was the same reason that the participants were so committed to ensuring that their recommendations were included in the study, the want and need to help other immunosuppressed families.

Our stories are different in that I am the only living-donor parent, all other families in the study received cadaveric organ donations. Many of the participants spoke about the difficulties they faced while waiting on the list for a transplant, and while our child was also on the list, we knew that I would most likely be her organ donor before they found a cadaveric organ, so our wait was less stressful in regards to the list specifically. We did get a couple of calls though, which we passed on because we could not get to Toronto in time and I thought that someone else should have the organ, considering I was cleared to be the donor at that point and we were
already arranging transport to Toronto for our scheduled surgeries. What I was not aware of before this research process was that even though I was accepted as a donor, they may not have been able to operate in the end, as this had happened within one of the participant families. In hindsight I am happy that I did not know, as I am sure that this would have increased my stress on the day of the transplant.

I remember not feeling afraid going into the surgery, but I was so worried about my child that I said to myself if something happens to my baby please let me go too, so we can be together. Looking back now, this was a very sad thought, and I was likely more stressed and depressed than I had ever realized during that time. I remember waking up and being told that the surgeries were a success; I was so happy and relieved. However, my heart breaks and I feel so badly for the participant family who woke up and were informed that the surgery could not be performed. I cannot imagine how that must have felt for them.

After the surgery both our baby and I recovered quickly. We were also discharged reasonably quickly and got to return home to Manitoba just in time for my husband’s birthday. Being in Toronto and away from our natural supports was hard, but most of all having to be away from my older child for several weeks was so very difficult. We were together as a family of four while the surgery was occurring, but my husband took our older child home to Manitoba after I was discharged, so that I could be with our younger child and so that our older child regained some normalcy while my husband returned to work. Throughout this process both my husband and I did not work for almost one year. We were very much in debt after everything was finished, and we had to look to crowd-source funding for help (we were able to raise about two thousand dollars through the funding). Neither of us had employment benefits at the time, and the medications were also incredibly expensive. It was a very difficult time financially for our
family, and we are still dealing with some of the debt now five years later. Nevertheless, it was of course worth it, and we did have plans to save ourselves financially if needed that included selling our house and our vehicle (fortunately it did not come to this).

Our older child was only two during the time of the transplant, which helped to negate any animosity or feelings of neglect, because he was always with one of us and he was so young. Also, the crisis was mostly resolved after a year, so for us it was rather short lived, in comparison to many of the participant families who struggled with medical concerns for years before the transplant. Our marriage remained strong throughout, but in hindsight we also likely would have benefitted from family counselling during that time. We have been to couple’s counselling since as required, which has been helpful.

Our family and friends were enormously helpful to us throughout everything; I do not know what we would have done without their love and support. We did lose relationships with some friends afterwards, specifically due to the fact that these people refused to vaccinate their children, and we have not seen any of these people since. All the participants within the study also expressed concerns about vaccinations to varying degrees, and a majority of the participants indicated that the government should be doing more to decrease vaccine hesitancy.

My husband and I have also talked quite a bit about our concerns associated with the costs of medications in Manitoba, and it seems as though Saskatchewan has a more comprehensive coverage system based on the information provided by the participants. None of the participants residing in Saskatchewan reported any stress in regards to the cost of medications, whereas all participants residing in Manitoba did report that the cost of medications is a concern. Consequently, it would likely help families if Manitoba would consider adopting a similar system. This way we could ensure that children always have access to life-saving
medications and reduce the financial burden to families. Another change that would likely be beneficial is more direct government funding for families of children who have to leave the province for life-saving care that is not available in their province of origin, as it was very surprising to us that more is not done to help families financially. We were lucky to be able to utilize help from agencies, including the David Foster Foundation and the Ronald McDonald House. I cannot express how grateful we were for the help, and the sense of being supported and validated. In terms of care, I thought that the care we received in both provinces was fantastic, and we had no concerns of note. However, as already mentioned, access to free family counselling would have been beneficial.

For us, managing the long-term immunosuppression has been quite difficult. Our child was far too young to be vaccinated before the transplant, and so we are very vulnerable to communicable diseases. We ask every family that our children are friends with if they vaccinate, and we have unfortunately had to limit contact with families if they do not vaccinate as per the recommendations from our medical professionals. It has been difficult to engage in this level of confrontation at times, but we know it is necessary to keep our children safe. When we were moving to a larger house following the transplant, we chose our neighbourhood specifically based on vaccination rates in an attempt to increase our chances that herd immunity is achieved (we sold our house in our initial neighbourhood because vaccination rates were very low). Cleaning has not been a problem, as we are typically meticulously organized people and quite thorough in that process. Making a weekly list of cleaning and laundry chores was definitely helpful in developing an effective routine.

Our immunosuppressed child experiences illness more frequently and severely than our other child, and any other child we know including our nephew. When our child becomes ill we
know there is a very good chance that we will end up attending a hospital ER by the end of the day, as our child tends to decompensate quickly. We have managed to narrowly avoid any additional admissions since the transplantation, but it has been close on several occasions, such as situations where we have agreed to come back daily for intravenous medications to avoid going inpatient. The fear of our child becoming ill is always on my mind. We have not traveled far from home and likely would not risk it until our child is older, as I cannot imagine what would happen if our child was to become ill outside of our country, or even our province for that matter.

We also have had difficulties accessing appropriate childcare, as many of the childcare facilities we reached out to were full, or apprehensive about managing the level of cleanliness and care that our child requires. We made the decision to forego childcare and we manipulated our lives to accommodate this decision. Although I did take maternity leave for both children, my husband took a longer paternity leave to stay home with them because I was working and in school. After our parental benefits ended I took late shifts while my husband worked days, and we both worked fulltime hours while caring for our children ourselves when at home. This did impact the amount of time that my husband and I saw each other. We only spent about ten minutes on average on weekdays together while conducting our “shift change” routines, where we would provide each other with an update of what happened and what was required. We maintained constant communication via text and phone, but the potential impact to our marriage of working opposite to each other for over five years has yet to be seen, as I have only recently transitioned to working days now that both of our children are in school fulltime. Should any problems arise, we do currently have access to counselling via my employment benefits, and we have and will continue to utilize these services as required.
In terms of the family stress theory and navigating the double ABC-X model, I feel as though our family adequately accessed new and existing resources to deal with the initial crisis, and to subsequently move into the bon-adaptation stage. The primary resources that we utilized included: fundraising for additional financial resources, the emotional support of our family and friends, and our knowledge of how to seek and access additional resources that benefited us (such as self-referring to various non-profit agencies to request additional compensation and/or funding). Notably, although it has of course been challenging at times, we have also experienced significant positive outcomes from living as an immunosuppressed family, including (but not limited to): increased parent/child bonding, increased family cohesiveness, increased time spent together as a family, and increased communication within the family. For example, while the experience of the surgery and living donation was difficult, we went through it together and often talk about how strong we are as a family and how lucky we are.

Our struggles with the long-term immunosuppression were the reason that I was interested in this topic in the first place, considering the serious impacts that the condition has had on our child’s wellness and our family as a whole. Through the conceptual exploration within this study, my goal was ultimately to capture the essence of what it means to live as a family with the condition of long-term immunosuppression following solid organ transplantation. Immunosuppression is too often referred to only as a necessary burden of a lifesaving procedure, and this is of course true, but what also needs to be brought into the conversation is that immunosuppression in itself is a lifelong condition. Additionally, it is a condition that carries with it acute and constant risks to wellness, fears of potential community threats to health such as vaccination hesitancy and the transmission of communicable diseases,
constant stress and worry, and significant financial impacts to immunosuppressed individuals and their families.

I am so grateful for this opportunity to contribute to the field of paediatric immunosuppression, and to be able to open up the conversation about immunosuppression as a condition. It was an absolute honour and a privilege to meet the families who participated in this study, and their strength and resilience has been an utter inspiration.

In conclusion, within this chapter I outlined the findings the study, including the autoethnography. Within Table Two I provided a map of all the themes that were identified within the interpretative phenomenological analysis throughout this study.
CHAPTER SIX

A CONCEPTUAL EXPLORATION OF STRESS, HEALTH, AND HEALTH INEQUITY
Conceptual Exploration of Stress, Health, and Health Inequity

Difficulties with health can cause stress, and stress can lead to further health difficulties, and so it appears that this relationship resembles somewhat of a vicious cycle. In regards to formally defining stress, as per existing literature: “any intrinsic or extrinsic stimulus that evokes a biological response is known as stress” (Yaribeygi et al., 2017, p. 1057). Stress can be acute, or a sudden onset, such as an impactful financial stressor or falling ill with a significant but temporary unforeseen illness. Stress can also be chronic, or long standing, such as the stress felt by families with children who are experiencing long-term medical difficulties, as noted by the families within this study.

Examples of stress impacting the families within the study were noted throughout each of the interviews. One participant spoke about how the stress she felt through the experience of her child having medical complexities caused her own childhood trauma to be triggered, and subsequently contributed to an increase in her anxiety and depression. Another participant spoke about how the stress and turmoil their family felt throughout the experience was like holding a magnifying glass up to the preexisting problems within their marriage. She disclosed that despite accessing counselling and actively doing all that they could to save their marriage, they ultimately sought a divorce, but remain amicable. Many participants also discussed how the stress negatively impacted their relationships with natural supports, as they did not feel supported throughout the process. For example, the condition of immunosuppression has many recommendations associated with it, including a need for increased hygiene and preventative medical practices, such as vaccinations and utilizing precautions to decrease the risk of contracting an illness (for example social distancing as required). Families noted that they felt stressed when their natural supports did not cooperate and assist with what was required to keep
their children safe, such as frequent handwashing, routine vaccinations, and screening for illnesses before coming into contact with their child.

Stress can have a significant impact to health, “stress can be either a triggering or aggravating factor for many diseases and pathological conditions” (Yaribeygi et al., 2017, p. 1057). Research has identified that stress can negatively affect body systems including: the overall brain functioning (including memory, cognition, and learning), the immune system, the cardiovascular system, the gastrointestinal system, and the endocrine system (Yaribeygi et al., 2017). For example, “the harmful effects of stress may receive more attention or recognition by an individual due to their role in various pathological conditions and diseases…for example, hormones, neuroendocrine mediators, peptides, and neurotransmitters are involved in the body's response to stress (Yaribeygi et al., 2017, p. 1072). It has also been indicated within previous research that stress has been particularly impactful on the ability for children to cope effectively, “children have explicit and articulate views on what they experience as stressful; how they are vicariously affected by global stressors and what they perceive the significant adults in their lives experience as stressful” (Pienaar, 2010).

A situation where a child is struggling with stress has the potential for a domino effect within the family, as parents and/or caregivers witnessing their children not only experiencing the shared family stressor, but also not managing well, may subsequently further negatively impact the parents and/or caregivers’ ability to cope with the stressor as well. For example, one participant family spoke at length about how they believe that their child is developing post-traumatic stress disorder (PTSD) symptoms in response to the extensive medical testing and medical procedures he has endured so far, which also negatively impacts their ability to manage stress as parents, as they are constantly concerned for his wellbeing. A previous study on
mothers with children who have been diagnosed with cystic fibrosis found that: “maternal adjustment was associated with lower levels of perceived daily stress, less use of palliative coping methods, and family functioning characterized by high levels of supportiveness” (Thompson et al., 1992, p. 573). Additionally, a previous study on mothers with children who have been diagnosed with congenital heart disease found that: “maternal adjustment was associated with high levels of daily stress and palliative coping techniques and was not significantly associated with severity of the cardiac defect” (Davis et al., 1998, p. 219). As indicated within these articles of research, stress management and coping for children is interconnected to the coping of their parent, and although this research was mostly conducted with mothers as participants (which impacts the overall ability to generalize the findings), this information would likely be able to be generalized to some extent to fathers and other caregivers. As noted in the aforementioned example of the family that is concerned about their child developing PTSD and is consequently additionally stressed, this may also contribute to further impacts to their child’s coping and stress management.

Other contributions to stress that were noted by families included negative financial impacts, not feeling financially supported, and not feeling protected and supported systemically. The participant families spoke about not being financially supported in terms of the current government funding structures in place for transplant recipients and families. The funding available varies by province of origin, for example in Manitoba more financial assistance is reportedly provided for those who need to travel for a medical procedure (such as potential for reimbursement for accommodation) which is not available in Saskatchewan. However, in Saskatchewan there is additional government financial coverage for paediatric medications (no medication will be more than $25.00 for a paediatric patient). In terms of not feeling protected
and supported systemically, families within this study discussed their frustration regarding a perceived lack of regulations to protect immunocompromised individuals. For example, one participant spoke about a lack of rules in support of vaccinations within the public school system. She explained that she cannot send her child to school with peanut products due to a broad rule in place to protect children with peanut allergies, but other parents can send their children to school unvaccinated which is thus failing to protect immunosuppressed children, as they are highly susceptible to communicable diseases with potential for fatal outcomes. Families also noted that the schools were not being cleaned as regularly as they would feel safe with, and although one participant reported that the schools did increase the cleaning requirements, the others described that no additional cleaning was introduced within the schools despite their continued advocacy. In regards to financial impacts, participant families reported that they experienced negative financial impacts resulting from the illness and required interventions. For example, one participant spoke about being tens of thousands of dollars in debt resulting from having to travel outside of their province of origin for the transplant procedure, and consequently not being able to work for about one year as result. Another participant family spoke about the continuing financial impacts of the additional requirements that are not funded, such as bottled water and cleaning supplies. The participant families that were located in a province without extensive medication coverage all reported significant stress and frustration regarding this lack of coverage, as the required medications can cost hundreds of dollars per month, and many families (my own family included) have to pay this fee out-of-pocket due to a lack of accessible funding (despite having insurance coverage).

The concerns that were reported within the experiences of the families living with immunosuppression indicate the presence of health inequity. As per Sick Kids Hospital in
Toronto, health inequity: “is achieved when we work towards reducing the differences in health outcomes that are avoidable, unfair, or biased” (Sick Kids Hospital, 2020). Health inequity can be seen within the additional and ultimately unavoidable costs that families are expected to pay, with funding that was described by participant families as inaccessible, insufficient, or non-existent. Many of the participant families reported going significantly into debt because of these costs, as well as the additional financial burden of not being able to work during the time of the transplant procedure, as this occurred away from their province of origin. Health inequity can also be seen within the systemic extensive protection of some children (such as those with peanut allergies) as opposed to other children who do not receive the same amount of protection (such as immunosuppressed children in regards to the required cleaning/hygiene practices, as well as preventative measures such as vaccinations). For example, parents of children who do not have health complexities resulting in the children being highly susceptible to illness have a choice in whether or not (and to what extent) they opt to engage with the recommendations of paediatric healthcare professionals, such as recommendations regarding the most effective vaccination schedules and health preservation recommendations (such as handwashing), whereas parents of children with medical complexities do not have this choice and rely on others to be vaccinated in hopes to achieving protection for their children via herd immunity.

Health inequities can increase chronic stress and impact all levels of family functioning. In regards to stress and family health, research has shown that: “daily stress, associated with lower social position and poor family functioning, can lead to adverse health outcomes” and “long-term poverty and family stress were strongly associated with less physical mobility and cognitive functioning at older ages” (American Psychological Association, 2020). Health inequities are also closely connected to the social determinants of health. As per existing
literature, there are two main contributing factors to the development of health inequities: “the first is the intrapersonal, interpersonal, institutional, and systemic mechanisms that organize the distribution of power and resources differentially across lines of race, gender, class, sexual orientation, gender expression, and other dimensions of individual and group identity,” and “the second, and more fundamental root cause of health inequity, is the unequal allocation of power and resources—including goods, services, and societal attention—which manifest in unequal social, economic, and environmental conditions, also called the social determinants of health” (Weinstein et al., 2017, p. 1). As per the experiences of the participant families within this study, the condition of immunosuppression impacts various aspects of the social determinants of health, including (but not limited to): income and social status (negative financial impacts were reported as a result of the illness and required interventions), employment and working conditions (parents were unable to work due to having to leave the province of origin, thus increasing financial stress), education and literacy (participants reported difficulties regarding the children attending the school environment safely, such as concerns regarding cleaning and hygiene within the schools), childhood experiences (the recommendations associated with the condition limiting social interactions for the children, such as canceling playdates after screening for illnesses), physical environments (participants described feeling systemically unsupported), social supports and coping skills (participants discussed the impacts of ongoing stressors, such as fears that their child would develop PTSD as a result of the medical oriented trauma), access to health services (as noted in conversations regarding their children’s long-term medical needs and various required appointments with specialists and routine medical tests, and how this impacts daily life), and biology and genetic endowment (the participant families experiences with having a child
born with medical complexities, and how this impacted them, such as potentially expanding the family afterwards).

Although health inequities, stress, family health, and the social determinants of health have been written about extensively within the academic literature, there appears to be no readily available literature in which these concepts were applied specifically to the condition of immunosuppression. This study aimed to not only apply these concepts to immunosuppressed individuals and families, but also provide a thorough description of what it means to live as an immunosuppressed family, as this topic has seemingly been sparsely written about previously. It is important to close gaps such as this within research for several reasons. Firstly, it is important that all medical conditions and populations are well represented within the literature and explored in academic studies, as this may produce new knowledge, important findings, and lead to crucial future research. Secondly, it is critical to conduct research in this area in order to make recommendations based on evidence that may benefit individuals with circumstances similar to those of the participants. Thirdly, it is important that patient voice is added to studies of this nature, to ensure that the findings and recommendations are correct and effective, in that the study accurately reflects the experiences of participants and the recommendations are based so closely to those experiences that the recommendations would likely improve the lives of others moving forward, if applied. The goals of this study included developing a framework to assist families who have a child who is being assessed for a solid organ transplantation, in addition to exploring and describing the experiences of the participant families regarding the essence of what it means to be an immunosuppressed family.

Additionally, it is imperative to note that researchers with lived experience can offer unique and valuable insights into phenomenon that is vaguely understood and potentially under-
researched. For example, I am a researcher with lived experience in this area. Consequently, when I was reviewing the available research regarding immunosuppressed individuals and families, I was quite surprised to find that this area of interest was seemingly not written about academically before. Living as an immunosuppressed family, we are acutely aware of the struggles and daily challenges associated with the condition, and so I knew inherently that this would be an important area of focus. Although there is an abundant amount of academic literature available on research using lived experience, beyond a finite number of articles regarding researchers with lived experience in the mental health field, literature also appears to be notably limited regarding researchers with lived experience in academia. More information about the role of researchers with lived experience would also likely be beneficial, in order to better understand how researchers with lived experience can be best utilized to contribute to their fields of interest, and to further define this role also in terms best practice. For example, to ensure that bias is reduced and bracketing is occurring throughout all aspects of the study as required.

In conclusion, within this chapter I provided a conceptual exploration of stress, health, and health equity in regards to individuals and families living with the condition of long-term immunosuppression following solid organ transplantation. This included how health, health equity, and the social determinants of health are interrelated, and how these concepts interact with stress and family health. As an increase in stress has been shown to contribute to negative health outcomes, monitoring stress and ultimately the health of families is critically important to help to encourage long-term health and overall wellness.
CHAPTER SEVEN

DISCUSSION
Discussion

The purpose of the study was to capture the essence of what it means to live as an immunosuppressed family. The state of immunosuppression causes significant impacts to the lives of immunosuppressed individuals and their families, and affects functioning throughout various aspects of everyday life. Immunosuppression is often referred to as a side effect following solid organ transplantation, but because of the impacts to functioning, it would likely benefit immunosuppressed individuals and their families for the condition to be regarded as a long-term medical condition.

Fifty-two supporting themes emerged from the interviews, across seventeen superordinate themes within the twelve organizational categories. The categories with the highest levels of reporting were: biology and genetic endowment, healthy behaviours, physical environments, income and social status, social supports and coping skills, and access to health services. Each theme within the categories was discussed by participants to varying degrees (Table Three). The themes with the highest level of participant engagement were: long-term management of immunosuppression (protecting the children and maintenance of health) (100%), vaccinations (concerns regarding vaccine hesitancy and the anti-vaccination movement) (100%), and organ donation registry (concerns regarding a lack of an opt-out system) (100%). The perception of stress management, impacts to relationships, financial impacts, and concerns regarding the children within the school system were also discussed significantly across several of the themes and superordinate themes within the various categories.

The phenomenon was approached within this study using an initial autoethnography, and subsequently interpretative phenomenological analysis, with the addition of the family stress theory (with the double ABC-X model) and the social determinants of health. As an author with
lived experience, the initial autoethnography was utilized as a means to analyze and explore my lived experiences in a regulated manner, with the intent of having these experiences become a part of the study in a meaningful but controlled way, while contributing to further frame the experiences of living as an immunosuppressed family.

Although autoethnography may be most traditionally associated with the study of culture, as evidenced throughout this study, there are components of living with a chronic medical ailment that may suggest that this population is part of a culture in this way, as it would otherwise be unlikely to be well understood by anyone living outside of this situation without specific context. For example, those who live with immunosuppression are advised to maintain high levels of cleanliness and hygiene, and engage in regular risk assessments throughout most aspects of daily life. These risk assessments, such as those pertaining to any potential risks in routine work or social situations, would likely be a foreign concept to those not living with a medical condition requiring this level of regular attention and assessment. To situate the lived experience in this context, the autoethnography was employed to explore these overarching aspects regarding the essence of what it means to live with immunosuppression.

These experiences were bracketed throughout the study, as although integrating the lived experience was important, it was also crucial to not allow these experiences to influence the interpretation of the experiences of the participants. However, although bracketing was implemented in this study as a means to isolate the lived experience, the lived experience did influence various aspects of the study, and thus must be observed accordingly. For example, each participant inquired as to the reason behind opting to study this specific phenomenon, and each participant was informed of the lived experience in this context (and throughout the interviews, as requested). As I would most likely be viewed as an “insider researcher” conducting this
research, this may have resulted in trust being established more quickly, and thus participants feeling open to discuss their experiences more freely than perhaps they might if working with a researcher without lived experience.

The social determinants of health were identified through an inductive manner within the autoethnography process as likely a beneficial means of exploring the experiences of participants, in order to capture the multifaceted aspects of living with immunosuppression. For example, it was noted in the autoethnography that living as an immunosuppressed family impacts all aspects of life, at times insidiously, and so it was determined that using a comprehensive framework to explore how this impacts all facets of functioning would likely be appropriate. Subsequently, all themes under the social determinants of health were emergent and generated exclusively by the accounts of the participants. Although the themes were not initially influenced by the autoethnography, the lived experiences were reflected upon and weaved throughout the discussion as appropriate, as a means to bind the data sets. Although much of what was discussed by the participants mirrored the lived experiences within the autoethnography, each story is unique and significant, and thus provides additional critical insight into the practical and emotional features of the specific experiences, as discussed by each particular participant in their own particular context, including those identified within the autoethnography.

Using interpretative phenomenological analysis, the emergent themes were developed first by making exploratory notes on the data set, and then by reducing the volume of data by focusing on substantial interrelationships, connections, and patterns within the data, in order to determine the most pertinent aspects of the data that exhibit the essence of the phenomenon. The themes were evident in the data, as well as the subsequent interpretation. The emergent themes that were identified were grouped and connected in order to determine superordinate themes by
utilizing the mapping process with all of the first possible themes that were identified. Within the mapping process, the themes were written on pieces of paper, which were then organized within a large space in order to explore the patterns within the themes via the form of spatial representation (Smith, Flowers, & Larkin, 2013, p. 96). This was then transferred into a table within a document for ongoing use. Throughout this process, any themes that were not robust and representational of the essence of the phenomenon were cut, or combined as appropriate, in order to strengthen the conceptual makeup of the theme groupings. The superordinate themes and supporting themes were then further organized based on the social determinants of health as a guiding framework. Throughout the following sections, the analysis of the themes is presented based on the interpretation of the data, situated within existing literature and the family stress theory.

The family stress theory was utilized based on the themes and superordinate themes that emerged from the experiences of the participants. Identified within the data was an opportunity to explore the stress experienced by families, as well as the needs of families to assist in addressing the stress and mitigating any risk to family functioning successfully, in order to avoid trending towards a mal-adaptive state. By using family stress theory and the double ABC-X model, these concepts were explored and framed within the context of increasing the resources available to families, such as additional supports and assistance, that may aid in maintaining the health and overall wellness of families who are living with immunosuppression following pediatric sold organ transplantation. The double ABC-X model was employed within this study without alteration, and no subsequent refinements are recommended as a result of this study. However, what may be novel was the application of the model to the development of a practical
clinical guideline to assist practitioners, and a potential recommendation as a result of this study is to widen the overall application of the model to further facilitate knowledge translation.

Table Three: Tracking the Occurrence of the Clusters of Related Themes

<table>
<thead>
<tr>
<th>Cluster of Related Themes (Social Determinants of Health)</th>
<th>Number of Participants who Reported a Theme within the Cluster</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td>5</td>
<td>62.5%</td>
</tr>
<tr>
<td>Biology and Genetic Endowment</td>
<td>8</td>
<td>100%</td>
</tr>
<tr>
<td>Healthy Behaviours</td>
<td>8</td>
<td>100%</td>
</tr>
<tr>
<td>Physical Environments</td>
<td>8</td>
<td>100%</td>
</tr>
<tr>
<td>Employment and Working Conditions</td>
<td>6</td>
<td>75%</td>
</tr>
<tr>
<td>Income and Social Status</td>
<td>8</td>
<td>100%</td>
</tr>
<tr>
<td>Social Supports and Coping Skills</td>
<td>8</td>
<td>100%</td>
</tr>
<tr>
<td>Access to Health Services</td>
<td>8</td>
<td>100%</td>
</tr>
<tr>
<td>Culture</td>
<td>5</td>
<td>62.5%</td>
</tr>
<tr>
<td>Education and Literacy</td>
<td>7</td>
<td>87.5%</td>
</tr>
<tr>
<td>Childhood Experiences</td>
<td>3</td>
<td>37.5%</td>
</tr>
<tr>
<td>Race/Racism</td>
<td>1</td>
<td>12.5%</td>
</tr>
</tbody>
</table>

Gender

Four study participants reported that the female caregivers reduced their working hours outside of the home in order to take care of their child with additional health needs, as opposed to the male caregivers. There have been several studies conducted that have identified that the careers of mothers, as compared to fathers, may be especially negatively impacted by caring for their children with complex medical needs, as mothers have been noted to provide a majority of the childcare responsibilities (Boyd, 2002; Schuster, Chung, & Vestal, 2011). Studies of families with children who have been diagnosed with autism reported the mother’s ability to work was the most affected by their child’s additional support needs, as compared to other members of the family (Baker & Drapela, 2010; Schuster, Chung, & Vestal, 2011). Additional research on families with children diagnosed with autism found that about 60% of the mothers stated that
they had not taken a job because of their child’s additional support needs related to the diagnosis of autism, and of those mothers who were employed, “more than half worked fewer hours to care for their child, one-quarter had taken a leave of absence, and nearly as many had turned down a promotion in order to care for their child” (Schuster, Chung, & Vestal, 2011, p. 101).

Furthermore, research found that mothers of children with complex medical needs that require the use of technical medical devices (such as technology required for nasogastric tube feeding) were much more likely to quit their employment in order to care for their child, and single mothers were fifteen times more likely to quit employment, as compared to mothers who identified as having a partner (Schuster, Chung, & Vestal, 2011; Thye, Kuhlthau, & Perrin, 1999).

Although study participants were all currently identify as being within heterosexual pairings, their sexuality was not explored. As this was not a topic of discussion with them, their sexuality will not be assumed to be heterosexual, in order to avoid projecting incorrect and potentially harmful inferences of the participants based on their current circumstances (such as not correctly identifying someone as bisexual based on a current heterosexual pairing).

Gender theory is defined as: “the study of what is understood as masculine and/or feminine and/or queer behavior in any given context, community, society, or field of study (including, but not limited to, literature, history, sociology, education, applied linguistics, religion, health sciences, philosophy, cultural studies). The term sex refers to categories of the biologically observable human body, female and male or intersex (i.e., nature), while the term gender refers to the categories of social expectations, roles, and behaviors, feminine and masculine (i.e., what is nurtured)” (Jule, 2014, p. 2464).
When exploring the responses of the participants from a gender theory perspective, it appears that the individuals who identify as female within the two couples in the study are responsible for the majority of the household and child-oriented responsibilities. Both of these female participants also are not working fulltime outside of the home currently, while the male participant within each pairing is the primary fulltime income-earner within the family. The decision regarding the female participant within these pairings to not work fulltime outside of the home may have been impacted by financial or educational reasons (both male participants reported obtaining a higher level of education before marriage than reported by the female participants within these pairings, but all did report post-secondary education). However, this decision may also have been impacted by the antiquated societal perception that females are expected to stay home to take care of the children while males work outside of the home. Although their perceptions of their current circumstances were not explored at length during the interview process, the participants did not appear overtly open to discussing why this was the decision made within their families, and participants were not incited to discuss anything that may have resulted in discomfort and/or potential discord.

It is a well-known fact that true equality has not been reached for women in multiple aspects of modern society globally, including the division of household labour and childcare responsibilities. In regards to keeping this in mind while researching families, “a sharp eye must persist in perceiving that both women and men exist in the reproductive and productive spheres, and ensure that old divisions, in new manifestations, do not obscure sightings” (Boyd, 2002, p. 470). As noted in the autoethnography, my husband and I divided the work and home responsibilities equally initially, and he took a paternity leave for both of our children after they were both born. However, he ended up taking the longer leave and I returned to work earlier
following the crisis period, and so his working hours outside of the home were reduced as opposed to mine. Two participants within the study discussed an equal division of labour and household responsibilities, but outside of my own experience, no participant reported that the father decreased working hours as compared to the mother.

Although it is not clear if these mothers within the study feel oppressed necessarily by being the ones to stay home with the children, what can perhaps be taken from this discussion is that children with complex medical needs may require special childcare that is not necessarily readily available to families. This affects the ability for the family to return to work, which in turn can often impact the mothers of the family more, as it is common for mothers to reduce employment in order to care for the children. In regards to developing an approach to addressing this concern, previous research has suggested that: “new childcare choices may emerge when the emotional/caring needs of children, women and men and a caring community may begin to be envisaged, beyond male and female, beyond the public and the private, beyond mothers at home and mothers at work - new childcare choices may emerge from a new conversation” (Boyd, 2002, p. 470). More financial support for families, and increased childcare options specific to children with additional medical needs, would likely ease this concern and limit the impact to the ability to work outside of the home for families.

**Biology and Genetic Endowment**

As of 2014, it was estimated that about 53,000 families in Canada were actively caring for a child with medically complex care needs (Flegel, 2014, p. 1195). Given the experiences shared by participants, in addition to my own lived-experience, it is clear that families of children with complex medical needs face stress, worry, and uncertainty on a daily basis, and this strain can cause families to become “fragile” (Flegel, 2014, p. 1195). The resulting fragility may
cause family discord and the individual decompensation of the family members. Of the situations that result in the dissolution of the family, one might say that the child survived but the family did not (Flegel, 2014, p. 1195). This is why it is imperative to ensure that families are receiving support, and have readily available access to support if required, throughout all stages of the process.

In regards to waiting on the list for a transplant, there have been several studies on the topic that provide insight into this experience. One study that focused on adults awaiting liver transplantation identified that all of the patients interviewed were actively “waiting” for something to occur, including: a procedure, for the medicine to work, and for life to return to normal; and ultimately this active act of perpetually waiting was found to be a significant experience in the essence of what it means to be anticipating a transplantation procedure (Brown et al., 2006, p. 136). Additional research focused on adults awaiting transplantation found that although the number of organ transplantations has increased globally along with medical advancements the number of organ donors has not similarly increased (Bjørk & Nåden, 2008, p. 289). Consequently, individuals are experiencing lengthy waits for organ donations, and the respondents reported significant “physical and psychosocial suffering” as a result (Bjørk & Nåden, 2008, p. 289). Bjørk & Nåden’s study also found that the individuals awaiting transplant were provided with little support during the waiting process; “the patients seemed resigned to the inevitability of their suffering” (2008, p. 289).

None of the participants in the present study identified being offered support specifically while on the waiting list for transplantation, but some did report that they were provided with enough information to feel more secure in the process. Although our family was a living donor family, we were on the waiting list for some time, and we were also not offered any support
during that process. Henceforth, the recommendation proposed by the participants of ensuring that a counsellor and/or social worker is involved throughout the process may also provide the specialized support required for families as they wait on the list for an organ. Other potential benefits of this intervention that were noted included: decreasing the risk for decompensation (individual and family), decreasing the risk of the dissolution of the family, increasing coping and overall wellness, and decreasing the risk for the development of significant mental health concerns.

Regarding the themes of being born ill and immunosuppression being considered a medical condition as opposed to a side effect, it was evident through the conceptual exploration within the findings that these themes intertwined and illustrated the essence of the experiences of the participant families, and what it means to be an immunosuppressed family. The journey for the participant families began with the initial diagnosis for their children, and all reported that their children were diagnosed either in utero or shortly after birth. Study participants described the fear and worry that accompanied the diagnosis, and the stress they felt throughout the process moving from diagnosis to transplantation. Following the transplant, all of the families within the study became immunosuppressed families, and shared the difficulties associated with this new state, including: severe and prolonged illnesses, increased medical vulnerabilities, and complications resulting from co-occurring disorders. Many of the participants advocated for immunosuppression to be considered and addressed as a medical condition, as opposed to a side effect of the medications.

Immunosuppression is defined as: “the suppression of the immune system and its ability to fight infection. Immunosuppression may result from certain diseases, such as AIDS or lymphoma, or from certain drugs, such as some of those used to treat cancer.
Immunosuppression may also be deliberately induced with drugs, as in preparation for bone marrow or other organ transplantation, to prevent the rejection of a transplant” (Medicine Net, 2017). Immunosuppression is often referred to within the literature as a side effect, either to medications or illness, but not often as a medical condition. The participants discussed that because we currently have no other options other than immunosuppressant medications for transplant recipients, until science advances, we need to consider this as a lifelong medical condition due to the significant impacts immunosuppression has on overall functioning. Within the essence of the narrative of participants was a want for others to know that a transplant is not an instant cure for the illness, but rather the illness is transformed into a new and permanent medical condition, immunosuppression.

**Healthy Behaviours**

Within the healthy behaviours category and the superordinate theme of long-term management of immunosuppression, and the supporting theme of protecting the children and maintenance of health, the participants extensively discussed the stress related to managing the numerous requirements that are recommended by healthcare clinicians to maintain the health and wellbeing of immunosuppressed individuals to minimize the risk of illness. The primary concerns regarding the recommendations appeared to be focused on cleanliness and hygiene, as opposed to the other recommendations, such as food and activity restrictions. Study participants noted concerns regarding cleanliness in the community (such as restaurants and stores), within the homes of loved ones (such as in-laws requiring reminders to keep their home clean), and within the school system (such as wiping down commonly touched surfaces and encouraging proper hand washing). No participant disclosed that keeping their own homes clean in order to protect their immunosuppressed child was a significant stressor. To assist families in advocating
for the needs of their children, and ultimately keeping their children safe, more education around what is required and why, as well as more involvement from decision makers within the school systems and other commonly frequented community settings, would likely be beneficial in working with families to ensure that children who are immunosuppressed remain safe, in regards to cleanliness and hygiene in community.

The next most discussed theme within this category was the medications that are required for the children who are immunosuppressed, primarily regarding the daily medication dosage schedules and the expenses of the medications for the participants who lived in a province without adequate government coverage. For concerns regarding the medication dosages, the participants indicated that it was difficult to prepare all the medications outside of the home. For example, one participant reported that she had to crush up some of the medications and administer them to her child within yogurt, and so this impacted their ability to attend family dinners that were scheduled around the same time as the medication schedule. Unsurprisingly, the parents of the children who were on more medications and daily medical interventions (such as tube feeding) reported more stress in managing these daily requirements, as compared to the parents of children with less intensive daily medical routines.

In regards to the reported concerns associated with the costs of the medications, this was something only reported by the participants who lived in a province without comprehensive government coverage. One Manitoban participant even recommended that Manitoba adopt the current system in place in Saskatchewan (no medication for a minor would cost more than $25.00). The participants who lived in a province with comprehensive government coverage identified no stress in regards to paying for their child’s medications. Based on the experiences reported by the participants who lived in a province without adequate government coverage, such
as Manitoba, more needs to be done by the province to ensure that families can afford medications and that this cost does not place additional stress and burden upon families with children who have medical complexities. Research that focused on medically complex Canadians who have claimed bankruptcy identified that although the universal healthcare system in Canada protects individuals against ruinous doctor and hospital bills, inadequate or nonexistent coverage of prescription medications and dental requirements can lead to unaffordable out-of-pocket costs, in addition to the loss of work that often occurs following an illness, which can leave Canadians vulnerable to debt and bankruptcy (Himmelstein et al., 2014, p. 7).

From the experiences shared by the participants, it is clear that the ongoing maintenance of their children’s health causes stress, and it appears that this stress is likely a chronic stress as opposed to an acute stress. Caregiving stress has been associated with “considerable demands imposed on parents responsible for the physical and emotional care of medically fragile children,” as well as “physical strains, financial constraints, emotional effects, and social isolation experienced by parents caring for children with such complex medical needs that may ultimately impact their physical and emotional health” (Kuster & Merkle, 2004, p. 257). Study participants appeared to navigate these chronic stressors by utilizing all the available resources to them successfully to avoid entering mal-adaptation and crisis. Resources that appear to be helpful based on the reported experiences include: financial resources (such as income), additional childcare provided by parents and/or close family, natural supports (to avoid isolation and to assist with providing care), and resourcefulness (such as finding alternatives to decrease the impact on the family).

To ensure that families are successful in this process, it may be beneficial for practitioners to consider implementing a framework to assess available resources, and the
family’s ability to respond to stressors and acute crisis situations, as a means to identify families that might be more vulnerable to entering crisis and mal-adaptation. A preliminary framework to help guide clinicians in order to provide a holistic assessment of the available resources and potential needs of families with children who are immunosuppressed was developed as a result of this study, and can be found in the implications section.

**Physical Environments**

Two prevalently discussed themes within this category were: vaccinations (concerns regarding vaccine hesitancy and the anti-vaccination movement) and organ donation registry (concerns regarding a lack of an opt-out system). These themes are located within the category of physical environments under the superordinate theme of feeling secure, protected, and validated within the community. The aforementioned themes were placed within this category because the majority of the contact with these systemic concerns takes place when the children are in physical environments within the community and outside of the home, which impacts how the families perceive their standing and identities within the community. For example, as every family in the study identified that they vaccinate regularly to help protect their children who are immunosuppressed, the majority of contact with individuals who are not vaccinated would then likely take place within the community, such as at school and extracurricular activities. The concerns regarding the organ registry are also issues that exist outside of the home and outside of the control of the families, and so this theme was also placed in this category, as the registry guidelines are imposed by the federal government and triaging within the organ wait list is managed by healthcare professionals, typically within hospital and acute care settings.

The importance of changing the current organ transplant registry system in Canada was a concern that was discussed by all eight (100%) of the participants in the study. According to the
Canadian Institute for Health Information: “in 2018, a total of 2,782 organ transplant procedures were performed in Canada (including Quebec), according to the latest data from the Canadian Organ Replacement Register (CORR) - a Pan-Canadian information system for organ failure in Canada” (Canadian Institute for Health Information, 2019). Additionally, “the deceased organ donor rate in Canada in 2018 (including Quebec) was 20.6 donors per million population, an increase of 42% since 2009. The living donor rate was 15.0 donors per million population, a decrease of 2% since 2009” (Canadian Institute for Health Information, 2019). Statistics have shown that although the rates of organ donation are increasing in Canada, supply still is not meeting demand; “at the end of 2018, there were 4,351 people on a waiting list for an organ transplant, including 2,890 who were active on the list. In total, 223 people died while waiting for a transplant” (Canadian Institute for Health Information, 2019).

Although information regarding the automatic opt-in organ registry system is currently limited, because the transition to this system is a relatively new direction, the few studies that have been conducted recently have shown that when applied an automatic opt-in organ registry system does ultimately increase the number of organs available (Li, Hawley, & Schnier, 2013; Shepherd, O’Carroll, & Ferguson, 2014). Spain has introduced the automatic opt-in organ registry system, and is considered to be the most successful country in the world in regards to organ donations, at a rate of 46.9 per million people in the population, or 2,183 people that annually become cadaveric organ donors (Mosaic Science, 2020). For context, this rate can be compared to Canada’s rate of 20.6 donors per million people in the population in 2018 (Canadian Institute for Health Information, 2019). It is clear that there is seemingly a much higher rate of organ donation when utilizing the automatic opt-in organ registry system as compared to the opt-out system currently in place in Canada.
Although the potential for changes to the current organ registry in Canada are being discussed in the media, it does not appear as though any firm direction has been decided at the federal level in regards to changing the system concerning presumed consent. In Canada, the need for organs is increasing and individuals are being urged to opt-in using the systems in place for their home province (Government of Canada, 2019). As of 2016, over 4,500 people were waiting for organ transplants and 260 people died waiting for a transplant (Government of Canada, 2019). Currently the Government of Canada identifies that they have developed an initiative called the Organ Donation and Transplantation Collaborative, with involvement of stakeholders including: provinces and territories (with the exception of Québec), Canadian Blood Services (CBS), patients/clients, families, clinical and/or administrative stakeholders, and academic and/or clinical researchers (Government of Canada, 2019). The current available information makes no mention of the development of an automatic opt-in organ donation registry in Canada, and the present mandate is identified as follows: “we will continue to improve our system and ensure that Canadians have timely and effective access to quality donation and transplantation services” (Government of Canada, 2019).

Every individual in the present study identified that they would advocate for and support an automatic opt-in organ donation registry in Canada, and identified that this development would increase the availability of organs, save countless lives (including the lives of children who are currently waiting on the list for transplantation), and save the country significant amounts of money in maintenance medical care, such as daily dialysis. They also discussed that this would not be robbing anyone of their autonomy, as anyone who did not want to become a donor would simply opt-out of the process, similarly to the current opt-in processes. Several of the participants reported considerable stress and fear while their child was waiting on the list for
organ transplantation, and an increase in available organs would not only decrease wait time but also likely decrease the extent to which a family would be within the acute crisis period, thus potentially increasing the likelihood that they are able to move towards bon-adaptation once leaving the crisis period.

Based on the experiences and recommendations of the participants, as well as the results of Spain’s progress in organ donations after implementing the automatic opt-in system, it appears that Canada would benefit from adopting a similar system nationally to increase organ availability, as the most recent data indicates that individuals are still dying while waiting for organs, because supply is not meeting demand (Canadian Institute for Health Information, 2019). Although there are currently conversations about this transition in Canada, based on the information available at this time it does not appear that any of the provinces or territories have adopted the automatic opt-in organ registry system as of yet. As previously noted, this transition would also likely save the healthcare system in Canada money and resources that are currently required for maintenance medical treatments. Thusly, it appears that the Government of Canada may benefit in various facets of operations should they consider the implementation of an automatic opt-in organ donation registry in Canada.

Concerns regarding vaccination hesitancy and the anti-vaccination movement were disclosed by all of the study participants. Vaccines are a well-known and effective medical intervention aimed at preventing diseases and increasing the lifespan of populations. However, in the last 20 years unfounded concerns have been raised recently by various groups regarding the safety of vaccinations, including the fear of vaccines causing conditions such as autism, and polio vaccine contamination with simian virus 40 (Motta, Callaghan & Sylvester, 2018; Pandolfi et al., 2019). Subsequently, there have been global outbreaks of preventable diseases, such as
measles, which have caused a significant number of deaths. Thus, several detrimental outcomes associated with the anti-vaccination movement as identified in recent research include:

“increased morbidity and mortality from preventable diseases, it jeopardizes research for new vaccines, [and] patients are reluctant to accept any form of immune-therapy, commonly referred to as vaccination” (Pandolfi et al., 2019, p. 6070). In regards to the fear that vaccines cause autism specifically, research has shown several traits to be associated with the anti-vaccination movement and vaccine hesitancy: “low knowledge about autism is associated with thinking one knows more than experts, overconfidence is associated with anti-vaccine policy attitudes, [and] overconfidence is also associated with support for non-experts’ role in policymaking” (Motta, Callaghan, & Sylvester, 2018, p. 274).

As per the Canadian Public Health Association, following the publication of a paper regarding the safety of vaccinations by Andrew Wakefield in 1998 (the paper was retracted by the journal in 2010 due to scientific misrepresentation), vaccination rates have decreased and the incidents of diseases prevented by vaccinations have increased, as the anti-vaccination movement subsequently became more prevalent (Canadian Public Health Association, 2020). Individuals who identify as disagreeing with the effectiveness and need for vaccines have indicated reasons including religious beliefs, that they feel as though the effectiveness of vaccinations is not accurate, and that they believe vaccinations are not safe and cause conditions such as autism (Canadian Public Health Association, 2020).

Additional research has shown that the numbers of nonmedical vaccine exemptions are rising, with increasing numbers of children entering kindergarten without vaccinations or without a complete vaccination schedule, which negatively impacts herd immunity and increases the risk of outbreaks of preventable diseases, such as measles (Zimlich, 2018). Recommendations to
address the anti-vaccination movement include urging stakeholders, such as government agencies, to get involved and to investigate the reasons that higher numbers of exemptions are occurring, and also to provide doctors with more and better tools to address vaccine hesitancy effectiveness on the frontlines of healthcare (Zimlich, 2018).

Although there appears to be an abundance of misinformation available, the clear majority of medical professionals globally proclaim that vaccinations are safe and an effective means to prevent illness. However, since these preventable diseases have been on the rise following the anti-vaccination movement, immunosuppressed individuals are at a higher risk for contracting these illnesses, as they cannot be vaccinated with live vaccinations, and rely on herd immunity to protect them. What appears to be missing largely from the overall narrative regarding vaccines are the voices of immunosuppressed individuals and their families. Every participant in this study expressed concern about the anti-vaccination movement, and based on the experiences of the participants, it is clear that this is of considerable worry to them as they are in fear for the safety of their children. Many of the preventable diseases targeted by routine vaccinations can be fatal, and those with a compromised immune system are particularly at risk. If vaccination rates continue to plummet the government will need to consider taking steps to protect those who are the most vulnerable individuals in these situations, children who are immunosuppressed.

The concern that the issues regarding what is required for immunosuppressed individuals to be safe and supported within the community are not being addressed systemically also indicates the presence of health inequity. Participants reported considerable fear for their safety as a result of the anti-vaccination movement and the recent resurgence of preventable diseases, yet no tangible changes are being made systemically to protect them. One of the study
participants stated that if she cannot send her child to school with peanuts or peanut butter, other people should not be able to send their children to school unvaccinated. This suggests that while some health concerns are being prioritized within the community, such as the school system banning peanuts due to allergies, the condition of immunosuppression is not currently being prioritized similarly despite the prevalence. This could potentially put immunosuppressed individuals at risk of contracting preventable illnesses that could be fatal.

As per the Government of Canada’s latest available survey data (2017), “90% of two-year old children had received at least one dose of measles vaccine, 76% of two-year old children had received all recommended doses (four) of diphtheria, tetanus and pertussis vaccine, and 2.3% of two-year-old children had not received any vaccine” (Government of Canada, 2020). Study participants suggested that the government should provide more advocacy and information to support vaccinations, as well as for the government to consider models that have been implemented in other countries to address the anti-vaccination movement, such as in Australia. Australia has implemented several campaigns through their federal government in order to address the anti-vaccination movement, including the ‘Get the Facts about Immunization’ campaign (a website to provide evidence-based information about vaccinations), as well as state and territory initiatives such as ‘Vaccidate’ (an app that reminds parents when it is time for a scheduled medical appointment for their child, such as routine vaccinations) and ‘Save the Date to Vaccinate’ (a website and app to remind parents when it is time to vaccinate their children), which aim to provide parents with evidence-based information about immunization to ultimately increase vaccination rates across the country (Australian Government, 2018). Another campaign is the “No Jab, No Pay” program (government payments are stopped if the child’s vaccinations are not up-to-date), and as per the Australian Government, the outcomes of this
program are as follows: “from 1 January 2016, No Jab, No Pay removed conscientious and religious objections as valid reasons for exemption from the immunization requirements for family payments. The Australian Government also extended the immunization requirements for Family Tax Benefit Part A Supplement to all individuals under the age of 20 years” (Australian Government, 2018). One participant in the study stated that Australian children are not allowed to attend public school if they are not vaccinated, but as per the information that is readily accessible, this does not appear to be a federal policy at this time (Australian Government, 2018).

The report issued by the Australian Government indicates that these campaigns have been effective in increasing the rates of childhood vaccinations and subsequently increasing herd immunity throughout the country (Australian Government, 2018). The Government of Canada would likely benefit from considering implementing policies similarly, which could also decrease the potential risk for families with medically vulnerable children to feel systematically discriminated against, as it would show that these concerns and risks to public health are being taken seriously. This could in turn decrease the risk of the contraction of these preventable diseases and possible outbreaks, which would save not only lives, but also the finances and resources that would be required to manage a potential outbreak.

Families with medically complex children can feel discriminated against if there is not enough support and consideration provided to address their child’s needs, and studies have shown that this discrimination can be perceived within the school system, peer groups, community, and governing institutions (Turner-Henson et al., 1994). Advances in modern medical care have improved survival rates for many illnesses, and as a result an increased number of children with complex medical needs are enrolling within the school system, which has produced a demand for the schools to evolve to meet their needs (Turner-Henson et al., 1994;
Walker & Jacobs, 1984). Negative impacts to the relationships of families with medically complex children and the school systems may be lessened with ongoing collaboration between the families and the individuals responsible for decisions and policy-making within the school systems. Including children and families within the planning process may provide a more effective and holistic outcome, as the perspectives of various stakeholders would be included, as opposed to the views of those within the school systems exclusively.

The perceived lack of safety and support that was discussed by study participants further highlighted the potential health inequities for immunosuppressed individuals and families. In order to assist in alleviating the stress and fear associated with community risks for immunosuppressed individuals and families, such as the potential of contracting communicable diseases and/or lack of appropriate cleanliness in community areas such as schools, the systemic barriers to health and safety need to be further assessed and ultimately addressed, in order to ensure that community spaces are more safe and accessible for everyone, including those who are medically vulnerable.

**Employment and Working Conditions**

Six study participants identified themes related to employment and working conditions. Maintaining work life balance can be extremely difficult for anyone at any given time, but when a family has a medically complex child this can become significantly more difficult. As discussed by the participants, families with medical complex children often cannot find appropriate childcare for their children due to the routine medical needs of the children that require knowledge and training, such as administering medications and tube feedings. If childcare is being provided outside of the family home with other children, such as a busy daycare facility, families must also ensure that this environment is clean and hygienic in order to
reduce the risks of their immunosuppressed child contracting a communicable illness.

Additionally, families must often stay home if their child is sick, as well as take time off in order to take their child to appointments with healthcare providers. This impacts the amount of time that parents and primary caregivers can allot to working outside of the home, which ultimately impacts the family income.

Research has shown that employers who are not supportive of employees with ill children negatively impact the family, in that they do not provide for the necessities of the employees, which are primarily flexible work arrangements and leave entitlements. This lack of benefits in turn causes an increase in stress and frustration for the employees and ultimately the families (George, Vickers, Wilkes, & Barton, 2008, p. 59). In regards to accommodating and positive employers, research has shown that supportive employment arrangements, such as flexible scheduling and supportive supervisors, had direct positive impacts on perceptions of control over work and family matters for the employees, and in turn positively impacted the families (Thomas & Ganster, 1995, p. 6). As identified by study participants, having a supportive employer can decrease the stress that is experienced by families during times of crisis. Additionally, having full (or close to full) wage compensation during the time of crisis, despite being away from work, was also identified as being beneficial by participants, as this decreased not only the stress but also the financial burden and resulting debt experienced by families.

**Income and Social Status**

Study participants spoke at length about the financial impacts of caring for an immunosuppressed child. In addition to the decreased ability for parents and caregivers to work outside of the home, many of the costs required for their children are not covered or subsidized by the government. Examples of additional out-of-pocket costs for families included: costs for
medications beyond what is covered, costs for travel (including food and accommodation) for required medical procedures (such as the transplant surgery), costs for additional medical supplies (such as what is required for the tube feedings), and additional costs associated with ensuring that the children have access to clean water (several participants only provide their children with distilled bottled water).

Negative impacts on financial resources places further stress and burden upon families who may already be fragile, which decreases other aspects of the social determinants of health, such as social supports and coping skills. For example, if families are having difficulties making enough money to cover all the required expenses, they may not have enough money to be able to afford extracurricular activities or attend social engagements with family and friends. Furthermore, if caregivers must work additional hours beyond fulltime to make up for these costs, this also negatively impacts the time that they are able to spend as a family. This translates to health inequity, as these are health related concerns that would likely be considered “unfair or unjust and modifiable” (Government of Canada, 2019). For instance, the costs of medication could potentially make this care inaccessible to families who do not benefit from programs like Pharmacare in Manitoba (due to high deductibles), and who cannot afford the medications for their children in provinces with inadequate government coverage, such as within Manitoba. Pharmacare is a program within Manitoba, and is defined by the Government of Manitoba as follows: “based on both your total family income and the amount you pay for eligible prescription drugs. The total family income is adjusted to include a spouse and the number of dependents, if applicable. Each year you are required to pay a portion of the cost of your eligible prescription drugs. This amount is your annual Pharmacare deductible. Pharmacare sets your deductible based on your adjusted family income” (Government of Manitoba, 2020). Although
the program does help families throughout the province, the families within the study identified that because they would not be considered as having a low income, their deductibles were far too high to be beneficial to them, and they continue to be negatively impacted by the high costs of the required medications.

Another example related to travel expenses that are not covered for families who have no other choice but to travel out of province to seek life-saving procedures, such as paediatric transplants, that are not performed in their province of origin. Should a family absolutely not be able to afford the additional financial expenses, this places barriers to care, and thus also increases health inequities. As per the Government of Manitoba, the following statement is made on the website regarding covering costs associated with out-of-province travel for required medical procedures: “if your out-of-province referral is approved, you may be reimbursed for reasonable transportation costs. Accommodations, meals, taxis, ambulance and other expenses are not covered” (Manitoba Health, 2020). As per the Government of Saskatchewan, in regards to out-of-province medical coverage, the following statement is made on the website: “certain services that the Ministry covers in Saskatchewan have been excluded from the reciprocal billing agreements. In such cases, the patient may be billed directly. If this happens, Saskatchewan will reimburse the patient at Saskatchewan rates for physician services and at agreed-upon rates for out-patient or hospital services. The cost of travel, accommodation and meals is not covered” (Saskatchewan Ministry of Health, 2020). Although Manitoba covers “reasonable transportation costs,” it is clear from these statements that the majority of costs for travelling outside of the province for critical medical care that is not available within either province are not covered.

Research focused on families with children who have been diagnosed with cancer has found that families incur considerable financial costs during the diagnostic, treatment, and
follow-up care periods, and the primary factors contributing to these costs are: “necessary travel, loss of income because of a reduction or termination of parental employment, out-of-pocket treatment expenses, and inability to draw on assistance programs to supplement or replace lost income” (Miedema et al., 2008, p. 173). All four of these factors were observed in the interviews with study participants: travel was necessary for each of the families because the paediatric transplants could not be facilitated within the province of origin due to a lack of resources; all families within the study reported a disruption to income and several participants reported having to reduce working hours outside of the home; many of the participants reported financial expenses associated with the illness and treatment; and families also reported that many of the expenses were not covered or subsidized by the government and thus they had to pay out-of-pocket for these expenses. All study participants discussed unavoidable negative financial impacts, which negatively impacted them during the crisis period and beyond.

**Social Supports and Coping Skills**

Study participants extensively discussed negative impacts to relationships and chronic stress. Negative impacts to relationships included: marital discord, impacts to relationships with the other children in the family, decreased ability to connect with natural supports (and potential risk for social isolation), and the loss of friendships. Chronic stress was noted to varying degrees across all areas of functioning and throughout all of the categories of the social determinants of health. As noted by the participants, the intervention of having counsellors and/or social workers involved and readily available (as well as free of charge) would also be helpful in decreasing the ongoing impacts of these concerns for the families.

Although the belief exists that children being born with a chronic illness universally negatively impacts a marriage, research has shown that this may be a falsity. A study found that
there was no impact to marital quality or perceived marital stability based exclusively on a child being born with a chronic illness, and identifies that the assumption that medically complex children would irreparably harm a marriage needs to be called into question (Eddy & Walker, 1999, p. 10). Additional research also found that there was no identifiable risk to marriage based solely on a child being born with chronic illness (Walker, Manion, Cloutier, & Johnson, 1992, p. 345). Thus, although these circumstances do place stress and strain upon a marriage, it appears that the existing assumptions have been challenged, and it has now been shown that it should not be assumed that this situation would automatically pose a risk to the marriage.

In regards to immunosuppressed families and childcare, research has shown that the supports available to families with children who have complex needs are at times not sufficient, and thus causes more stress for the families, as “the extent to which parents can care for their children’s health is largely determined, however, by their working conditions, including flexibility in duties, locations, and schedules, as well as other employer-provided benefits” (Schuster, Chung, & Vestal, 2011, p. 110). Currently, standard schools and daycares are likely not equipped to provide complex care to children who might require additional resources, including: access to physicians/nurse practitioners for consultation, clinical social workers, psychologists, nutritionists, dentists, or dental hygienists; with the addition of some (or all) of the aforementioned resources, these facilities could potentially provide a variety of routine preventive and minor acute or chronic care services; and access to these additional resources may result in the increased accessibility of these services to families, the alleviation of pressure on the medical system and the families, and likely also increase the abilities of the parents to work outside of the home (Schuster, Chung, & Vestal, 2011, p. 102). This would also be an additional resource for families to utilize to avoid trending towards mal-adaptation, as long-term care of
children with complex medical needs can continue to exhaust the resources that are available to families, which may leave them additionally vulnerable to crisis.

**Access to Health Services**

Accreditation Canada defines quality as: “the degree of excellence; the extent to which an organization meets clients’ needs and exceeds their expectations” (Accreditation Canada, 2020). Access to quality healthcare is an important part of wellness for those who have complex medical needs. High quality care, that is patient and family oriented, prioritizes specific values, including: “excellence in care delivery, ethical values, involvement, professionalism, value for money, cost of care, commitment to quality, and strategic thinking” (Carney, 2011, p. 523). Although several of the study participants identified that they found that the care that they received once returning home from the location in which the transplant procedure was conducted was inadequate, this may have been compounded by the reality that much of the finances and resources nationally would likely be pooled into facilities where these procedures are conducted, as opposed to every facility in the country. This would likely be considered part of the aforementioned characteristics of quality in healthcare, respecting the value for money in providing care. It appears that the primary concern reported by the participants was regarding the characteristic of accessibility and involvement in providing care, because a majority of the participants identified that they felt as though the teams within the province of origin were less involved and less accessible, which also indicates negative health inequity occurring.

Another concern that was raised by participants was a lack of support and care during transition points within the healthcare system. The transition points in care that were noted were the transition from hospital (in the area in which the transplant was conducted) to home (the province of origin), and the transition from the youth healthcare services to the adult healthcare
services. Transition points in care “have emerged as an important point of vulnerability in the health care system where medical errors and clinical deterioration can occur” (Josephson, p. 183, 2015). Research has found that in regards to transition points in care, and key root causes of failed transitions include: inadequate provider communication, substandard education of the patient and caregivers, decreased timely outpatient follow-up, failure to address comorbid chronic conditions, decreased community support, and inadequate access to care (Josephson, p. 183, 2015). Based on the experiences of the participant families, it appears that they experienced potential breakdowns in communication between providers, poor follow-up in outpatient services, a lack of community support, and difficulties accessing appropriate care and resources (one participant described that they felt as though they “fell through the cracks” of the medical system). Participants advocated for counsellors and/or social workers to be available and readily accessible, in order to support families through transitions and act as liaisons between the families and their multiple healthcare provider teams.

Culture

Studies have indicated that spirituality and religious beliefs may contribute positively to the ability to cope with stressors (Graham, Furr, Flowers, & Burke 2001; Krok, 2008). Spiritual care has also been emphasized as important within healthcare settings in order to care for the “body, mind, and spirit” of the patient holistically (Savel & Munro, 2014, p. 278). Five of the study participants noted that spirituality is of importance to them, including participation in organized religion and spiritual beliefs to varying degrees. For example, one participant reported being a spiritual person and spoke at length about these beliefs, and how her spirituality has been crucial to her coping journey. Another participant also described herself as being a spiritual person, but did not identify these beliefs as being a primary focus in her life, currently or during
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the crisis period. For the participants who identified that religion and spirituality are important factors within their lives, it appears that it has been positive. However, there was an exception of a participant that had questioned her faith during the crisis period and said that she had not necessarily drawn heavily from her faith since in terms of coping. She appeared to be fairly neutral on the subject of spirituality as a coping mechanism at the time of the interview. Another family explained that their church is important to them and also supportive, and their church community threw a fundraiser for them to help cover their medical costs. Hence, spirituality and religion may be a resource to decrease stress and increase coping for those who choose to utilize it, and may ultimately help move individuals who identify with spirituality and religion towards bon-adaptation during times of crisis.

Studies that suggest that religion and spirituality are associated with better outcomes in terms of psychological wellbeing have been challenged by additional research that shows that there is no correlation, and so it appears that the matter remains largely unsettled (Zuckerman, 2009, p. 956). Studies have shown that atheists cope similarly well, as compared to those with religious and spiritual beliefs (Wilkinson & Coleman, 2009). Research that has analyzed the coping skills of both groups ultimately found that both groups, regardless of their beliefs, were coping well, and identified that “a strong atheistic belief system can fulfil the same role as a strong religious belief system in providing support, explanation, consolation and inspiration” (Wilkinson & Coleman, 2009, p. 337).

Within this study, five participants identified with spirituality and religion, and the remaining three participants indicated that they are not spiritual in any way. All of the study participants were found to be coping well and none were in acute crisis at the times of the interviews. As per the experiences of the participants, it appears that there was no link to
spirituality and effective coping evident, as there were no notable differences between those who identified with spirituality as compared to those who did not.

**Education and Literacy**

The constant need for efforts to limit the contraction of diseases and the impacts of illness to immunosuppressed children in the community, such as within the school system, was a concern noted by all of the participants. Research focused on children who are immunosuppressed following liver transplantation has shown that the children missed school more often as compared to their peers who did not experience medical complexities (Asonuma et al., 1998; Gilmour et al., 2010). This research also found that the children who are immunosuppressed were involved in special education services more frequently, although fortunately the majority of the children were reported to have minimal impacts to their quality of life following the transplant and resulting long-term immunosuppression (Asonuma et al., 1998; Gilmour et al., 2010).

Regarding paediatric transplant recipients and school functioning, as per Sick Kids Hospital: “some transplant patients can be delayed in reaching developmental milestones because of the impact of the organ disease on their body and isolation from their peers,” and “long absences from school can make it difficult for a transplant patient to keep up with school work” (Sick Kids Hospital, 2016). Archival research found that children who are chronically ill missed substantially more school days, at an average of sixteen per school year, as compared to children who do not experience chronic illness, who missed an average of seven days per school year (Fowler, Johnson, & Atkinson, 1985, p. 683). Furthermore, children who suffered from spina bifida, sickle cell disease, or epilepsy, as well as children who were also experiencing low socioeconomic status, were at particular risk for difficulties at school (Fowler, Johnson, &
Atkinson, 1985, p. 683). Research has also found that school absences can lead to children who experience medical complexities feeling hopeless about the future, and can also leave medically complex children feeling depressed with low self-esteem (Sexson & Madan-Swain, 1995, p. 359). Additionally, “aspects of the illness or its treatment, the child's emotional response to the illness, prolonged absence, and learning problems” may negatively influence school functioning, such as medically complex children being less engaged in school as compared to their peers (Sexson & Madan-Swain, 1995, p. 359).

Although research focusing on specific ailments has been conducted and published, more recent statistics on overall chronic illness in children were not readily accessible within the context of peer-reviewed research, and so additional research in this area would likely be beneficial. All three of the participants who had children who are too young to be in school identified stress regarding the upcoming transition into the school system, and the remaining five participants with school age children reported difficulties in this transition as well as within the school system. Outside of homeschooling as an option, children will spend a considerable amount of their young lives within the physical environment of a school. Thus, guidelines developed by the school systems specific to immunosuppressed children, as well as an interdisciplinary cooperation between the schools and medical professionals, would likely be beneficial in ensuring that the needs of immunosuppressed children are taken into consideration and addressed in order to ensure that immunosuppressed children remain safe and healthy within this environment.

**Childhood Experiences**

One of the study participants disclosed significant concern that her child is developing post-traumatic stress disorder (PTSD) from the numerous procedures and ongoing required
medical tests (such as blood work). When explored with the other participants, none shared these concerns, and although some discussed that the tests were quite difficult when their children were very young, most indicated that their children are coping well now that they are older. The participant who reported the concerns related to PTSD was the parent of the youngest child within the study, and so it would likely be interesting to see how these concerns progressed as time went on.

Regarding children being potentially at risk of developing symptoms of PTSD following significant medical interventions, research has shown that experiencing acute and/or prolonged medical procedures can cause children to have symptoms ranging from distress to post-traumatic stress disorder (Marsac et al., 2014, p. 399). For transplant patients specifically, “post-traumatic stress symptoms are quite prevalent in transplant recipients, although full-scale posttraumatic stress disorder may not be that common” (Supelana et al., 2015, p. 23).

Play therapy has been noted in research as a means to help identify how children with medical complexities, as well as their siblings, experience and cope with medical concerns, and also to assist in processing the resulting stress (Nabors et al., 2013, p. 212). This concern was identified in the present study, as the participant who reported that she is concerned that her child is developing PTSD is seeking play therapy to help her child with any potential impacts from the medical procedures. Based on the available research this would likely be an effective intervention to assist her child as required, as well as to alleviate her own stress regarding how this may continue to impact him moving forward, and ultimately help the family to avoid moving towards a crisis state based on the stress and fear associated with ongoing medical procedures and required follow-up testing.
Also noted in the study was the fear and anxiety that parents experienced regarding their child’s health and prognosis. Two of the eight participants reported significant ongoing worry that their child’s illness would become terminal. Previous research on parents of children with complex medical needs has identified that these parents experienced higher rates of mental health concerns (such as anxiety and depression), as compared to parents with healthy children (Sick Kids Hospital, 2020). Research has also indicated that parents of chronically ill children may be at higher risk for mortality and cardiovascular diseases (Sick Kids Hospital, 2020). The recommendations identified were that parents should be screened for anxiety and mood disorders within the initial assessments, in order to offer early interventions and assistance as required (Sick Kids Hospital, 2020). These recommendations are congruent with the recommendations from the participants within the study, as many stressed the importance of ongoing family therapy throughout the process to foster family wellness and to prevent any adverse impacts to the mental health of the family.

**Race/Racism**

One participant identified concerns regarding race, as she stated that because her child is of a rich racial background, finding him an appropriate organ donor was challenging. As per the Gift of Life Donor Program, “although organs are not matched according to race/ethnicity, and people of different races frequently match one another, all individuals waiting for an organ transplant will have a better chance of receiving one if there are large numbers of donors from their racial/ethnic background. This is because compatible blood types and tissue markers - critical qualities for donor/recipient matching - are more likely to be found among members of the same ethnicity” (Gift of Life, 2020). To mitigate this concern, the Gift of Life Donor
Program identifies that an increase in diversity among organ donors would have the potential to increase the access to transplantation for everyone (Gift of Life, 2020).

**Family Stress Theory and the Double ABC-X Model**

Within the double ABC-X model, the crisis is treated as the precipitating event, and a post-crisis period of adjustment was added to the original model (the ABC-X model by Hill) in order to gauge how the family responds to the initial crisis but also to the events that follow (Smith & Hamon, 2017; Hill, 1943). There are three components within the double A factor. The first component is the initial stressor, which in this study was the child’s illness and resulting transplant procedure. The second component is the change in the family following the stressor, and the third component is the stress that is caused by attempting to cope with the initial stressor. For the families that participated in the study, this describes the impact to the family following the acute medically unstable period and the resulting stress, such as trying to rearrange their lives to accommodate lengthy hospital admissions that are required for their child. The double B within the model represents the new and existing resources that are used to address the initial stressor. Families in the study discussed using existing resources, such as natural supports and existing finances, as well as new resources acquired, such as teams of medical specialists and finances gained by fundraising, in order to address the stressor. The double C represents the perceptions and experiences of the family during the initial stressor, while utilizing their resources, and moving forward. The double X factor at the end of the model captures how the family is coping in the post-crisis stages, for example if they are coping well they would be considered to be in bon-adaptation, or if they are continuing to struggle they would be considered to be moving towards mal-adaptation. Participant families all appeared to have utilized their new
and existing resources effectively and were within a bon-adaptation state at the time of the interviews.

All families appeared to have temporarily been in an acute crisis at the beginning of the medically unstable period. However, the crisis did not progress to the point where it debilitated any of the family’s abilities to organize themselves in order to be able to cope with and manage the crisis, and thus they were able to adequately move through the stages of the model and ultimately reach bon-adaptation while avoiding a chronic crisis state. Many of the participants recommended that family counselling be made readily available to families to ease this process, which would also likely assist families in moving beyond the crisis and towards coping in a healthy way, especially families who may be vulnerable to trend towards mal-adaptation. For example, families who may be experiencing pre-existing family and/or marital discord may benefit from initial assessments and subsequent offerings of additional resources (such as family and/or couples counselling) to assist in managing the crisis period and to avoid trending towards mal-adaptation.

**Gender and Family Stress Theory**

In regards to gender and the family stress theory, it appears that all the families in the study navigated the situation successfully with the resources that they had available to them, and all participant families subsequently appeared to be within a state of bon-adaptation at the time of the study. However, one participant appeared stressed about her staying at home with the children, although she did not seem to be acutely in crisis as a result of the situation, and stated that as of recently she is now returning to work in the evenings. Other participants did not report any immediate stress and/or crisis under this category. This suggests that the families have indeed utilized their resources, and/or acquired additional resources (such as family members to
assist with childcare), in order to move away from mal-adaptation in this aspect of their experiences, and towards bon-adaptation. However, with children the situation is fluid, because as they grow their care needs change, and so these situations will likely ebb and flow in terms of stress and the utilization of resources as the families move forward.

The participant families who described the female caregiver staying home to provide care as opposed to the male caregiver also stated that they currently do not have any acute financial stress, and so it appears that finances may have been a factor in the decision for the mothers to remain at home with the children. One participant did not report any financial stress specifically, but did explain that she is currently transitioning back to work and cannot afford to attend university presently, which suggests that financial stress may still be impacting their lives and opportunities, to some extent. Although the division of working hours may have the potential to cause some level of marital discord within the pairings, no participant family indicated that they were experiencing any acute marital stress at the time of the interviews.

**Biology and Genetic Endowment and Family Stress Theory**

Although it appears that the families were all within a state of crisis in times of acute illness, these families also seem to be quite skilled at utilizing their available resources to avoid remaining in crisis. For example, a participant explained that her sister came with them when they had to travel out-of-province for treatment, in order to support them but also to help look after their other children. Another participant mentioned that her mother came from out-of-province to be with them for support during significantly acute stages of treatment, when they were not sure if their child would survive. A third family indicated not only the importance of their natural supports, but also of their church. They stated that their church has been very
supportive and even helped with fundraising to assist them with the financial implications of treatment.

When the topic of searching for answers to their children’s medical complexities was explored, none of the participant families identified that this is a significant focus for them currently. Some participants did discuss that initially they were focused on finding answers and essentially “a cure,” but as their journeys progressed the participants explained that their children’s health and the maintenance of their health was always their true primary focus, rather than finding a label and an absolute cure, as this was not feasible.

As all families did not discuss any serious stressors at the time of the interview, it can be inferred that they have all accessed the resources that they had available to them (such as their medical providers, as well as family and friends for support), as well as sought new resources (such as seeking additional information and referrals), in order to move through the double ABC-X model not only during the acute medical crisis period, but subsequently for additional serious illnesses, to regain homeostasis and to reach bon-adaptation.

**Healthy Behaviours and Family Stress Theory**

Although the required medical procedures for the children cause ongoing stress for families to varying degrees, all the families within the study continue to utilize their resources to move successfully through the stress to remain in bon-adaptation, as per family stress theory and the double ABC-X model. The resources that they identified having utilized included: family support, information and advice from medical providers, and making the medical appointments more fun (like going out for lunch afterwards). Based on the perception of the stressor, the families reported differing levels of stress associated with the medical interventions. For instance, one participant mentioned that the tests are very difficult for her child, and that she is
concerned that he will develop post-traumatic stress disorder (PTSD) resulting from the medical testing and surgeries. Alternatively, another study participant stated that she believes that the ongoing medical interventions made her child stronger, and she is not worried that her child has developed PTSD. A consistently reported observation from all the participants with older children was that as the children age they are able to tolerate the medical testing to a greater degree, as compared to when they were younger. For example, the participant family with the youngest immunosuppressed child in the study expressed a considerable amount of concern regarding the potential for the development of PTSD following medical treatments, and so these concerns may dissipate with time as he grows older.

Several participants identified that they believe that more access to mental health oriented supports (such as counselling) for immunosuppressed children and families would be beneficial. As per the family stress theory, in regards to moving through the double ABC-X model, this additional resource may assist families in maintaining coping, and to avoid mal-adaptation during the periods of extensive medical interventions that are required for the children when they are the most medically vulnerable. For instance, one specific intervention that was being explored by a participant was play therapy to help her child process all of the stress and potential trauma associated with the required procedures and medical testing.

**Physical Environments and Family Stress Theory**

Based on the experiences disclosed by the participants, it appears that the issue of vaccine hesitancy and the anti-vaccination movement adds to their chronic stress to varying degrees, as it increases their child’s risk of contracting preventable diseases that can have serious and potentially fatal outcomes for their immunosuppressed children. They navigate this stressor by using the information that is available to them to make decisions to help keep their child safe.
For example, many participants ask about vaccination histories of other children, as per the recommendations of their healthcare providers, and will not let their children play with other children if they are not vaccinated. Two participants also discussed instances of vaccine hesitancy within their own families which impacted their ability to spend time together. Several participants described that advocating for change regarding current vaccination policies is something that they engage in to feel helpful and empowered, and some even described this as a means of coping.

In regards to experiences disclosed by participants about safety in the community, such as within the school system, this too appears to add to the chronic stress, but families utilize resources such as the staff within the schools to help keep the children safe. They also depend on the staff to inform them of any potential risks such as an outbreak of illness. For example, three of the participants explained that the schools contacted them right away when there was a potential outbreak of chicken pox within the schools, and they kept their children home until it was safe for them to return.

In regards to concerns reported by participants about the current state of the organ donation registry in Canada, it appears that this stressor was acute during the waiting period for an organ, and remains something that every participant believes needs to be addressed, in order to increase the number of organs available, decrease wait times, and to ultimately save lives. The participants also discussed how changing the organ donation registry system would also save the healthcare system money and resources, such as decreasing the need for routine medical maintenance procedures (such as dialysis).

As per the family stress theory and the double ABC-X model, it again appears as though each family has utilized their resources (such as accessing new information, speaking to
healthcare providers about their concerns, and advocating for change) to address the aforementioned concerns in order to remain within the bon-adaptation stage, and to consequently avoid transitioning into mal-adaptation. However, the aforementioned stressors are likely causing undue stress for the families, as well as contributing to health inequity for immunosuppressed individuals and families, and thusly should be addressed ideally by systemic mitigation.

**Employment and Working Conditions and Family Stress Theory**

It appears that the participants who reported themes within this category all had supportive employment, and this assisted them in moving beyond the crisis period and into a bon-adaptive state. This is congruent with existing research that has cited the benefits of supportive employment for families facing medically complex crisis situations. The participants in the study also identified that being paid while on leave to address the crisis was incredibly helpful, and contributed to a decrease in stress and financial burden. Several of the participants identified that they were provided with full (or close to full) wages during their leaves of absence; one participant reported that this leave was a special leave granted at full pay, and other participants identified that they were subsidized by paid benefits (such as vacation and/or sick leave). Employment stress, financial stress, and subsequent debt can add to the risk of families trending towards a mal-adaptive state, as per the family stress theory and the double ABC-X model.

Many of the participants also discussed the need to take time off of work with little notice, such as having to stay home with their child if their child is sick. Additionally, participants discussed that taking time off of work was also frequently required in order to take their children to appointments with their medical care providers. Resources such as supportive employers, flexible hours, understanding the need for absences, and paid leaves can decrease this
risk for families, and help to maintain their ability to cope with the crisis effectively, in order to remain within a bon-adaptive state.

**Income and Social Status and Family Stress Theory**

Although the families within the study appeared to have pulled their resources together to manage the stressors in order to avoid entering a mal-adaptation state, some reported going significantly into debt. For example, one participant identified that the debt was around 70,000 dollars for their family. As a researcher with lived experience, I can attest to the fact that five years later we are still impacted by the debt we incurred resulting from not being able to work and needing to leave our province for a life-saving transplant. We were very close to filing for bankruptcy and losing all of our assets, including our home.

The resources that the participant families discussed in terms of addressing financial stress included: online crowd-source funding, fundraisers, and independent donations from family, friends, and the community (such as a church or school). As previously noted, families also stated that paid leave from work was beneficial to reduce financial stress as well.

The range of the reported incomes for the participants did vary notably, from low to high socioeconomic status. A reported high income for an individual family did not appear to prevent being impacted negatively by the incurrence of debt throughout the experience. For example, the two participant families with the highest reported incomes also explained that they struggled considerably financially at times. Those who reported lower incomes also reported being impacted financially, however they also explained that they were able to manage and are not impacted crucially long-term. However, what appeared to influence the experiences of financial impact significantly was the province in which the participants reside in. For example, Manitoba was reported to have far less opportunities for long-term coverage and financial assistance as
compared to Saskatchewan, in regards to medication coverage and expedited access to necessary supports and services. Participants residing in a province that was reported to have less available access to medical compensation and coverage did describe more financial stress, as compared to participants who reside in a province that was described to have adequate or excellent access to coverage, regardless of reported income. Although it is widely documented that lower socioeconomic status can result in a negative impact to health, and can be a contributor to health inequity, the dialogue provided by participants within this study based on their experiences also stresses the importance of locally accessible compensation and assistance opportunities in mitigating financial risk to families who are facing medical challenges.

Debt contributes to the risk of entering a crisis state in most circumstances, and has the capacity to pull families back towards crisis and mal-adaptation. Should the aforementioned financial stressors be addressed at the government level, it would likely assist families throughout the process to help them move towards bon-adaptation, as it would decrease the financial burden and subsequent debt in these circumstances by subsidizing medication, medical needs, and travel costs. All of the study participants discussed the need for the provincial governments of Canada to provide more funding to families who have to travel outside of their province of origin for medical care, and they recommended that accommodation, transportation, and food should be completely covered in these instances.

Although the eight study participants reported themes related to income and social status, including debt resulting from the process, it appears that all of the participant families have utilized their resources effectively in order to manage the crisis and remain within bon-adaptation, as per the family stress theory and the double ABC-X model. All participant families
reported that they were not in a state of acute crisis at the time of the interviews, and no participant identified that they are significantly impacted by debt at present.

Social Supports and Coping Skills and Family Stress Theory

Study participants discussed resources that they utilized that were essential to their coping, including: friends and family for support, making time to spend with their spouse (such as date nights), spending time together as a family, and taking time to engage in self-care alone (such as attending counselling, attending float spas, playing video games, and shopping). Other resources that were identified as beneficial to overall wellness and coping were community support (such as support and understanding from their children’s school), spirituality, access to consistent, accessible, and knowledgeable medical teams, and supportive employers.

Four out of the eight participants recommended family counselling to be more accessible and encouraged for families who have children with complex medical needs throughout the entire process. Four out of the eight participants also identified that they are currently actively engaged in counselling for various reasons, and find it to be beneficial. Family counselling is a form of psychotherapy that is typically delivered to the group of family members, with the goal of facilitating support and understanding (The Centre for Addiction and Mental Health, 2020). This type of therapy can be helpful in situations involving various types of stress and/or change, such as coping with illness and grief, and the benefits and outcomes of family counselling can include: “talk about each person's hopes, encourage everyone to talk about their experiences and listen to each other, clarify each person's beliefs, values, needs, hopes and assumptions so that everyone understands each other, help families stop blaming each other and begin exploring how everyone can work together to make positive changes, help people understand the impact of their words and behaviours on other members of the family, help families talk about the challenges
they're facing, [and] support families as they work through their own goals” (The Centre for Addiction and Mental Health, 2020).

Having the additional support of available counsellors and/or social workers would likely assist families in moving away from the potential risk of entering the mal-adaptation stage and towards the bon-adaptation stage following an acute crisis, based on the aforementioned benefits associated with the family counselling model. Although four study participants reported that they are currently accessing counselling, all eight participants advocated for more access to mental health and wellness supports for immunosuppressed individuals and families. All of the participant families appeared to utilize their available resources, and acquired new resources as required, in order to remain within a bon-adaptation stage post-crisis.

**Access to Health Services and Family Stress Theory**

The participant families within the study reported being involved with multiple care providers, such as primary care, home care, hospitals, and specialists. Several of the participants discussed difficulties that they encountered during transition points in care. Transition points in care occur when an individual transitions from one area of care to another, such as a discharge from an inpatient hospital admission to managing in community with outpatient supports. Transition points in care are important, “establishing smooth transitions between these areas of care are critical to managing chronic conditions so that they do not worsen, potentially leading to hospitalizations that might have been avoided” (Health Quality Ontario, 2020). Safe, high quality, patient oriented, and reliable care that is coordinated effectively, including: “the right drugs, monitoring, and timely access to services and procedures,” can considerably improve quality of life, decrease the risk of additional medical complications, as well as lessen the stress on families and the health care system (Health Quality Ontario, 2020).
Based on the reported experiences of the participants it would likely be beneficial to increase the support that is received by immunosuppressed families during the transition home from a lengthy inpatient hospital admission, and to increase the amount of long-term supports that are available to them within their province of origin. This intervention would ideally increase the amount of resources readily available to the families (such as extra support during transition points in care and more accessible specialists), and thus decrease stress and subsequently the risk of families trending towards mal-adaptation during these vulnerable times, as per the family stress theory and the double ABC-X model. Although all of the participants advocated for additional resources, they also all appeared to utilize their available resources throughout the process, in order to remain within a bon-adaptation stage post-crisis.

**Culture and Family Stress Theory**

No racial and/or cultural background information was collected in any form from the participants within this study. No participant within the study self-disclosed any racial or cultural background information for themselves. However, one participant did identify that her child has a rich racial background, including Indigenous heritage.

The theme that was the focus within the category of culture was spirituality and coping; five of the participants reported that they identified with spirituality to some extent. Based on the experiences of the participants, it appeared that spirituality and/or religion was identified by some as being supportive and beneficial to coping, whereas others identified that spirituality and/or religion is not something that they require or engage in to any extent. One participant explained that although she was a spiritual person at one time, she did not draw heavily upon spirituality during the crisis period, and this time in her life led her to question her faith.
Regardless of reported beliefs, all families appeared to be coping adequately, and none discussed being within a crisis period at the time that the interviews were conducted.

As per the family stress theory and the double ABC-X model, it appears that all of the individuals in the study, regardless of the reported presence or absence of spirituality, have utilized their resources in order to cope with the stressors that they have faced thus far, in order to remain within a state of bon-adaptation. Three of the eight participants spoke at considerable length about the importance of spirituality (organized and unorganized) in their lives, and all three also identified that spirituality was helpful within the coping process during the periods of acute crisis and beyond. Five participants answered the exploratory questions posed to them regarding the role of spirituality in their lives, but did not discuss spirituality independently at any point throughout the interviews.

**Education and Literacy and Family Stress Theory**

Based on the experiences disclosed by the participants, it is evident that the transition to school is a significant concern due to the children’s susceptibility to illness. The participants with young children who were not yet within the school system reported considerable stress regarding this upcoming transition. One participant family explained that because they work with small children and are aware of the lack of hygiene within the environments at times (such as young children not being able to understand that they have to cover their mouths when they have to cough), they are considering placing their child in a private school, which is likely not something that they would have considered if she was not immunosuppressed. Participants with older children reported difficulties within the transition to the school system, including worrying about hygiene within the school, having to strongly advocate for their child’s needs, and worrying about vaccine hesitancy and the potential resulting risk of contracting communicable diseases.
Research on chronically ill children transitioning to school stresses the importance of the following to assist in the successful facilitation of the transition: “home and family involvement that includes homebound instruction strategies, flexible school days, using differentiated instructional strategies, increasing child autonomy, and addressing affective issues” (Shaw & McCabe, 2007, p. 74). As per the family stress theory and the double ABC-X model, more resources to assist families with the transition into the school system, such as potential clinical medical professionals working as liaisons with the professionals within the school division to identify and support the needs of children with medical complexities, would likely be beneficial in reducing stress and fostering adaptation for the children and families. All of the families within this study appeared to be utilizing all available resources in order to remain within a bon-adaptation stage post-crisis.

**Childhood Experiences and Family Stress Theory**

Several of the study participants identified concerns related to childhood experiences for their immunosuppressed children. One participant reported significant concerns regarding her child developing PTSD symptoms in response to the medical procedures and the required routine medical testing that he has experienced. The other seven participants disclosed that they were not actively concerned about the potential for their child developing PTSD. Additionally, two of the participants spoke frequently throughout the interviews about their fears regarding their child potentially becoming terminally ill (he is medically stable currently). This was not discussed by the remaining six participants. None of the families appeared to be actively in crisis at the time of the interview, and all appeared to be utilizing their resources to navigate the stressors in a healthy and effective manner. Resources that were noted as being helpful were consultations with their
medical professionals (in order to develop a plan to address any mental health concerns) and counselling (in order to help manage lingering anxiety and ongoing negative intrusive thoughts).

As previously noted, families would likely benefit from early screening for any indications of anxiety and/or mood disorders, in order to offer assistance early to prevent additional decompensation (Sick Kids Hospital, 2020). Children should also be monitored for symptoms of mental health concerns, and resources should be offered as required in order to prevent these concerns from worsening (Sick Kids Hospital, 2020). As per the family stress theory and the double ABC-X model, these additional measures to ensure wellness would likely help to identify families that may be at risk of remaining in crisis, as well as individuals who are trending towards a mal-adaptive state, in order to provide resources and tailored interventions to foster overall wellness and effective coping.

**Race/Racism and Family Stress Theory**

One participant explained that her child’s rich racial background impacted the availability of a compatible organ that would lead to long-term success and decrease the risk of organ rejection, which increased their wait on the organ list and subsequent stress while in the acute crisis period. Although this participant mentioned that had they waited any longer for the transplant she was not sure her child would have survived, they ultimately got the call and his surgery was a success. She stated that her natural supports were very important to her coping at that time, and helped her immensely throughout the process. As per the family stress theory and the double ABC-X model, it appears that the family utilized their resources, such as assistance from natural supports, in order to navigate the crisis period effectively. The participant stated that they are not currently experiencing any acute stressors and/or crisis at the time of the interview, and so it appears that they have successfully moved into a bon-adaptation state.
Strengths and Limitations of the Study

A potential limitation of the study that has been considered was the choice to not interview the paediatric immunosuppressed individuals directly. This may have led to the adult caregivers miscommunicating or misinterpreting the experiences of the children and/or families, and may not have captured the experiences of the children accurately, which then misses an integral part of the family. The choice to not interview the children directly was made in regards to the ethical concerns of researching children as well as ensuring that all families could participate. For example, families with very young children, or children who are nonverbal, would have been excluded from participation if the study design included interviewing the children directly. Another risk that was considered was the potential for distress that the children may experience when discussing their experiences within the research process, as they were the direct recipients of the medical interventions. Children may not be able to articulate their needs to the extent that adults can, and so in order to avoid potentially re-traumatizing the children without the guarantee of sufficient clinical intervention, they were not included in the interview process.

Another potential limitation was that the participants were all similar in terms of educational backgrounds, in that they had all attended post-secondary education. However, the information regarding the type and duration of the post-secondary education was not collected, and so all post-secondary education (completed, not completed, college, or university) was counted as post-secondary education, which suggests that there remains potential for variation among participants. The participants were also diverse in regards to age, as well as socioeconomic status and number of children. Additional possible limitations were that there
were two fathers as compared to six mothers who participated in this study, and that this study was not longitudinal in design.

A notable strength of the study was that a study of this nature, focusing specifically on immunosuppression in paediatric individuals using a qualitative approach, was not found to have been conducted before. This makes this study possibly the first of its kind, and the outcome of this study will ideally open up a dialogue about immunosuppression as a condition, as opposed to immunosuppression being considered exclusively as a side effect following solid organ transplantation.

In conclusion, within this chapter I provided a discussion that explored the results of the study, situated the results within the previous research, as well as investigated how the results intersected with the family stress theory. Within this chapter I also explored the potential strengths and limitations of the study.
CHAPTER EIGHT

RECOMMENDATIONS AND IMPLICATIONS
Recommendations from the Participants

The patient narrative that is gathered within the approach of interpretative phenomenological analysis is important, as it provides insight into the experiences, perceptions, and recommendations of individuals and families within the medical system that may not otherwise be captured. In addition to the aforementioned primary concerns and resulting recommendations that were brought up by the participants throughout the interviews, the participants also offered tangible advice for families who may find themselves in this situation, and they urged that these recommendations be included in this study. There appeared to be an underlying sense of community and responsibility among the participants, and a genuine desire to help others by sharing their experiences, tips, and advice to make life easier for other immunosuppressed families.

Although these recommendations were discussed throughout the findings and the discussion sections within this study, as these recommendations were noted as being of utmost importance to include by all of the participants, they have also been presented within the following section in table format in order to ensure that they remain at the forefront, as this was a contribution and request directly from the participants.

The primary resources to assist with the entirety of the process that were recommended by study participants were counsellors and social workers. These resources would ideally be made readily available to families throughout the process, in order to provide support, additional resources, and therapeutic intervention for the entire family as required. This recommendation would also likely assist in the management of the concerns reported regarding what is required to maintain the health and wellness of the children who are immunosuppressed by the families daily. For example, social workers may be able to provide resources and also communicate with
the schools in order to advocate for what is required in keeping children who are immunosuppressed safe within the school system, as well as potentially provide information about how to apply for further subsidization of the required medications. Table Four (below) provides an overview of all the recommendations provided by the participants.

Table Four: Recommendations from Participants

<table>
<thead>
<tr>
<th>Recommendation</th>
<th>Number of Participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Call people the day of to ensure there are no illnesses before planned get-togethers.</td>
<td>1 (12.5%)</td>
</tr>
<tr>
<td>Medications should be fully covered.</td>
<td>8 (100%)</td>
</tr>
<tr>
<td>More support and resources for vaccinations are required.</td>
<td>8 (100%)</td>
</tr>
<tr>
<td>Changes need to be made to protect immunosuppressed children from risks of contracting communicable diseases.</td>
<td>8 (100%)</td>
</tr>
<tr>
<td>There should be an organ registry system that requires individuals to opt-out.</td>
<td>8 (100%)</td>
</tr>
<tr>
<td>You can use online support groups to acquire medical products for lower costs.</td>
<td>2 (25%)</td>
</tr>
<tr>
<td>You can use blended real food in feeding bags for children who are tube fed.</td>
<td>1 (12.5%)</td>
</tr>
<tr>
<td>More financial support should be provided to families.</td>
<td>4 (50%)</td>
</tr>
<tr>
<td>Support groups are helpful for both support and resources.</td>
<td>4 (50%)</td>
</tr>
<tr>
<td>Various agencies aimed at helping families in these circumstances are supportive.</td>
<td>5 (62.5%)</td>
</tr>
<tr>
<td>Manitoba should implement a system similar to that in Saskatchewan (no more than $25.00 per medication for children).</td>
<td>2 (25%)</td>
</tr>
<tr>
<td>Counselling should be readily available and free for families to prevent negative impacts to the family unit.</td>
<td>4 (50%)</td>
</tr>
<tr>
<td>Children should be monitored for signs of medical trauma and PTSD.</td>
<td>1 (12.5%)</td>
</tr>
<tr>
<td>Develop a phone tree to help with other children and responsibilities at home while waiting on the organ transplant list.</td>
<td>1 (12.5%)</td>
</tr>
<tr>
<td>Have a go-bag packed to be ready to attend hospital quickly while waiting on the organ transplant list.</td>
<td>1 (12.5%)</td>
</tr>
<tr>
<td>Give children their own school supplies and discourage sharing to prevent contraction of illness.</td>
<td>1 (12.5%)</td>
</tr>
<tr>
<td>Keep a medical file for the immunosuppressed child.</td>
<td>1 (12.5%)</td>
</tr>
</tbody>
</table>
Access to peer support would be helpful for families with immunosuppressed children. | 2 (25%)
---|---
EAs are helpful in protecting immunosuppressed children while they are at school. | 2 (25%)
Support groups for immunosuppressed older children and teenagers about making healthy choices would be beneficial. | 3 (37.5%)
Access to compensated food and parking for parents with children who are admitted to hospital. | 3 (37.5%)

The recommendations range from practical advice, such as developing a phone tree during the wait on a list for an organ to ensure that any responsibilities are covered once a call is received, to therapeutic interventions, such as family access to a family counsellor throughout the crisis period and beyond to reduce impacts to wellness. There were four recommendations that were universally agreed upon and recommended by all eight of the participants within the study: medications should be fully covered, more support and resources regarding vaccinations are required, changes need to be made to protect children who are immunosuppressed from risks of contracting communicable diseases, and there should be an organ registry system that requires individuals to opt-out as opposed to having to opt-in. The participants noted these recommendations as being the most crucial to addressing the stressors that are faced by immunosuppressed individuals. However, each recommendation on this list was made with enthusiasm and conviction with the hope that this might help an immunosuppressed family in various ways.

**Implications**

The implications of the study fall under two categories: implications to social policy and implications to healthcare policy specifically. In regards to implications concerning the current policies in place via the Government of Canada, based on the experiences and recommendations of the participants within this study, it would likely be beneficial for the federal government to
revisit current policies regarding the present state of the organ donation registry, and to consider moving towards the automatic opt-in organ registry system nationally, as this would save the lives of those currently waiting for transplant but would also likely reduce costs of required maintenance medical procedures, such as daily dialysis. Participants have also asked for more support and protection for immunosuppressed families in the current climate of anti-vaccination movements and vaccination hesitancy, as we are seeing a resurgence of preventable diseases, and children who are immunosuppressed are particularly at risk, as contracting these illnesses could be fatal.

In regards to implications concerning healthcare providers, based on the experiences and recommendations from study participants, it would likely be beneficial for the healthcare system to consider a more holistic approach to providing care and support to immunosuppressed families. This would involve taking into consideration what is required for each family in terms of resources and other supports, in order to assist the families in times of crisis, but to also assist in maintaining a healthy family baseline in regards to functioning, adaptation, and stress management. Asking each family questions during the initial assessment process that encompass aspects of the social determinants of health would likely provide clinicians with a more well-rounded understanding of what each family may require in order to be successful throughout the process. This can include an assessment of available resources such as finances, necessities of life (food, shelter, and clothing), psychosocial stressors, and natural supports. Referrals to help facilitate overall wellness for the family could include: social work, family counselling, financial counselling, dieticians, and other outside resources that are province specific, such as emergency shelters, respite, and free meal options. Table Five (below) outlines a potential framework for
practitioners to utilize in assessing the needs of families who are entering into a medical procedure that will result in their child incurring the condition of immunosuppression.

Table Five: Framework for Clinicians in Working with Immunosuppressed Families

<table>
<thead>
<tr>
<th>Area of Interest</th>
<th>Yes</th>
<th>Unsure</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Does the family have concerns currently involving debt?</td>
<td>• Refer to social work.</td>
<td>• Explore current financial concerns with the family.</td>
<td>• Reassess financial status with the family in 1 to 6 months from time of initial assessment.</td>
</tr>
<tr>
<td></td>
<td>• Provide with resources for free financial counselling.</td>
<td>• Determine with the family if referrals should be made now, or if they would prefer a reassessment.</td>
<td></td>
</tr>
<tr>
<td>Does the family currently have access to additional finances if required?</td>
<td>• Reassess financial status with the family in 1 to 6 months from time of initial assessment.</td>
<td>• Explore current financial resources with the family.</td>
<td>• Refer to social work.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Determine with the family if referrals should be made now, or if they would prefer a reassessment.</td>
<td>• Provide with resources for free financial counselling.</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>• Provide with resources on employment for additional income if appropriate.</td>
</tr>
<tr>
<td>Does the family have insurance coverage for medications?</td>
<td>• Reassess insurance benefits in regards to how much of the medication costs are covered in 1 to 6 months from time of initial assessment.</td>
<td>• Provide with numbers to contact their insurance providers.</td>
<td>• Refer to social work.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Encourage to contact their HR department at their place of employment.</td>
<td>• Provide with resources for additional medication coverage (province specific).</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Reassess after contact is made regarding the outcome.</td>
<td></td>
</tr>
<tr>
<td>Does the family have insurance coverage</td>
<td>• Reassess insurance benefits</td>
<td>• Provide with numbers to</td>
<td>• Refer to social work.</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Question</td>
<td>Actions</td>
<td></td>
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<td>------------------------------------------------------------------------</td>
<td>-------------------------------------------------------------------------</td>
<td></td>
<td></td>
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<tr>
<td>for other medical requirements if not otherwise covered (such as travel, medical devices, and special diets)?</td>
<td>in regards to how much of the medication costs are covered in 1 to 6 months from time of initial assessment. contact their insurance providers. Encourage to contact their HR department at their place of employment. Reassess after contact is made regarding the outcome. Provide with resources for funding agencies (nonprofit) or other government organizations that may be able to assist with coverage (province specific). Refer to dietician.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Does the family have any concerns regarding providing the necessities of life currently (such as food, shelter, and clothing)?</td>
<td>Refer to social work. Provide with resources on emergency family shelters, free food options, and free/discounted clothing options (all province specific). Refer to dietician. Explore current tangible resources with the family. Determine with the family if referrals should be made now, or if they would prefer a reassessment. Reassess the status of resources with the family in 1 to 6 months from time of initial assessment.</td>
<td></td>
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<tr>
<td>If the family has other young children, do they have support and assistance with childcare if required?</td>
<td>Reassess family status with the family in 1 to 6 months from time of initial assessment. Explore current childcare resources with the family. Determine with the family if referrals should be made now, or if they would prefer a reassessment. Refer to social work. Refer to family counselling. Provide with childcare and respite service resources (province specific).</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Is there any substantial family discord currently?</td>
<td>Refer to social work. Refer to family counselling. Provide with mental health and wellness service resources (province specific). Explore the current status of the family in regards to discord (marital or other). Determine with the family if referrals should be made now, or if they would Refer to social work. Refer to family counselling. Provide with childcare and respite service resources (province specific). Reassess family status with the family in 1 to 6 months from time of initial assessment.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Does the family have questions and/or concerns about their future as an immunosuppressed family?</td>
<td>Schedule additional appointments with the healthcare team as required.</td>
<td>Explore current experiences and perceptions of care and their future with the family.</td>
<td>Reassess family status with the family in 1 to 6 months from time of initial assessment.</td>
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<tr>
<td></td>
<td>Refer to family counselling.</td>
<td>Determine with the family if referrals should be made now, or if they would prefer a reassessment.</td>
<td>Provide the family with all the contact numbers for the healthcare team in order to stay accessible.</td>
</tr>
<tr>
<td>Does the family feel as though they have adequate natural supports?</td>
<td>Reassess family status with the family in 1 to 6 months from time of initial assessment.</td>
<td>Explore the current status of the family in regards natural supports as a resource.</td>
<td>Refer to social work.</td>
</tr>
<tr>
<td></td>
<td>Encourage them to contact their natural supports to update them to the situation.</td>
<td>Determine with the family if referrals should be made now, or if they would prefer a reassessment.</td>
<td>Refer to family counselling.</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Provide with childcare and respite service resources (province specific).</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Provide with support group contact information (province specific).</td>
</tr>
<tr>
<td>Do all members of the family have access to primary care currently (general practitioner)?</td>
<td>Reassess the status of the access to primary care with the family in 1 to 6 months from time of initial assessment.</td>
<td>Determine with the family if referrals should be made now, or if they would prefer a reassessment.</td>
<td>Provide with information about finding a general practitioner. Submit referrals if able and/or appropriate.</td>
</tr>
<tr>
<td>Does the family have any other concerns about their child that have not yet been addressed?</td>
<td>Explore the concerns with the family as soon as possible.</td>
<td>Explore current experiences and perceptions of care and their future with the family.</td>
<td>Reassess family status with the family in 1 to 6 months from time of initial assessment.</td>
</tr>
<tr>
<td></td>
<td>Schedule additional appointments</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
| Does the family require help speaking with the school division about keeping their child safe while at school? | • Refer to social work.  
• Refer to family counselling.  
• Provide with other resources and options regarding medical liaison services with the school division as able. | • Determine with the family if referrals should be made now, or if they would prefer a reassessment. | • Reassess family status with the family in 1 to 6 months from time of initial assessment.  
• Provide contact numbers for social work team in order to stay accessible. |
| Does the family have access to culturally appropriate and/or spiritual care if required? | • Reassess family status with the family in 1 to 6 months from time of initial assessment. | • Determine with the family if referrals should be made now, or if they would prefer a reassessment. | • Refer to social work.  
• Refer to spiritual care.  
• Provide with culturally appropriate mental health and wellness service resources (province specific). |

**Concluding Remarks**

There does not appear to be readily accessible research into the experiences of families with children who are immunosuppressed, and so the purpose of this study was to serve as a means of understanding their experiences and the essence of what it means to live as immunosuppressed through the conceptual exploration of the findings. Furthermore, this study was conceived as a means of exploring the stressors families with children who are immunosuppressed experience specific to the state of immunosuppression and the resulting
impacts of the condition on the functioning of the families. What was clear throughout the interviews was that all of the participant families were remarkably insightful and resilient, and also displayed a notable sense of community and a desire to help other immunosuppressed families in any way that they could. As a researcher with lived experience as an immunosuppressed family, the results and recommendations that were uncovered in this study echoed my own experiences, and the sentiment across the interviews was that more needs to be done at a systemic level to help protect children who are immunosuppressed, and to support immunosuppressed families. As this appears to be the first study of its kind, additional research into this phenomenon would likely be beneficial as a means of gaining a more thorough understanding of the experiences of immunosuppressed families, and to develop further recommendations to assist families. A preliminary framework was created in order to guide clinicians during the initial assessment of families entering into the transplant procedures to determine their current inventory of resources, their ability to access additional resources, and whether or not the family may be vulnerable to crisis and mal-adaptation. This will ideally serve as a means to provide more holistic care to families. This intervention may also decrease the amount of health inequity experienced by families, as the additional resources may decrease the negative impacts to the family functioning across all domains of the social determinants of health, and thus improve the family’s wellbeing, access to medications and necessities for medical travel, and perceptions of safety within the community. Moving forward, further research may assist in the development of supplementary interventions to the framework that was developed within this study, and/or additional interventions, that are targeted and effective in order to support and maintain the health and wellbeing of the individuals who are immunosuppressed and their families.
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Appendix

Question Guide for Interviews

The interviews will be primarily semi-structured, although interviewees will also be asked some closed-ended questions mainly for demographic information. Names will be acquired for reasons of identification and consent, but will not be used throughout the study.

General Information

The participants will be asked to provide their name, age, identified gender, city of residence, marital status, level of education, number of children, and identify their household socioeconomic status from a series of options (such as 0 – 20,000). The participants will then be asked to discuss the medical recommendations associated with immunosuppression that they engage with. Finally, they will be asked to describe their child’s health, and the overall health of their family. They will be asked to elaborate during subsequent questions.

Semi-Structured Interview

The participants will be asked several questions regarding health, the social determinants of health, and stress.

- Health related questions: the individuals will be asked about how healthy their child is, including how often they are sick, and how this impacts the family in terms of family wellness and stress. For example, if a child is sick and admitted to hospital frequently the individual will be asked about how this impacts the child and the rest of the family, and about how they cope with other stressors in addition to the stress resulting from the illness and/or admissions. They will also be asked about the health of other family members.
- Income and social status: the individuals will be asked if and/or how their income and overall socioeconomic status has been impacted since their child has become immunosuppressed. They will also be asked about how their socioeconomic status affects their ability to engage with the recommendations associated with immunosuppression. The individuals will be asked to discuss their stress levels regarding income and socioeconomic status, and how this has changed since they became an immunosuppressed family.

- Employment and working conditions: the individuals will be asked if and/or how their employment status has been impacted since their child has become immunosuppressed. They will also be asked about how their employment affects their ability to engage with the recommendations associated with immunosuppression. The individuals will be asked to discuss their stress levels regarding employment, and how this has changed since they became an immunosuppressed family.

- Education and literacy: the individuals will be asked if and/or how their education and the education of their children have been impacted since their child has become immunosuppressed. They will also be asked about how their education affects their engagement with the recommendations associated with immunosuppression and their abilities to communicate with the medical professionals. The individuals will be asked to discuss their stress levels regarding education, and how this has changed since they became an immunosuppressed family.

- Childhood experiences: the individuals will be asked if and/or how their own childhood experiences impact how they are able to manage currently, childhood trauma will not be
discussed in order to avoid re-traumatization. They will also be asked how they believe the experiences of their children will impact the children moving forward.

- Physical environments: the individuals will be asked if and/or how their physical environments impact how they are able to manage currently, such as their housing and their community. Whether they feel supported by their community and whether they feel as though the communities do enough to protect immunosuppressed individuals will be explored. They will also be asked about how their physical environment affects their ability to engage with the recommendations associated with immunosuppression. The individuals will be asked to discuss their stress levels regarding their physical environment, and how this has changed since they became an immunosuppressed family.

- Social supports and coping skills: the individuals will be asked to describe their social supports and coping skills. They will also be asked about how they manage acute and chronic stress, and how their social supports do or do not assist in the management of stress.

- Healthy behaviours: the individuals will be asked about their ability to maintain the health of their family collectively. The recommendations associated with immunosuppression may also be further explored, such as how their child reacts to the recommendations and if the recommendations cause any discord. They will also be asked about how their stress levels impact their ability to engage in self-care and relationship maintenance.

- Access to health services: the individuals will be asked to describe and critique their access to health care services. They will be asked about how services could change to better accommodate their needs, and if they feel that there are any specific interventions
that are missing or lacking based on their experiences. They will be asked about how
their child responds to services, if they feel supported by services, how they feel about
the dynamics between themselves and practitioners, and how their interactions with their
supports impact their stress.

- Biology and genetic endowment: the individuals will be asked about how they feel about
the condition that led to the need for transplantation. General information about the
condition leading to transplantation will be collected in this section, such as the name and
type of condition/disease, in order to better understand each case and the responses of
caregivers in each family. For example, if the condition is hereditary, how does this
impact biological caregivers?

- Gender and culture: gender and culture will be explored, in terms of how the social
determinants of health intersect with the identity of the families, and how this may
influence and frame family experiences. Potential feelings of disempowerment and
oppression and how this may impact interactions within the medical field and within
community will be discussed as applicable.