The Experience of Adolescent and Young Adult Transplant Recipients Transitioning to Adult-Focused Care: A Constructivist Grounded Theory

by

Angie Lim
BSc, University of Toronto, 2000
BScN, Toronto Metropolitan University, 2005
MN, Toronto Metropolitan University, 2009

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We acknowledge and respect the lək̓ʷəŋən peoples on whose traditional territory the university stands and the Songhees, Esquimalt and W̱SÁNEĆ peoples whose historical relationships with the land continue to this day.

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Supervisory Committee

Dr. Lenora Marcellus, Supervisor
School of Nursing

Dr. Vera Caine, Departmental Member
School of Nursing

Dr. Hilde Zitzelsberger, Outside Member
Faculty of Health Sciences, Ontario Tech University

Abstract

The healthcare transition for adolescent and young adult (AYA) organ transplant recipients is a critical yet understudied period, marked by a shift from pediatric to adult-focused care. This transition process presents unique challenges, including adherence to immunosuppressive regimens and addressing psychosocial factors that impact long-term graft survival and patient well-being. In this constructivist grounded theory (CGT) study I explored how AYA kidney and liver transplant recipients manage the transition process and identify how nurses and healthcare practitioners support psychosocial adaptation. Through in-depth interviews with transplant recipients, their families, and pediatric nurses, the study generated a substantive theory representative of AYA transplant recipients' experiences and adaptations during the transition process. The primary objective was to understand how AYAs prepare for and engage in the transition process. The secondary aim was to identify strategies for healthcare providers to support their psychosocial well-being. A CGT approach, grounded in symbolic interactionism and constructivism, was employed to systematically gather, synthesize, analyze, and conceptualize qualitative data, ultimately constructing a theory, *Riding the Wave of Change: Transforming Through Transition*, that captured the complexity of AYA transplant recipients' experiences. This study holds significant implications for nursing practice, as it fills a gap in the literature by addressing the underrepresentation of nursing voices in transition research. By generating a midrange substantive theory, the study enhances nursing knowledge on the transition experience and informs policymaking, practice, and research in the field of healthcare transitions for AYA organ transplant recipients. The findings provide valuable insights for pediatric and adult healthcare providers to better support AYA patients and their families during this critical period.

Keywords: healthcare transition; transplant; adolescent; young adult; grounded theory

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Acknowledgments

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Chapter One: Introduction

Solid-organ transplantation is an established therapeutic approach for end-stage, organ-specific diseases and prevails as a leading treatment for pediatric patients with organ failure (Bell & Sawyer, 2010; Fernandez & Foster, 2022; Katz et al., 2020; Kim & Marks, 2014; Mogul et al., 2018; Miloh et al., 2017; Ng et al., 2012; Wright et al., 2019); however, because transplantation is a chronic condition requiring ongoing monitoring, solid organ transplantation is a treatment modality, not a cure. Since the introduction of transplantation, the number of solid organ transplants performed worldwide has continued to increase (Bell & Sawyer, 2010; Black et al., 2018; Fernandez & Foster, 2022; Kim & Marks, 2014; Miloh et al., 2017; Ng et al., 2012). In Canada, pediatric transplant rates are considerable, with 1482 solid organ transplants performed between 2018 and 2021 (Canadian Institute for Health Information, 2019; 2020; 2021; 2022).

With continued advances in both the surgical and medical management of transplantation, the outcomes for pediatric transplant recipients have improved significantly (Bell & Sawyer, 2010; Burra, 2012; Ekong et al., 2019; Ghelichi-Ghojogh et al., 2022; Kim et al., 2020; Kim & Marks, 2014; Lerret & Stendahl, 2011; Miloh et al., 2017; Ng et al., 2012). For example, the five-year survival rates for liver and renal transplant recipients are estimated at around 90-96% (Black et al., 2018; Cuenca & Yeh, 2019; Ekong et al., 2019; Ghelichi-Ghojogh et al., 2022; Kassebaum et al., 2016; Miloh et al., 2017; Rana & Godfrey, 2019). In Canada, pediatric-focused healthcare systems provide transplantation care to patients 0-18 years of age, after which there is a transfer to adult-focused care. Thus, provided these improving survival rates, AYA transplant patients will eventually transition from pediatric to adult-focused care. Despite the success of transplantation as a treatment option, AYAs experience adverse outcomes during the transition period from pediatric to adult healthcare, with the most common and impactful effects being frequent emergency room visits, increased hospital admissions, graft failure, and death (Aujoulat, 2010; Burra, 2012; Cuenca & Yeh, 2019; Fernandez & Foster, 2022; Fredricks, 2010; Pankhurst et al., 2020; Prestidge et al., 2012; Rea et al., 2022; Wright et al., 2019). As AYA transplant recipients transition into adult-focused care, their adherence to treatment plans becomes increasingly crucial in managing the adverse outcomes of this period.

The concept of adherence is used to describe behavioural outcomes that are in alignment with the plan suggested by a healthcare team. The World Health Organization (WHO) defines adherence as "the degree to which the person's behaviour corresponds with the agreed recommendations from a health care provider" (2003, p. 3) and is often used interchangeably with other terms such as compliance and concordance. As will be unpacked in the next chapter, researchers use adherence in many ways with no agreed-upon definition (Aujoulat et al., 2010; Bissonnette, 2008; Gardner, 2015; Vrijens et al., 2012). There is also an ongoing critique of the paternalistic nature of the concept of adherence, that is underpinned by the assumption of maintaining or following medical treatment plans or orders (Fawcett, 2022), presenting a paradoxical challenge for transplant recipients with whom we aim to promote autonomy, independence, and self-management, yet adherence is essential for their survival.

Non-adherent behaviours in transplant recipients may include not taking medications as prescribed or missing follow-up medical appointments, thereby placing them at risk of rejection or graft loss (Cuenca & Yeh, 2019; Fernandez & Foster, 2022; Griva et al., 2018; Pankhurst et al., 2020; Wright et al., 2019). Non-adherent behaviours are common among AYA transplant recipients, with non-adherence rates almost four times higher in the pediatric transplant population when compared to adults (Burra et al., 2011; Cuenca & Yeh, 2019; Hammond et al., 2021; Pankhurst et al., 2020; Wright et al., 2019). Consequently, graft loss and mortality rates are highest in adolescent transplant recipients compared to all other pediatric transplant recipients and are considerably worse amongst adolescents and at the time of transition to adult care (Aujoulat, 2010; Burra, 2012; Cuenca & Yeh, 2019; Fernandes & Foster, 2022; Fredricks, 2010; Griva et al., 2018; Hammond et al., 2021; Pankhurst et al., 2020; Rea et al., 2022; Wright et al., 2019). Nevertheless, despite significant advancements in pediatric transplantation, the transition research to support the AYA population has not progressed at the same rate.

Given the propensity for non-adherent adolescent transplant recipients to require frequent hospital admissions for rejection treatment, many researchers have historically focused on non-adherence to post-transplant regimens rather than on this group's psychosocial and developmental needs. Although non-adherence significantly impacts the outcome of their transplanted organs and quality of life, there is a disproportionate focus on the physiological implications of non-adherence within the dominant discourse of transplant practitioners. Additionally, there has not been enough emphasis on the underlying psychosocial impact of the transition to support AYA's experiences to influence positive health outcomes. The focus of researchers has just recently begun to shift from patient outcome or graft survival rates to also reflect long-term considerations such as allograft health, immunosuppression complications, global functional and mental health, and overall quality-of-life (Amatya et al., 2020; Cuenca & Yeh, 2019; Ng et al., 2019).

Healthcare transition is the deliberate and intentional movement of AYAs with chronic medical and physical conditions from a pediatric-centred to an adult-oriented healthcare system (Blum et al., 1993; Kaufman & Pinzon, 2010; Toulany et al., 2022). This transition period signifies a critical period for AYA's developmental trajectory that may have significant and enduring implications, especially for those AYAs with chronic medical conditions (Calabrese et al., 2022; Cuenca & Yeh, 2019). Although there have been significant advancements in pediatric transplantation, the healthcare transition research to support this population has progressed slower. Additionally, limited research focuses on the broader implications for AYA transplant recipients and their families during the transition process, complicated further by the variability of transition assessment and the need for a theoretical transition model (Toulany et al., 2022), that will be discussed in more detail later. These gaps are problematic and concerning, given the psychological, social, and personal factors that arise from transplantation and transition, alongside the typical developmental changes experienced by AYAs during this time in their lives. In this study, I explore adolescents' and young adults' (AYA) experiences living with a solid organ transplant and the processes they used to adapt and transition to adult-focused care.

1.1 Statement of the Problem

The goal of organ transplantation is to restore health and function in transplant recipients; yet, to achieve this goal, adherence by patients is required to ensure long-term graft survival and function. Consequently, post-transplant life necessitates a sustained medical follow-up that includes regular clinic visits and bloodwork for rejection screening and immunosuppression monitoring (Burra, 2012; Cuenca & Yeh, 2019; Fernandes & Foster, 2022; Kim & Marks, 2014; Pankhurst et al., 2020; Papaz et al., 2018). Despite the improvements in patient survival, post-transplant life is complicated by the frequent experience of various side effects resulting from immunosuppressive drug therapy. These include growth delay, higher susceptibility to infection, possible malignancies, and cosmetic effects that may impact the daily life of patients and normative development that parallels adolescents with other chronic illnesses such as diabetes, cancer, or congenital cardiac conditions (Burra, 2012; Davis et al., 2014; Kim & Marks, 2014; Salto-Alejandre et al., 2021; Sanders-Pinheiro et al., 2018). As a result, despite the many advancements in transplantation, adolescent transplant recipients continue to experience poor graft survival, lower overall long-term success, and suboptimal patient survival when compared to other pediatric age groups (Aujoulat, 2010; Burra, 2012; Cuenca & Yeh, 2019; Fernandes & Foster, 2022; Fredricks, 2010; Pankhurst et al., 2020; Rea et al., 2022; Wright et al., 2019).

Given the increased number of pediatric organ transplants performed and the improved survival rates into adulthood, it is imperative to address the transition needs of this unique AYA population (Calabrese et al., 2020; Cuenca & Yeh, 2019; Lawrence et al., 2020; Pankhurst et al., 2020; Wright et al., 2019). A focus on transition has significant implications for patients and families. For example, Prestidge et al. (2012) found that 24% of patients who transferred to adult care without participating in a transition clinic at British Columbia Children's Hospital were estimated to experience either death or graft loss two years after the transfer. In contrast, none of these devastating outcomes was noted in those who had attended a transition clinic (Prestidge et al., 2012). Another significant consideration is the greater societal impact associated with healthcare costs of transplantation and poor outcomes. The per-patient price for renal transplant recipients in British Columbia who transferred to adult care without participation in a transition clinic in 2012 was $17,127–$38,909CAD, or $40,956–$61,470CAD for patients losing their graft and returning to dialysis, versus $11,380– $34,312CAD for those who attended a transition clinic (Prestidge et al., 2012). Rea et al. (2022) argue that transition to adult care does not guarantee adherence regardless of the opportunity to participate in a transition clinic. Thus, Rea et al. (2022) emphasize that transition success should be examined longitudinally with consideration to both interventions and support to maintain AYA's successful retention in adult healthcare following their transition.

1.2 Purpose of the Study

An exploration of the available research contributing to our understanding of patients' experiences, as detailed in Chapter Two, highlights a limited understanding of how a healthcare team can best support AYAs with the psychosocial impact of transplantation and transition. This exploration of the continued discourse regarding psychosocial considerations and transition underscores the importance of nursing research on the meaning of these experiences for AYA organ transplant recipients with an opportunity for nurses to demonstrate leadership in the healthcare transition field to support policymaking, practice, and research (Bailey et al., 2022; Bell et al., 2008; Betz, 2012; Hewitt-Taylor, 2008; Lerret & Stendhal, 2011; Toulany et al., 2020). Accordingly, a better understanding of AYA transplant recipients' transition to adult-focused healthcare will provide critical information for adult and pediatric healthcare providers alike so that we might better support patients and families.

In this study, I aim to understand how AYA transplant recipients manage the transition process to adult-focused care, developing a substantive theory representative of their experiences and adaptations. The overarching research question is: *How do adolescent and young adult kidney and liver transplant recipients manage the transition from pediatric to adult care?* The primary objective of this study is to determine how AYAs prepare for and engage in the transition process. The secondary aim is to identify how nurses and healthcare practitioners can support the psychosocial adaptation of AYA transplant recipients in their transition.

1.3 Personal Situatedness

It was my first-hand experience with my sister's transition to adult care in the congenital heart program that sparked my initial interest in this topic. The journey of my sister, navigating through the complexities of transition from pediatric to adult care, ignited a curiosity within me. My curiosity deepened as I embarked on my professional journey as a nurse, where I witnessed a strikingly similar narrative repeating across transplant recipients who were transitioning into adult care. I spent fifteen out of my last eighteen years in pediatric nursing on a pediatric multiorgan transplant unit. The experiences I encountered in those years were profound. Observing patients discontinuing their medications, coupled with signs of depression, social withdrawal, and the development of eating disorders, underscored the stark, deeply personal impact of the transition process. The ramifications of these challenges were severe, potentially leading to catastrophic outcomes such as graft loss and, in the most extreme cases, death.

These experiences, while challenging, intensified my dedication to exploring this phenomenon. This interest was furthered by anecdotal comments from adolescent transplant recipients and their families, driving home the urgency and importance of this topic. A recurring theme early in my exploration was their reluctance to leave the pediatric hospital; they felt anxious, afraid, and woefully unprepared for the journey ahead. This compelling narrative further inspired me to delve deeper into this critical juncture in the life of these young individuals. As I pursued my Master of Nursing my focus on transition solidified; I was privileged to collaborate and gain knowledge from McCurdy, a pioneering figure in the realm of transplant transition, where I supported the development and implementation of a Transition Orientation Day at a leading adult care centre. This partnership between adult and pediatric hospitals provided valuable insights into the real-world challenges and the inherent systemic issues faced by these individuals. These varied experiences, along with my enduring engagement at the local level in supporting transition-centric programs and maintaining regular connections with patients and their families, amplified my aspiration to explore more profoundly the experiences of AYA transplant recipients, serving as a catalyst for my pursuit of doctoral studies in this area.

1.4 Research Design

Building upon my personal journey and the resonating stories of adolescent transplant recipients, my decision to examine the healthcare transition of AYA transplant recipients using a constructivist grounded theory (CGT) approach was inevitable. CGT was employed as an inductive comparative methodology that provided systematic guidelines for gathering, synthesizing, analyzing, and conceptualizing qualitative data to construct a theory (Charmaz, 2000; 2006; 2014; Schreiber, 2001). This methodology is based on symbolic interactionism and constructivism, a perspective that suggests individuals use constructions developed from created realities to help make sense of their experiences and give meaning to events and phenomena through sustained and complex social interactions, that will be explored in more depth in Chapter Three (Charmaz, 2000; 2006; 2014).

CGT methodology is congruent with the aim of this study and was an appropriate approach to answering the research question. Constructivist GT emphasizes the need to understand the context of transplant recipients allowing for an understanding of their actions and experiences. This approach helped elucidate how AYAs managed their transition and the relationship between AYA transplant recipients, the healthcare environment, and the healthcare providers contributing to the transition experience.

The use of CGT to examine AYA transplant recipients' healthcare transition enabled the discovery of theoretically complete explanations, which in turn, led to the formulation of a logical, systematic, and explanatory GT of the population's experience (Charmaz, 2014). The use of GT allows researchers to capture and understand healthcare experiences, which is why it has a strong history of contributing to theory development and explanation in healthcare (Foley & Timonen, 2015). With my deeply rooted connection to nursing practice, engaging in a GT study offered an opportunity to enrich nursing knowledge of transition by generating a midrange substantive theory. The CGT methodology perfectly aligned with the aim of this study and proved an ideal approach to answering the research question, emphasizing the importance of understanding the context of transplant recipients and enabling a comprehensive understanding of their actions and experiences. This approach served as an invaluable tool in revealing how AYAs managed their transition and the multifaceted relationship between AYA transplant recipients, the healthcare environment, and the healthcare providers shaping the transition experience. Through this approach, I was able to illuminate a detailed and nuanced narrative of this significant transition, ultimately contributing to the evidence base and supporting improvements in transitional care.

1.5 Relevance to Nursing

Although there is a beginning shift in recent years with some increased attention related to AYA transplant recipients and their experience with transplantation, the dominant focus remains on the implications for self-management and adherence after transitioning to adult care, with the prevailing voices remaining those of physicians (e.g., Amatya et al., 2020; Anton et al., 2020; Burra, 2012; Cuenca & Yeh, 2019; De Pasquale et al., 2010; Fegran et al., 2014; Fernandez & Foster, 2022; Gabriel et al., 2017; Gokoel et al., 2020; Kim et al., 2020; Kim & Marks, 2014; Korus et al., 2011; Lawrence et al., 2020; Ng et al., 2019; Pai et al., 2011; Pankhurst et al., 2020; Samuel et al., 2011; Stevens et al., 2021; Sundaram et al., 2007; Wright et al., 2019). This focus results in limited knowledge about the developmental pathways that lead to outcomes, such as non-adherence or poor healthcare transitions, or the meaning of the experiences for AYAs as they transition. To shift the focus represents an increasing awareness that psychosocial factors may influence adherence and healthcare transition. Although an encouraging progression in knowledge development on the AYA transplant transition experience, the voice of nurses as key healthcare providers close to the experiences of the population is noticeably underrepresented within the existing research landscape (Betz, 2012; Ladores, 2015; Gabay & Tarabeih, 2022; Pape & Ernst, 2022; Raina et al., 2018).

Despite the dominant voice of physicians, likely due to the original focus on adherence and graft survival for adolescent transplant recipients, there are emerging nurse leaders in the transition domain. The work, as seen in the scholarship of Meleis et al. (2000), McCurdy et al. in 2006, Betz and colleagues (Betz, 2013; Betz et al., 2013; Betz et al., 2016), Lerret and Stendahll (2011), and Ladores (2015) demonstrates the critical role that nurses play in the research and support of transition care.

As a leading nursing scholar, Meleis first introduced the concept of transition to nursing in the 1960s, further developing a middle-range transition theory focused on the human experience, response, and consequences of transition on individuals' well-being. Similarly, Betz and colleagues have conducted several systematic reviews examining transition service models (Betz, 2003, 2008, 2009; Betz et al., 2016) and the transition needs of both parents and AYAs, specifically for AYAs with special healthcare needs (Betz et al., 2013; Betz et al., 2015). Betz (1996) was also an early contributor to the transition landscape, calling for nurses to lead in supporting adolescent transitions and continuing her call to action for nurses in 2003 and 2013. Comparably, Kaufman, now a retired pediatrician and adolescent health specialist, has roots in nursing and was a leading researcher in transition. Kaufman (2006) contributes to our understanding of the role of teenage development in AYA transition in collaboration with other healthcare team members, including nurses, physicians, psychologists, and social workers (Amaria et al., 2011).

More recently, through a critical review of the literature, Ladores' (2015) proposes a new working definition for healthcare transitions for AYA with chronic health conditions as "a potentially stressful and emotional process in which flexibility and negotiation between the patient, parents, pediatric health care providers, and adult health care providers are necessary to facilitate achievement of autonomous health-related decision-making and self-care within the adult health care setting" (p. e126), while also highlighting the vital role that nurses play in the areas of education, practice, policy, and research. Similarly, Doucet et al. (2022), Catena et al. (2018); Mackie et al. (2016), explore programs and recommendations for supporting pediatric healthcare transitions for patients with medical complexities, chronic illness, and congenital conditions. It is encouraging to see the work of these prominent nurse leaders in the field of transition research. With the increasing attention of the healthcare community toward healthy and successful transitions for AYA transplant recipients, nurses can continue to contribute to the discourse on psychosocial considerations, acting as leaders of research in this field and supporting AYAs as they transition to adult care.

1.6 Structure of the Dissertation

This dissertation consists of five chapters. In this first chapter, I present a brief overview of pediatric organ transplantation, non-adherence, and the challenges facing AYA transplant recipients as they transition into adult-focused healthcare, highlighting the significance of the problem. In Chapter Two, I provide an overview and conceptualization of developmental theories and the concepts of transition, solid organ transplantation, and adherence with a more comprehensive exploration of transition; I also discuss its relevance to nursing and the current literature to frame this research study. In Chapter Three, I discuss the key tenants of Grounded Theory (GT) methodology supported by the rationale for using GT methods for this study. In this discussion of GT, I provide a historical overview, philosophical underpinnings, and study details. I discuss the conceptual foundations that frame my approach to this research study, the constructivist approach used to explore the meaning of transition with participants, and the process for conducting this GT research study: recruitment and sampling, inclusion and exclusion criteria, data collection and analysis methods, ethical conduct of the research, dissemination of findings, and the limitations. In Chapter Four, I present the study findings, including a GT addressing how AYAs manage their transition experience into adult-focused care. In Chapter Five, I discuss the key findings of my study in the context of the extant literature, beginning with the discussion of how AYA transplant recipients manage their transition to adult-focused care with a summary of the study situated within the context of the existing research. Chapter Five concludes this dissertation with a discussion of the implications and recommendations based on the study results for nursing practice, healthcare organizations, research, and policy development, followed by concluding remarks about the study.

Chapter Two: Literature Review

In research studies that use constructivist grounded theory (CGT) methods, the literature review provides context enabling researchers to situate their study within existing researchers' work to enhance the robustness of research while recognizing that the researcher is an active part of the process (Charmaz, 2014). Remaining consistent with CGT methods, I acknowledge that I bring many years of experience as a registered nurse with a background in pediatric transplantation practice. In this literature review chapter, I explore, analyze, and critique selected conceptual and empirical works about adolescent and young adult (AYA) development, treatment adherence, and transition from pediatric to adult-focused care highlighting methodological limitations and study design implications to address gaps in our knowledge. This literature review helps to frame my dissertation research and identify key considerations that guided this study, allowing for an enhanced understanding of the meaning of transplant recipients' experiences as they transition into adult-focused care. The chapter concludes by discussing the study rationale and initial questions that guided this research in more depth.

2.1 Introduction to Adolescent and Young Adult Development

Adolescents are a unique group who are considered neither children nor adults, and undergo complex psychological, emotional, physical, and intellectual changes simultaneously with tasks of typical development (Alderman et al., 2019; Bell & Sawyer, 2010; Burra, 2012; Fegran et al., 2014; Fernandez & Foster, 2022; Lerret & Stendhal, 2011; Matsuda-Abedini et al., 2022; Sawicki et al., 2011, 2015). The transition into adulthood is a critical period in adolescence that, if not adequately achieved, can result in a failed transition to adult-focused care, whereby AYAs feel that they have not lived up to expectations or feel neither not heard nor seen (Fegran et al., 2014; Fernandez & Foster, 2022; Kim & Marks, 2014; Kranzler et al., 2019; Lerret & Stendahl, 2011). These feelings can lead to additional stress and negative health implications for transplant recipients, such as depression, increased admission rates, and non-adherence to treatment recommendations (Burra, 2012; Fegran et al., 2014; Kim & Marks, 2014; Raina et al., 2018). The transplant experience has physiological, psychological, and social impacts on AYA transplant recipients and their interactions with families, friends, and the healthcare team, which may impact their transition to adult care (Fegran et al., 2014; Kim & Marks, 2014; Lerret & Stendahl, 2011; Raina et al., 2018). Therefore, the psychosocial changes experienced by AYAs need to be acknowledged, considered, and incorporated into the nursing care of transplant recipients during their transition to adult care.

Accordingly, we should regard the goal of achieving healthy psychosocial adjustment, age-appropriate adaptive and social functioning, and successful healthcare transition with the same importance as graft function for AYA transplant recipients. In other words, it should not be considered a *good outcome* when a patient takes their medication and achieves satisfactory graft function but has poor psychological functioning. For example, it is concerning to think of AYA transplant recipients who are adherent and have functioning grafts as being successful if they are also excessively anxious, dependent, or unable to function successfully in social, academic, or occupational domains. These psychosocial manifestations result in difficulty transitioning to adulthood and to the adult healthcare system (Burra, 2012; Fegran et al., 2014; Kim & Marks, 2014; Lerret & Stendahl, 2011; Raina et al., 2018).

2.2 Developmental Theories

Defining the period of AYA is essential to understand the aspects of typical development that coincide with this unique group; researchers aim to understand ways to improve the healthcare transition for AYA transplant recipients. Several theories have emerged since the early 1900s to explain the changes occurring in AYA development, beginning with the biological view (Table 1), and may guide our understanding of how they construct themselves in a world that is constructing them (Broderick & Blewitt, 2019; Kroger, 2004).

Table 1

Theories of Adolescent and Young Adult Development

Developmental Task Emphasized	Primary Theorist	Year	Focus Area
Biological	G. S. Hall A. Gesell J. Tanner	1904 1925 1955	Focus of the period is physical and sexual development determined by genes and biology.
Psychological	S. Freud A. Freud	1920 1936	Focus on adolescence as a period of sexual excitement and anxiety.
Psychosocial	E. Erikson	1950/ 1963/ 1968	Focus is on personal identity and interpersonal attitudes; spans the entire lifespan with an emphasis on social contexts.
Cognitive	J. Piaget	1923	Focus is on formal operational thought; moving beyond concrete, actual experiences and beginning to think in logical and abstract terms.
Ecological (interaction between individual and environment)	U. Bronfenbrenner	1979	Focus is on the context in which adolescents develop; adolescents are influenced by family, peers, religion, schools, the media, community, and world events.
Behaviorism	J. Watson B. F. Skinner	1913 1938	Focus only on observable and quantifiable behaviors; all human behavior can be described in terms of environmental influences
Social Cognitive Learning	A. Bandura	1977	Focus is on the relationship between social and environmental factors and their influence on behavior. Children learn through modeling.
Cultural	M. Mead C. Gilligan	1960s 1994	Focus is on the culture in which the child grows up.
Psychosocial	J. Marcia	1993	Focus on normative conflict occurring in adolescence; the opposition between identity achievement and identify confusion. Four identity statuses: foreclosure, identity diffusion, moratorium, and identity achievement.
Emerging Adulthood	J. Arnett	2000	Focus is on increased independence from social rules and expectations.

Applying a developmental model in assessing an individual's needs can guide healthcare practitioners in organizing what is known about individuals and gaining insight on how to intervene (Broderick & Blewitt, 2019). To centre the understanding of AYA experience, I will focus on Erikson and Arnett’s developmental theories. Erikson's Theory of Psychosocial Development is one of the earliest examples of developmental contextualism, stressing the interaction between the individual and social context over time. This theory provides a psychosocial lens to development, capturing the importance of family, peers, and the healthcare team. From this approach, Erikson assumes that adolescence ends at age 18, after which individuals enter adulthood and pursue different life goals, such as establishing a family. Accordingly, Arnett’s Theory of Emerging Adulthood provides insight into the experience of AYAs, with particular attention to how they manage increased independence in the context of a solid organ transplant.

2.2.1 Erikson’s Theory of Human Development

Erikson's (1993) theory is one of psychosocial development in which he implies that each stage includes a critical period for essential psychological qualities of the self to emerge and strengthen to continue to develop and progress in the subsequent stages successfully. Erikson (1993) maintained that personality develops in a predetermined order through eight stages of psychosocial development, beginning during infancy and continuing throughout the lifespan, with early childhood representing a deeply critical period. The first five stages are achieved during youth from infancy to 18 years of age, and the last three stages throughout adulthood from age 18 until death. These stages include (1) Trust versus Basic Mistrust; (2) Autonomy versus Shame and Doubt; (3) Initiative versus Guilt; (4) Industry (Competence) versus Inferiority; (5) Identity versus Role Confusion; (6) Intimacy versus Isolation; (7) Generativity versus Stagnation; and (8) Ego Integrity versus Despair.

Within each stage, individuals may experience a psychological crisis because of their changing characteristics initiated by biological maturation or decline, cognitive changes, advancing or deteriorating motor skills, and the resultant changes in others' attitudes, behaviours, and expectations (Broderick & Blewitt, 2019; Erikson, 1993). The psychological crisis experienced during each stage may positively or negatively affect their personality development (Erikson, 1993). Thus, as per Erikson's theory, an individual's self-development is formed through interpretations of oneself about their experiences, context, and relationships with others, in addition to some innate elements (Broderick & Blewitt, 2019). Erikson suggests that society's assurances can mediate the inevitable challenges of childhood by providing some degree of safety, integrity, and individuality in which children's personalities can strengthen and mature (Broderick & Blewitt, 2019; Erikson, 1993). From Erikson's (1993) theory, we can see that the early years of childhood and adolescence are fundamental in building the foundations necessary to cope with the challenges of adulthood development.

These foundations may be significant for pediatric transplant recipients, as they sometimes experience separation from their caregivers while hospitalized; they also feel fear and pain from medical procedures and treatments. Medical experiences in childhood may challenge children's sense of trust toward others and society, as they may be under the care of strangers to whom they must surrender control of their bodies (Broderick & Blewitt, 2019; Erikson, 1993). Furthermore, this challenges their sense of control and competencies, as well as their sense of identity and self-perceptions (Broderick & Blewitt, 2019; Erikson, 1993). These events' psychological impacts and developmental disruptions can cause immediate or short-term traumatic responses to intrusive medical events. Ultimately, this experience may alter or interfere with their long-term healthy development of identity, autonomy, self-worth, socialization, attitudes, and adaptation to diverse situations and environments (Broderick & Blewitt, 2019; Erikson, 1993). Therefore, to understand how AYAs experience transition, the first five stages pertinent to psychosocial development will be primarily discussed and considered.

This balancing to support positive psychological development is representative of features common to all eight stages within Erikson's theory. Balancing each psychological crisis requires finding a point between positive and negative feelings, with the positive outweighing the negative. There is a need for sensitivity and responsiveness to an individual's needs by others to achieve this balance. We also see that the attitudes toward oneself and others emerge together, exemplified by the development of trust in others and the resulting confidence in oneself (Broderick & Blewitt, 2019). Ultimately, the successful resolution of a crisis at one stage helps facilitate the successful resolution of future crises. Conversely, unsuccessful resolution at an earlier stage may stall progress and make maladaptive behaviours more likely later in life for AYAs.

The stages that children deal with developmentally begins with Industry versus Inferiority and is experienced by children aged 6 to 12 years (Erikson, 1993). During this period, children develop a sense of industry or competence internalized through their capacity to meet society's expectations in achieving academic and social skills, influenced predominately by the social and educational demands of their school life (Broderick & Blewitt, 2019; Erikson, 1993). Conversely, children who experience repeated difficulties that interfere with their ability to acquire these skills successfully may feel as though they have not fulfilled society's expectations, resulting in feelings of an intense sense of inadequacy, inferiority, or lack of competence (Erikson, 1993). Children who are unsuccessful in developing healthy levels of trust, autonomy, and initiative in the previous psychosocial stages may subsequently experience challenges in creating an adequate sense of competency during this stage (Erikson, 1993). Conversely, a child with too much prominence on competency can develop difficulty accepting failures, resulting in challenges with self-regulation and adjustment (Erikson, 1993). Therefore, some failures are inevitable and necessary (Erikson, 1993). This stage is essential for healthcare providers to consider, as we can assist a patient that experiences challenges during this time by helping them to regain a sense of competence and confidence in themselves (Erikson, 1993).

The final stage of psychosocial development experienced during childhood is Identity versus Role Confusion (Erikson, 1993). During this stage, children between the ages of 12 to 20 enter adolescence and then progress to young adults as they move toward adulthood by consolidating their maturing physical and cognitive abilities and making choices about values and vocational goals (Broderick & Blewitt, 1993; Erikson, 1993). Based on social influences and interactions and the psychological challenges and strengths developed in the previous psychosocial stages, AYAs in this stage begin to reassess who they are, thereby forming a sense of identity and fidelity (Broderick & Blewitt, 2019; Erikson, 1993). The self-exploration during this time is facilitated mainly by social interactions with peers and gaining social responsibilities such as employment (Erikson, 1993). Through continued attempts to re-evaluate the self and consolidate their experiences, successful AYAs will develop a healthy sense of self and identity, understanding their societal roles and intimate relationships (Erikson, 1993). Therefore, a healthy balance between a sense of self, role, and direction must be achieved during this stage to result in the long-lasting positive qualities of identity and fidelity (Broderick & Blewitt, 2019; Erikson, 1993). Conversely, AYAs with past adverse experiences or who did not achieve the developmental tasks of previous stages will result in role confusion and an inability to establish a sense of self (Broderick & Blewitt, 2019; Erikson, 1993). Furthermore, an impaired sense of identity at this stage of maturity will most likely persist into adulthood, posing maladjustment issues (Erikson, 1993).

Although psychosocial development continues into adulthood, as presented by Erikson's last three stages of development, earlier childhood experiences and interactions with caregivers and society significantly influence an individual's emotional and behavioural adjustment to the responsibilities of adulthood (Broderick & Blewitt, 2019; Erikson, 1993). In other words, when an individual has developed trust, autonomy, initiative, competency, and identity through the previous stages of psychosocial development, the demands of adulthood are more easily met, thereby attaining the psychological resources to adjust and cope with the inevitable challenges of life (Erikson, 1993). For example, as adolescents enter the sixth stage, Intimacy versus Isolation, young adults work toward achieving love through a willingness to share their identity with others and commit to affiliations and partnerships (Broderick & Blewitt, 2019; Erikson, 1993). However, achieving positive adjustment in previous stages is necessary for success;

failing to accomplish this stage results in distancing from others and a fear of intimacy (Broderick & Blewitt, 2019; Erikson, 1993).

2.2.2 Critique of Erikson's Theory of Human Developmental

Despite the broad uptake of cognitive approaches to development, some researchers and practitioners debate their usefulness, critiquing developmental theories, such as Erikson's, for excluding emotional and cognitive development. Another critique of Erikson's developmental approach is that it is mainly limited to developmental stages without adequate attention to personal traits or motivation. Price and Patton (2003) expand this critique of Erikson's theory as an overly simplistic conceptualization of universal human experience presented in a linear, progressive, and unidirectional manner, which does not hold universally for all people. This view extends the well-established feminist critique of Birns (1999) and Caffarella (1993) that purport that the voices and experiences of women, racial and ethnic minorities, and those with lower socioeconomic status are ignored and regarded as inferior within traditional developmental models. Further critiques of stage theories emphasize that the 'universal' definition equates to a definition representative of the Western, Caucasian male from middle-class industrialized countries rather than inclusive of a diversity of developmental experiences (Smart 2011). Jordan and Tseris (2018) bolster these early critiques to highlight the ableist connotations within such models by labelling characteristics as abnormal or unhealthy within the biomedical paradigm of disability.

Given these challenges, theorists proposed new developmental approaches to address these domains. Thus, despite the predominant focus that permeates the literature from the 1980s and 1990s, adolescence is no longer believed to be a period of storm and stress defined by problem behaviours such as conflict with parents, mood disruptions, and risky behaviours, as described initially by Hall in 1904 (Arnett, 1999; Broderick & Blewitt, 2019; Steinberg & Morris, 2001). Instead, contemporary adolescent development theorists emphasize understanding the diversity of adolescents and view adolescence as a period of continued development, especially regarding cognitive, physical, social, and emotional functioning and interpersonal relationships, recognized within the ecological, social cognitive learning, and culture.

2.2.3 Arnett's Theory of Emerging Adulthood

An alternative contemporary approach to conceptualizing development is the work of Arnett (1999, 2000, 2015), who describes the period of *Emerging Adulthood* as the transition from 18-25 years old. Arnett's theory builds from prior identity development models while extending them significantly. Identity is a critical component of adolescent development (Arnett, 2000, 2006; Erikson, 1992). Specifically, identity exploration is the extent to which an individual explores their feelings or experiences before reaching adulthood, which Arnett (2006) describes as the experiences that are the basis for all life decisions. This view is aligned closely with Erikson's identity development models. Arnett (1999, 2000, 2015) proposes the term Emerging Adulthood, which he defines as the distinct period between the teens and twenties, specifically between 18 to 25 years of age, with an accepted and prolonged independent role exploration, usually in Western industrialized societies.

The transition from adolescence to young adulthood is a distinct and unique developmental period that Arnett (1999, 2000, 2015) contends should be conceptualized distinctly from adolescence and full adulthood due to life's many facets and variability. *Emerging adulthood* begins after high school completion, marked by increased independence from social rules and expectations (Arnett, 1999, 2000, 2015). Typically, emerging adulthood marks the first time individuals can self-govern, for example, living independently. Whereas Erikson identified the negativity and instability that may result when young people fail to successfully navigate critical stages of identity development, Arnett contends that these experiences are a normative part of identity development during this crucial period.

Emerging adulthood also involves exploring romantic relationships and an optimistic view of the future, including educational and vocational opportunities (Arnett, 1999, 2000, 2015; Broderick & Blewitt, 2019). Specifically, the five distinct features that characterize the age of emerging adulthood are identity exploration in areas of relationships and work; instability underpinned by changes in residence, jobs, and relationships; the development of self-reliance required for adulthood; the experience of ambivalence in describing themselves as an adult; and perceiving a variety of available life choices (Arnett, 2000, 2006, 2015; Broderick & Blewitt, 2019). However, while earlier theorists tend to focus on a few critical tasks for successful movement through stages of identity development, Arnett (2006) characterized several dimensions along which individuals might differ during emerging adulthood without stressing specific accomplishments for successful navigation during this developmental transition.

Arnett (2006) further characterizes emerging adulthood as a period of freedom and *self-focus*, whereby emerging adults move toward other-focus, assuming more adult social roles, such as marriage and full-time employment (Arnett, 2006; Broderick & Blewitt, 2019). This shift of Erikson's intimacy versus isolation stage is characterized by a time of identity exploration. As a result, the thought is that emerging adults wait longer to marry, have children, and become employed because they are busy sensation-seeking and gaining multiple experiences before assuming adult roles and responsibilities (Arnett, 1999, 2000, 2015; Broderick & Blewitt, 2019). Consequently, the behaviours typically associated with sensation-seeking and gaining experiences are also associated with risky behaviours, such as engaging in unprotected sex, substance use, or driving at high speeds or while intoxicated (Arnett, 1999, 2000, 2015; Broderick & Blewitt, 2019).

Although typically associated with a positive trajectory, AYAs may experience disappointment in achieving goals during emerging adulthood, potentially leading to depression (Arnett, 1999, 2000, 2015; Broderick & Blewitt, 2019). Arnett submits that emerging adults report a feeling of not entirely being an adult but also not wholly being an adolescent, an element of identity development referred to as *feeling in-between* (Arnett, 2000; Broderick & Blewitt, 2019). Arnett (2000) describes the qualities most critical to these feelings as challenges related to accepting self-responsibility, making independent decisions, and becoming financially independent. Unique to Arnett's theory is the concept of existing between adolescence and adulthood, which captures the struggle to commit to adult roles and is also reflected by emerging adulthood in the experience of young adults who have fewer restrictions than in adolescence, but with increasing responsibilities as an emerging adult (Arnett, 1999, 2000, 2015; Broderick & Blewitt, 2019).

2.2.4 Critique of Arnett's Theory of Emerging Adulthood

Although Arnett's theory of emerging adulthood is considered helpful in highlighting the impact on youth transitions influenced by technology and globalization, Bynner (2005) argues it has limited application given the dependence on the period between graduation from high school and continuing education and employment opportunities. Arnett (2000) contends that this theory is only relevant to those in industrialized societies who have the economic means for a prolonged adjustment to adulthood. Others maintain that although this may hold for young adults of higher socioeconomic status (SES), for example, in higher education, it is only sometimes valid for those of lower SES (Bynner, 2005; Hendry & Kloep, 2010). In other words, emerging adulthood is more representative for those of upper and middle classes of Westernized societies, in which there are societal pressures of postponed adulthood to pursue higher educational or occupational careers, but less so for individuals of lower SES (Bynner, 2005; Hendry & Kloep, 2010).

2.3 Developmental Considerations for Adolescent and Young Adult Transplant Recipients

When critical psychological advancements are disrupted during childhood, as is often the case in chronic illness or transplantation, individuals are at higher risk for psychological challenges that negatively impact their healthy psychosocial growth into adulthood. If these challenges remain unresolved or untreated, AYAs are at increased risk of developing negative and maladaptive psychological consequences such as anxiety, mood imbalances, distorted self-concepts, social dysfunctions, and other mental health challenges that persist into adulthood

(Erikson, 1993). However, suppose an adverse or distressing circumstance arises for an individual at any stage of development. In that case, they may experience a disruption or regression of the positive and healthy psychological gains developed in earlier stages (Erikson, 1993). For example, AYA organ transplant recipients may experience a disruption in trust and autonomy previously resolved in Stages 1 and 2 as they cope with their illness and the transition to adult-focused care while simultaneously trying to resolve the challenges of Identity versus Role Confusion in Stage 5, and intimacy versus isolation in Stage 6. This experience is an important consideration that helps frame the significance of the transition period for transplant recipients and the vital role nurses hold in responding to the needs of AYAs during this period.

Considering emerging adulthood in the context of healthcare transition for transplant recipients, the risk-taking and sensation-seeking behaviours may be problematic because their transplanted organ and immunosuppressive medications place them at higher risk and susceptibility to illness. For example, the unintended outcome of unprotected sex may be a sexually transmitted infection, increasing morbidity for an immunosuppressed individual. Moreover, fewer responsibilities and expectations may jeopardize AYA transplant recipients' successful transition to adult care because they may struggle with assuming self-care responsibilities and adhering to their post-transplant medical regime.

This view of emerging adulthood is broadly accepted amongst scholars as an appropriate lens to use when discussing older adolescents and young adults, as seen in the uptake and use of the term in the literature (Bell et al., 2008; Bell & Sawyer, 2010; Betz et al., 2013; Betz et al., 2015; Betz et al., 2016; Bomba et al., 2016; Gorter et al., 2011; McDonagh & Kelly, 2010). For example, McDonagh and Kelly (2010) and Bell and Sawyer (2010) suggest that emerging adulthood helps describe many young people with special healthcare needs because they tend to experience challenges in achieving typical milestones and tasks of adulthood. Through this research study, insights into the transition experience to understand better how to meet AYAs' needs, support positive feelings toward self and others, and, ultimately, the transition process are gained. Accordingly, I consider a psychosocial development perspective to examine and help understand the experience that transplantation and transition can present for AYAs' psychological and psychosocial development.

2.4 Conceptualizing Development Within This Research Study

It is clear that the developmental focus has shifted over the years. Nevertheless, there is yet to be a general theory of normative AYA development, nor one that is widely accepted. Therefore, I support Steinberg and Morris (2001) in that all aspects of the multiple theories remain relevant. Consequently, when working with AYAs emerging into adulthood, we must consider all aspects of their development. Considering various aspects of development is essential because each element plays a role in their development process and may impact AYA transplant recipients' transition to adult care.

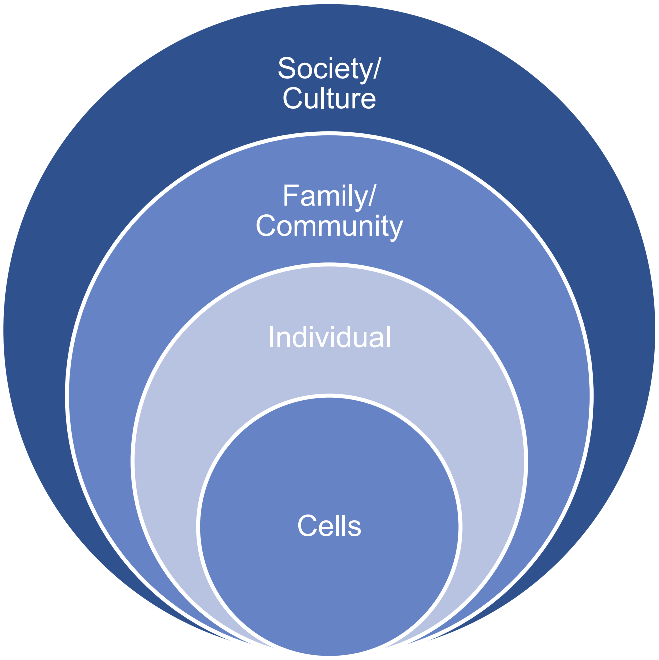
Therefore, it was also important to consider age terminology to understand the development of AYAs to ensure that I captured the target population within this study. Although the typical description of the adolescent period encompasses the ages 12 to 18 years by Erikson, there is some overlap with the developmental period described as young adulthood (18-25 years) and emerging adulthood (18-25 years). However, there needs to be a standard or universal definition or description regarding age terminology that researchers consistently use within the literature. Instead, there is the frequent interchangeable use of the terms *teen, teenager*, *adolescent*, and *youth* to refer to the life stage between 13 and 18 years of age and before discharge from pediatric healthcare services. However, the term youth is also used synonymously with young adults and often refers to the stage before achieving full adulthood. Thus, despite the terms young adult and adolescent sometimes being used interchangeably by many authors, for this research study, I use the term *adolescent and young adult (AYA)* to capture both Erikson's adolescent developmental stage and Arnett's well-respected work.

2.5 Adolescent and Young Adult Development in the Transplant Recipient

To further understand the conceptualization of human development, I delve into the contextual implications of the environment and relationships with family, peers, and the healthcare team to help frame the study of the effects of transition on AYA transplant recipients. The construct of development is inherently relational, embodying the organized, successive, multilevel, and integrated systemic changes across an individual's life course (Lerner, 2001). Bronfenbrenner (1977), for instance, in his ecological systems theory, underscores the pertinence of the interplay between micro and macro influences on human development. Yet, the understanding of these influences necessitates further exploration, particularly with respect to the balancing of various influences and their intertwined complexities. Antonucci and Webster (2014) offer a visual representation of these multilevel influences of human development, wherein each level mutually influences the others, as illustrated in Figure 1, which with each group characterizing a critical aspect of development.

Figure 1

Linking the Micro to the Macro Multiple Levels of Influence



This representation is commendable in its ambition to encompass a holistic view of development, yet its consideration of cellular and molecular functioning as a part of the greater environmental influences, such as the healthcare setting, might run the risk of oversimplification. The crux of their argument is that growth and development are not unidirectional or fixed (Antonucci & Webster, 2014), a standpoint that echoes contemporary thought. This insight underscores that relationships significantly influence development, particularly salient for AYA transplant recipients, whose interactions with family, peers, nurses, and other healthcare members constitute key elements in their development. However, further research is warranted to better understand these dynamics and their implications on the developmental trajectory.

Additional elements such as the transplant recipients' environment, sexual orientation, and gender identity are potential factors that may influence the transition to adult care. This viewpoint necessitates further examination, as it may oversimplify the intricate dynamics of identity development and the transition experience, potentially marginalizing or overshadowing other equally significant aspects of their lived experiences. Hence, an expanded, nuanced, and context-sensitive lens is warranted to more holistically understand and represent the multifaceted nature of human development.

2.5.1 Environmental Impacts on Development

Frequent hospital admissions or changes from the pediatric to adult healthcare environment may affect AYA transplant recipients' development. Specifically, McCurdy et al. (2006) highlight the significance of the hospital environment and suggest that the transition process for pediatric transplant recipients can be challenging and traumatic, characterized by feelings of sadness, fear, shock, and reluctance to leave the familiar pediatric centre. Furthermore, this provides an understanding that AYAs' experiences do not happen in isolation and must consider other vital indicators, specifically parental and healthcare provider involvement and broader social, contextual, and environmental factors. For example, the maternal level of education extends beyond SES, and Oswald et al. (2013) hypothesize that mothers with lower levels of education are less able to educate their children with healthcare system information to help facilitate their successful transition to adult care.

Similarly, without receiving proper and adequate preventative healthcare in childhood, AYAs are less likely to seek preventive care in adulthood and through the transition, may form a weaker AYA link to the adult system at the time of transfer. However, studies conducted in the context of an American healthcare system may not hold relevance for Canadian AYAs; although many aspects of the work in other countries, such as Oswald et al. (2013), expand our understanding of healthcare environments and transition, several contextual, political, and economic differences between countries may impact the experiences of AYAs with chronic health conditions.

In considering normative AYA development for program and policy planning, it is essential to consider this group individually and within broader contexts. For example, considering AYAs in the context of their family, peers, school, neighbourhood, and healthcare providers enrich our understanding of AYA transplant recipients' transition to adult care. The implication of environmental contexts and stressors as AYAs move from the pediatric to an adult-focused healthcare centre are also important considerations as they may impact their development and transition experience (Antonucci & Webster, 2014). By considering environmental context and valuing all aspects of development, researchers ensure that transition planning is systematic and integrated across all elements of AYAs' healthcare access points, beginning at the time of diagnosis.

2.5.2 Sexual Orientation and Gender Identity and Developmental Impacts

The terms gender and sex are often used interchangeably by scholars within the literature, thereby demonstrating a lack of consistency between the use of the terms (Bottorff et al., 2012; Rioux et al., 2020). *Gender* is commonly accepted as a social construct that impacts many determinants of health and intersects with culturally defined experiences of femininity and masculinity and emerges in various individual health practices (Bottorff et al., 2012; Kaur, 2015; Marmot, 2014; Mauvais-Jarvis et al., 2020; Reisner et al., 2015; Rioux et al., 2020). As such, gender is equally important as biological sex when considering health and understanding the impact and influences that gender has on the behaviours of patients, families, healthcare practitioners, and communities (Bottorff et al., 2012; Kaur, 2015; Marmot, 2014; Mauvais-Jarvis et al., 2020; Reisner et al., 2015; Rioux et al., 2020). *Sex,* often envisioned as a binary biological construct, differs significantly from gender, wherein a person is assigned as either male or female at birth (Bottorff et al., 2012; Mauvais-Jarvis et al., 2020; Rioux et al., 2020). The term *cisgender* (or cis) is an adjective for people whose gender identity corresponds with their assigned sex at birth (Rioux et al., 2020). In contrast, *transgender* (or trans) is an adjective describing people whose gender identity does not align with their assigned sex at birth (Mauvais-Jarvis et al., 2020; Rioux et al., 2020). Although the term gender is underpinned by an understanding of a multiplicity and fluidity of masculine or feminine traits that may coexist and be expressed by individuals to varying degrees (Mauvais-Jarvis et al., 2020; Rioux et al., 2020), Rioux et al. (2020) refer to *gender modality* as more inclusive terminology to refer to an individual’s experience of gender in relation to their assigned sex at birth. Thus, gender modality includes, but is not limited to, cisgender and transgender realities.

Attention to gender modality in research is an important consideration and one recognized by the Government of Canada. In 2021, the Canadian Census evolved to address the gap in gender diversity by revising the question on sex to capture ‘at birth’ and adding a question on gender to capture cisgender, transgender, and non-binary options, reflecting societal changes (Statistics Canada, 2022). The results from the 2021 Canadian Census further illuminate the significance of attending to gender, with 1 in 300 above 15 years and 1 in 100 between 20-24 years being non-binary or transgender (Statistics Canada, 2022). A closer look at the AYA demographic shows that 0.79% of Generation Z (born between 1997 and 2006) identify as transgender or non-binary (Statistics Canada, 2022). This data accompanies

Canada's social and legislative changes, acknowledging transgender, non-binary, and LGBTQ2+ in general, thereby increasing the recognition and probable comfort for younger generations to report gender (Statistics Canada, 2022).

The social aspects of gender can also influence biological processes and sex, rendering one's sexuality variable and not necessarily fixed and congruent (Bottorff et al., 2012; Kaur, 2015; Mauvais-Jarvis et al., 2020; Reisner et al., 2015). Thus, in the context of organ transplantation, AYAs' experience includes coping with abrupt bodily changes while simultaneously managing sexual interests and forming new kinds of relationships (Perry & Pauletti, 2011). An added consideration related to sex and gender for AYAs with chronic illness is the delayed onset of puberty (Kaufman et al., 2010; Lerret & Stendahl, 2011; Schaefer, 2007). Because this may impact the development of sexual identity and act as an additional stressor, healthcare professionals should be aware and address this; however, our knowledge about this issue and its impacts on AYA transplant recipients is limited. Exploring gender modality experiences and how they may impact the ways AYA transplant recipients negotiate relationships will aid the healthcare team in understanding how patients meet challenges introduced by sex and gender and the transition to adult care (Perry & Pauletti, 2011; Reisner et al., 2015).

Another aspect to consider is that of sexual identity, which constitutes a complex and multifarious construct that encompasses various dimensions, such as an individual's sexual orientation, preferences, behaviours, and attractions, which collectively contribute to the formation of one's overall self-concept (Harvey et al., 2020). As a critical element of personal identity, sexual identity profoundly impacts myriad aspects of an individual's intrapersonal and interpersonal experiences. The intricate process of sexual identity development and understanding is inherently dynamic and subject to the influences of various biological, psychological, social, and cultural determinants (Harvey et al., 2020). In scholarly discourse, sexual identity is recognized as an amalgamation of multiple components, including sexual orientation, which refers to a persistent pattern of emotional, romantic, and/or sexual attraction towards individuals of the same gender, different gender, both genders or none at all (Harvey et al., 2020; Suen et al., 2020; Zhang et al., 2020). This encompasses diverse orientations, such as heterosexuality, homosexuality, bisexuality, and asexuality (Harvey et al., 2020).

Furthermore, the process of sexual identity development is significantly influenced by the individual's sociocultural milieu, which comprises various aspects, including societal norms, values, beliefs, and expectations. Exploring and understanding sexual identity necessitates comprehensively examining the interplay between these multifaceted determinants (Suen et al., 2020). Recent research in psychology and related disciplines have underscored the importance of adopting an intersectional approach to studying sexual identity (Harvey et al., 2020; Suen et al., 2020; Zhang et al., 2020). This entails acknowledging and analyzing how diverse aspects of an individual's identity, including gender, race, ethnicity, and socio-economic status, intersect with and inform their sexual identity. Such an approach enables a more nuanced understanding of individuals' challenges and opportunities as they navigate the complexities of sexual identity development in the contemporary sociocultural landscape (Suen et al., 2020).

The extant scholarship on the intersections of gender identity, sexual orientation, and healthcare transition is limited, save the work of Sawicki et al. (2011) and Van Staa et al. (2008), who highlight gender differences and identify higher self-advocacy skills in adolescent females and higher self-reported readiness for transition in adolescent males, respectively. However, within these studies, participant gender modality was not discussed as gender diversity was not commonly addressed during that period, but rather progress in these areas has occurred within the last decade (Rioux et al., 2020). Similarly, Oswald et al. (2013) identify sex and gender as essential determinants for a successful transition for youth with special healthcare needs in an American context, but like Sawicki et al. (2011), gender modalities are not addressed in their survey that identified AYA females are more likely to successfully transition to adult healthcare than males (Oswald et al., 2013). Oswald et al. (2013) conclude that research is needed to understand how gender influences AYA transplant recipients' relationships with nurses and the healthcare team and the subsequent impact on transition. This finding is consistent with other researchers who identify gender differences as affecting the transition to adult healthcare. However, it is crucial to problematize this perspective; it is not only about acknowledging gender differences in a binary sense, but also about capturing the complexities of gender diversity modalities. This omission in current research necessitates a more critically nuanced and inclusive approach to account for the entire gender spectrum and its potential effects on healthcare transition experiences. Thus, I suggest that this should include gender diversity modalities as well.

Another consideration is the gender of the healthcare team member and AYA, which may impact not only the relationships and experiences of the patient in transition but also how AYAs meet the challenges of gender and negotiate their sex and gender into adulthood. Bottorff et al. (2012) recommend that future study considerations reflect gender (socio-cultural), biological (sex) factors, and gender relations that may impact health and illness. Mauvais-Jarvis et al. (2020) highlight that gender relations or how people interact or are treated by others based on their ascribed gender, as well as institutionalized gender associated with power distribution between males and females in social institutions, may influence health differently than biological sex. Consequently, patients may receive different responses, care, or interventions based on triggered responses from healthcare practitioners due to their gender modality. Sex and gender are linked intricately to the transition process and the care relationship forged between the patient, nurse, and healthcare team. Thus, considering these questions, sex and gender are biological and social factors that may influence the nursing care of AYAs living with solid organ transplants, in which a diverse population of transplant recipients, healthcare practitioners, and family caregiver participants help understand gender in the posed questions.

2.5.3 Cognitive Development and Transplantation

Adolescence and emerging adulthood represent phases of profound cognitive metamorphosis, including the transition from concrete to increasingly nuanced abstract cognition (Kaufman, 2006; Yurgelun-Todd, 2007). This prevailing narrative portrays AYAs as having fixed perceptions without the ability to appreciate variations in situations or concepts (Kaufman, 2006). However, this depiction warrants critical reflection, as it risks reductive interpretation and a deterministic perspective of the cognitive abilities of adolescents and young adults. Concrete thinking characterizes AYAs' difficulty in identifying common themes and the tendency to generalize rules to changing conditions (Kaufman, 2006). In the development of abstract thinking, AYAs move toward improved organization, decision-making, planning, and response inhibition (Yurgelun-Todd, 2007). While this developmental trajectory appears well-supported, it arguably risks oversimplification, potentially diminishing the dynamic cognitive diversity among individuals within these age brackets. This conventional understanding is buttressed by neurobiological research employing magnetic resonance imaging (MRI) as a tool, signifying that substantial structural-developmental changes transpire in the brain during AYA (Choudhury et al., 2006; Yurgelun-Todd, 2007). The prevailing consensus among developmental psychologists is that these structural-developmental modifications influence AYAs' abstract reasoning and processing speed abilities, engendering shifts in attention (Yurgelun-Todd, 2007).

Adolescents and young adults with chronic illness may also experience the complicated development of abstract reasoning skills due to potential developmental delays from adolescence and young adulthood to adulthood. As AYAs are still developing their abstract thinking, a typical cognitive-developmental limitation for this group is a lack of appreciation of the long-term consequences of their current actions. Additionally, transplant recipients may be at higher risk for psychosocial development and autonomy delays, achieving these milestones later (Bell et al., 2008). Thus, despite understanding their underlying illness and transplant treatment regimes, subtle variations in their daily routines or medical needs may lead to confusion and result in treatment non-adherence (Kaufman, 2006). For example, although AYAs know that immunosuppressive medications must be taken daily at the same time, without developing abstract reasoning skills, they may decide to skip the dose entirely if they sleep past the dose time rather than taking it late when they awake.

With an awareness of intra-individual development, we can better understand how individuals develop over time across cognitive, social, and emotional domains throughout their life course (Antonucci & Webster, 2014). For example, individuals develop from a fundamental level to a more complex and advanced level over time (Antonucci & Webster, 2014). Nevertheless, AYA development extends beyond individuals with a discernible influence from their social network and the broader community. Each interaction influences their development, including those with parents, siblings, family members, friends, neighbours, teachers, and coworkers (Antonucci & Webster, 2014). This social network includes their healthcare teams for transplant recipients, beginning with the pediatric team and then transitioning to the adult-focused care team. This extended social network reinforces the finding that all aspects of development are significant, thereby illustrating why multiple developmental theories exist rather than one overarching general theory of development. Therefore, cognitive development for AYA transplant recipients as they transition to adult-oriented care and self-management is an important consideration to help guide healthcare providers' support for this population.

2.5.4 Social and Emotional Development

Adolescents and young adults undergo regular emotional changes that impact their emotional capacity, thereby improving their affective modulation and discrimination of emotional cues (Yurgelun-Todd, 2007). Emotional changes often present through the relationships developed with family members, peers, and healthcare teams in the case of AYAs with chronic illness. Social and emotional development are essential aspects of healthy growth and ageing, guiding children to achieve a degree of personal autonomy in a context of dependence on their parents (Molinari et al., 2010). Through this process, AYAs gradually increase their autonomy while still seeking to maintain bonds with their parents (Molinari et al., 2010).

Adolescents and young adults who perceive excellent communication and a strong bond with an adult are less likely to engage in risky behaviours (Lerret & Stendahl, 2011; Resnick et al., 1997). Similarly, psychosocial factors, such as insufficient family support, denial, and low self-awareness, may impact AYA transplant recipients, specifically adherence, with other crucial associations identified between personal and family characteristics, family support, and AYA development (Beal et al., 2016; Feinstein et al., 2005; Fruggeri, 2010; Lerret & Stendahl, 2011; Yurgelun-Todd, 2007). AYAs often grapple with anxiety and denial as they realize that their chronic illness sets them apart from their peers; despite continued attempts at normalization, denial is a defence mechanism against anxiety and depression and is associated with self-destructive behaviour (Feinstein et al., 2005). Ergo, the study by Feinstein et al. (2005) indeed offers valuable understanding the potential hinderances impacting the transition experiences of AYAs. Yet, this examination requires a more comprehensive critique, considering the potential interplay of a multitude of other psychosocial factors that might also be integral to their transition journey. The significance of social and emotional development for a successful healthcare transition in AYA transplant recipients is indisputable. However, the current literature often constrains these domains to the individual level, potentially oversimplifying the complexity of the developmental process. The roles of family, nursing staff, and the healthcare team need to be considered as paramount within these domains of development, not as external agents, but as actively involved participants in the construction and negotiation of these developmental pathways. In essence, the current research provides a valuable foundation for understanding the AYAs' experiences, yet it necessitates a more nuanced and integrated approach that considers the multidimensional nature of their transition experiences. An expanded critique that considers the dynamic interplay of individual, interpersonal, and institutional factors could serve to illuminate the intricate realities faced by AYA transplant recipients.

2.5.5 Relationships with Nurses and the Healthcare Team

Developing trusting and supportive relationships with nurses and the healthcare team is essential in developing independence, self-management, and adherence for AYAs with chronic health conditions (Betz, 2021; Disabato et al., 2019; Lerret et al., 2015; 2017; Lerret & Stendahl, 2011; Rieger et al., 2019). In the transition protocol presented by Rieger et al. (2019) for renal transplant recipients, a structured multidisciplinary approach that includes nurses is imperative to enhance graft function during this critical period. Within their protocol, Rieger et al. (2019) outline the role of the transplant nurse in providing education and support to patients and families, but also encourage and build personal responsibility for AYAs. Lerret and Stendahl (2011) underpin that communication between the family, nurses, and the healthcare team is essential in supporting patient health and the quality-of-life post-transplant. Adolescents and young adults must believe their feelings are heard and respected, as the relationship between AYA transplant recipients, families, nurses, and healthcare team members are significant (Lerret & Stendahl, 2011). Although this assertion is undoubtedly valid, the current conceptualization of communication could be critiqued for its potential lack of depth. The study seemingly offers a unidirectional perspective, focusing on the transmission of information rather than the co-construction of meaning through relational engagement. Moreover, the emphasis on the need for AYAs to feel that their feelings are acknowledged and respected within their relationships with transplant recipients, families, nurses, and healthcare team members (Lerret & Stendahl, 2011) is indeed a significant consideration. However, a more critical lens might question the balance of power within these relationships and interrogate whose voices are privileged in these interactions.

Echoing this perspective, Lerret et al. (2017) reflect on the care of children post-transplant, suggesting that nurses are best positioned to support their transition through their ability to anticipate and understand their complex care needs. This viewpoint could be critiqued for its potential implicit reinforcement of traditional hierarchies within healthcare settings. While nurses undeniably play a crucial role, it is essential to critically interrogate the systemic structures that may perpetuate the disempowerment of patients and families in their own healthcare journeys. Thus, a more nuanced understanding that elevates patient autonomy and agency is warranted.

The study conducted by Korus et al. (2011) using a qualitative descriptive design and phenomenological inquiry rooted in focus groups from a Canadian perspective exposes significant stressors for AYA kidney transplant recipients stemming from communication breakdowns with the healthcare team. Thus, Korus et al. (2011) reinforce the importance of the relationship between AYAs and the healthcare team, finding that AYAs cope with the stress of transplantation by gaining knowledge and developing meaningful social support. The healthcare team, specifically nurses, supports adolescent knowledge needs by providing information and emotional and instrumental support, knowledge development, patient autonomy, and self-management throughout the transplantation and transition continuum (Betz, 2021; Korus et al., 2011). Korus et al. (2011) expanded the scope of the focus groups and the study rigour by using multiple data sources, conducting two focus groups with adolescents, two with parents, and one with healthcare professionals. This work underscores the importance of the relationship between nurses and the healthcare team to support optimal psychosocial functioning for AYA transplant recipients as they adjust to post-transplant life and transition to adult-focused care (Korus et al., 2011). However, the inherent power dynamics within these relationships and their potential to influence the authenticity of shared experiences need further interrogation. The emphasis on the role of nurses and the healthcare team in facilitating optimal psychosocial functioning for AYA transplant recipients post-transition underscores a caregiver-centric model, potentially obscuring the agency and resilience of the AYAs themselves.

Betz (2021) suggests that this dynamic presents an opportunity for nurse scientists and expert clinicians to innovate and advance healthcare transition research and practice. Specifically, Betz (2021) identifies abundant opportunities for pediatric and adult nurses to collaborate to identify and implement novel approaches to advance new models of care. Although a laudable proposition, this may present a potential for over-reliance on expert-driven solutions. Expanding this perspective to include patient-led initiatives and co-design principles could enrich the understanding and development of novel care models. Essentially, while the current research is informative, it also beckons a shift towards more inclusive, power-sharing, and collaborative approaches.

Rutishauser et al. (2011) delve into the psychological complexities adolescents with chronic health conditions and their parents confront, focusing primarily on anxiety and the perception of inadequate information. However, adopting a critical perspective, the study's emphasis on feelings of comfort with the pediatrician, anxiety, and perceived lack of information can be questioned for potentially reducing these complex dynamics to linear cause-and-effect relationships. A more nuanced understanding might consider the co-construction of these experiences within a network of socio-cultural, institutional, and interpersonal contexts. Additionally, while the research's non-disease-specific focus on preferences regarding the timing and setting of the transition to adult healthcare services provides valuable insights, it arguably underemphasizes the highly individualized nature of these preferences. A critique might call for a more family-centred approach, recognizing the diversity of AYA experiences and values rather than attempting to standardize an optimal transition protocol.

Rutishauser et al.'s (2011) recognition of the critical roles of social support, family and peer relationships, and environmental contexts in AYA development aligns with broader developmental theories. Still, the conceptualization of these factors could be critiqued for its potential overemphasis on the adaptive capabilities of AYAs. A more holistic view might explore the systemic barriers and facilitators that influence these dynamics, foregrounding the shared responsibility of healthcare providers in creating supportive environments. The portrayal of transition as a departure from familiar supports to an unfamiliar environment with a new healthcare team underscores the stressors inherent in the process. However, this narrative might be critiqued for potentially pathologizing the transition process, emphasizing its challenges over the potential opportunities for growth and development. A strength-based perspective might illuminate the resilience and agency of AYAs in navigating these transitions, offering a more balanced view of the experience.

The centrality of nurses in supporting patients through transition has been established and well-articulated through the work of Meleis since the 1960s; however, the role of nurses in supporting AYAs transplant recipients' transition is not clearly defined (Betz & Coyne, 2020). Despite the identified challenges for AYAs as they transition to adult care, healthcare transition is still an emerging field and remains in the exploratory stage of model development (Betz & Coyne, 2020; Disabato et al., 2019). This is highlighted by a systematic review by Betz et al. (2016), in which they contend that there needs to be a healthcare transition model to support the role of inpatient nurses, and a national survey by Disabato et al. (2019) finding the vital role of pediatric nurses in supporting healthcare transition for AYAs with chronic illness would be enhanced by specialized interdisciplinary transition training. The critical role of nurses in supporting healthcare transition through leveraging relationships with AYAs and their families underpins the comprehensive edited book by Betz and Coyne (2020). Betz and Coyne (2020) position nurses as leaders and partners in transition work to support the development of evidence-informed practices and practice models of care for AYAs with chronic or long-term conditions. Through care coordination, promotion of family-centred care, and understanding of the health-illness continuum, nurses are well-positioned to support healthcare transitions for AYAs (Betz & Coyne, 2020).

However, upon a deeper critique, Betz and Coyne's (2020) assertion that nurses are leaders and partners in transition work, fostering the evolution of evidence-based practices and care models, may be seen as a well-intentioned overstatement. The readiness for such an expanded role would require system-wide support and significant additional training, a reality often overlooked in these discussions and potentially downplays the need for broader systemic, policy, and educational interventions that can truly empower nurses to fulfil this pivotal role effectively.

2.5.6 Relationships with Family

Family relationships offer support and guidance across AYAs' changing contexts, such as managing social networks with peers, graduating from high school, beginning post-secondary studies or vocational work, and moving to independent-living arrangements (Mitic et al., 2021). Although developing independence and separating from parents are the ultimate goals of AYA development, the patients require supportive guidance and acceptance from parents and family (Mitic et al., 2021; Nguyen et al., 2016; Toulany et al., 2022). The AYA separation from parents may prove challenging for parents of AYA transplant recipients, who may be fearful as they adjust from parenting a once medically fragile child to a maturing, medically complex young adult (Betz et al., 2015; Toulany et al., 2022). In a systematic review, Betz et al. (2015) examined the transition needs of parents, identifying seven themes centred around parental challenges with adapting to transition-related changes, the stress of ending relationships with the pediatric care team, and the uncertainty of moving to adult care.

Thus, it is sometimes a challenge for parents to relinquish control and management to their children due to a lack of confidence in their children's ability to manage their condition and difficulty in accepting a less active role in their care (Amaria et al., 2011; Betz et al., 2013; Betz et al., 2015; Clarizia et al., 2009; Lerret & Stendhal, 2011; Nguyen et al., 2016; Nicholas et al., 2018; Reiss & Gibson, 2002; O'Sullivan-Oliveira et al., 2014; Oswald et al., 2013; Rapley & Davidson, 2010; Reiss & Gibson, 2002; Toulany et al., 2022; Wang et al., 2010; Wright et al., 2017; Young et al., 2009). As such, parents may be reluctant to grant independence because they fear that increased autonomy may contribute to non-adherent behaviours (Beal et al., 2016; Bell et al., 2008; Betz et al., 2015; Chaturvedi et al., 2009; Clarizia et al., 2009; Fegran et al., 2014; Feinstein et al., 2005; Hislop et al., 2016; Lerret & Stendhal, 2011; Nguyen et al., 2016; Nicholas et al., 2018; Reiss et al., 2005; Sarigol Ordin et al., 2017; Wright et al., 2017).

This assertion, however, seems to oversimplify the complex interaction between independence, self-care, and adherence; it does not fully account for the potentially transformative effect of autonomy on AYA self-management abilities or the role of self-efficacy, which might contradict the presumed negative relationship between autonomy and adherence. Thus, a broader perspective incorporating the nuanced influences on parental attitudes and AYA adherence behaviours would enrich our understanding of this complex transition process.

Feinstein et al. (2005) suggest that AYAs with insufficient family support, low self-awareness, or both may demonstrate non-adherent behaviours, leading to poor clinical outcomes. A survey on adult care transition indicates that social-care-related transition issues limit positive health outcomes (Kerr et al., 2017; Kerr et al., 2020). Likewise, Bell et al. (2009) highlight that the transition process involves the family, patient, and healthcare team, with communication, education, and action as essential tasks to achieve. Clariza et al. (2009) examine participant perspectives of transition preparation through interviews with patients and parents and surveying healthcare workers, demonstrating that families have a predominant role in managing the health and care of AYAs. Their significant finding illustrates that 95% of parents accompanied the youth to medical appointments, with 68% staying for the visit and 45% continuing responsibility for medication administration (Clariza et al., 2009). However, Clariza et al.'s (2009) focus on quantifiable indicators such as parental presence at medical appointments and involvement in medication administration seems to downplay the complexities of the relational dynamics, individual family roles, and the influence of socio-cultural contexts that can significantly affect the transition process.

Moreover, Wright et al. (2017) confirm parents' active role in the transition process but also highlight the struggles parents face in navigating their changing roles. Li et al. (2021) and Wright et al. (2017) rightly acknowledge the need to incorporate families into transition planning, yet the question of how remains largely unanswered. Further research should thus explore strategies to optimally integrate families in transition planning and care, considering the diverse family structures, cultural backgrounds, and unique family dynamics that characterize the population of AYA transplant recipients.

Some authors report that families may also resist the transition to adult services if they perceive providers to be less accommodating of family members' participation in their child's care and decision-making (Betz et al., 2013; Giarelli et al., 2008; Nguyen et al., 2016; Nicholas et al., 2018; O'Sullivan-Oliveira et al., 2014; Reiss & Gibson, 2002; Reiss et al., 2005). Oswald et al. (2013) draw on the National Centre for Health Statistics Division for Health Interview Statistics to identify the individual, family, or broader system components associated with a successful transition. Through literature review and alignment with the variables included in the survey dataset, Oswald et al. (2013) defined a successful transition that provides six key elements and five significant predictors of success. These predictors include a) having a mother with a college education; b) being female; c) having received all routine preventative care required in childhood; d) having adequate health insurance in childhood, allowing them to receive all care required; and e) having doctors or other care providers in childhood who listened to them and their parents carefully. Exceptionally alarming is that only one in five participants, or 21.6% of young adult participants in 2007, experienced a successful transfer to adult care (Oswald et al., 2013). This finding, although now dated, further reinforces the imperative need to understand the transition experience of AYA transplant recipients better to improve their success in this process.

One notable shortcoming of Oswald et al.’s (2013) study is the focus on individual and familial characteristics, such as mother's educational level or insurance status, as predictors of successful transition. While these factors undoubtedly play a significant role, this approach may underplay the systemic and structural factors that also shape transition experiences. These factors might include the healthcare system's readiness to accept transitioning patients, the approachability and flexibility of adult healthcare providers, and broader socio-economic and cultural contexts. Moreover, despite the large sample size, study limitations include constrained participant responses due to the indicators presented within the survey and they might have missed important subjective aspects of the transition process not captured in the survey data. Consequently, Oswald et al. (2013) may have only captured the importance of indicators of a successful transition if the indicators were part of the survey. In contrast, participant interviews or focus groups may have elucidated different perceptions. Given that the study was conducted in 2007, the results may not represent current experiences. The past decade has seen significant changes in healthcare delivery, technology, and policy that may affect transition experiences. Therefore, it would be essential to replicate the study with more recent data and possibly expand the range of indicators considered. This could provide a more current, comprehensive picture of what constitutes a successful transition and how best to facilitate it for AYAs with chronic conditions.

2.5.7 Relationships with Peers

In addition to family relationships, peer relationships also serve an integral role in AYA development. AYAs tend to seek peer approval, placing high value and importance on social relationships (Korus et al., 2011; Lerrett & Stendahl, 2011; Mitic et al., 2021). As AYAs develop, they begin to cultivate a sense of belonging and self-worth and gauge normalcy based on their shared interactions with others; therefore, these relationships play a crucial function in establishing autonomy and independence for AYAs (Bell et al., 2008; Dobbels et al., 2005; Fegran et al., 2014; Lerret & Stendahl, 2011; McCurdy et al., 2006; Mitic et al., 2021). This body of literature clearly underscores the importance of peer relationships in AYA development and the transition to adulthood, however, there seems to be a predominate focus on the dynamics of the relationships and the psychological impacts on the AYA, potentially lacking the exploration of concrete strategies and interventions to nurture these relationships, especially in the context of AYAs with chronic conditions such as transplant recipients.

Another issue that emerges in the exploration of peer relationships is the complexity and potential tension between the AYAs' desire for normalcy and their experience of being different due to their chronic illness despite continued attempts at normalcy (Feinstein et al., 2005). Given the significant role that social support and peer relationships play in AYA development, it is crucial to consider the impact these relationships may have on AYA transplant recipients' adherence to treatment regimes, risk-taking behaviours, and successful transition to adulthood (Bell et al., 2008; Fegran et al., 2014; McCurdy et al., 2006). AYAs with chronic illness experience vulnerability, feelings of being different from others, a desire for normalcy, and a need for strong social support (Larouche & Chin-Peuckert, 2006; McAllister et al., 2006; Rumsey et al., 2004). While it is undoubtedly critical to validate these feelings and concerns, the reviewed literature seems to position chronic illness as inherently alienating. This perspective could risk reinforcing a narrative of isolation and difference rather than embracing and normalizing diversity and unique experiences in the adolescent population.

2.6 The Concept of Transition

The concept of transition is broad in scope and refers to the movement from one stable state to another, characterized by a process triggered by change (Blum, 1995; Blum et al., 1993; Schumacher & Meleis, 2010). Once the event is anticipated, the transition begins, marked by different distinct and unique stages and milestones defined by both the process and outcomes (Blum, 1995; Blum et al., 1993; Schumacher & Meleis, 2010). The transition then represents typical and atypical events, either on a personal or social level, such as the onset of puberty, graduation from high school and movement into the workforce, or the beginning of parenthood. Adolescents and young adults experience typical transitions as they move from childhood to adulthood, accompanied by developmental changes that often require adaptation because of subsequent changes to relationships, situations, and their environment (Blum, 1995; Blum et al., 1993; Schumacher & Meleis, 2010). However, not surprisingly, the developmental transition process to adulthood is more complicated for AYAs living with complex health conditions, such as organ transplants. For example, whereas a typical developmental achievement during AYA is to assume responsibility for one's health, AYA transplant patients must achieve this while directing their complex healthcare rather than relying on their caregivers. Given the many transitions individuals may experience in their lives, one may think of transition as a primary social process.

Meleis et al.’s (2000) transition theory is broadly used in nursing practice with a framework to help individuals navigate changes in health and well-being, including changes in health status, care settings, and life events, while also providing a framework for understanding the psychological, social, and cultural factors that impact an individual's ability to adapt to change. This theory can also be used to help develop interventions to support individuals through the transition process. The framework identifies four key conditions and three dimensions, as illustrated in Appendix A. The key conditions that are necessary for a successful transition are: (1) the presence of a triggering event that initiates the transition process; (2) the negotiation of the transition process; (3) the acquisition of new skills and knowledge; and (4) the integration of the new identity or status into one's sense of self. The three dimensions include: the nature of transitions, the transition conditions, and patterns of response, with consideration to context conditions, including personal, cultural, social, and environmental factors, crucial in shaping the transition process (Meleis et al., 2000).

The Nature of Transitions includes the type and magnitude of change that individuals may experience (Meleis et al., 2000). Within this domain are individual health status, care settings, and life events which range from minor to significant shifts. The type of transition delineates the nature of transitions: developmental, situational, health/illness, or organizational. Meleis et al. (2000) classify the transition patterns based on multiplicity and complexity. As such, individuals may experience multiple transitions sequentially or simultaneously. Transition is characterized by a series of discrete stages that individuals traverse as they prepare for and experience change. The degree of awareness that individuals exhibit during this process is evidenced by how their knowledge of the transition aligns with their expected set of cognitive, behavioural, and emotional responses and perceptions, which are based on the experiences of others going through similar transitions (Meleis et al., 2000). Transition conditions represent environmental, social, and cultural factors that shape the transition process and can impact an individual's ability to change. Such factors include physical, emotional, and cognitive aspects, as well as support systems, resources, and the social and cultural context in which the transition occurs (Meleis et al., 2000). Meleis et al. (2000) describe Patterns of Response as the third dimension of their transition theory, which refers to how individuals respond to change and the strategies they use to adapt to the transition. These strategies are shaped by the individual's life experiences, personal characteristics, and transition conditions and may include problem-solving, decision-making, or coping mechanisms (Meleis et al., 2000).

Likewise, according to Musamali (2018), a transition is a process initiated in response to a change event where periods of disruption and distress trigger an adaptive response resulting in change. These transitions occur across various life contexts, such as environmental changes, developmental stages, and significant life events, which, if left unmanaged, can complicate and derail adapting to change. In healthcare, a good transition outcome refers to a patient who successfully moves from one care environment or structure to another, with a seamless adaptation resulting in positive health outcomes. This may be seen in patients transitioning from hospital to rehab care, home to assisted living, or pediatric to adult care (Meleis et al., 2000).

2.6.1 Understanding the Difference Between Transfer and Transition

Blum et al. (1993) describe healthcare transition as a holistic, multifaceted, and active process that requires attention to AYAs' medical, psychosocial, and educational needs as they transfer from child- to adult-centred care. Thus, given this broad description, it is unsurprising that there is variability in how the term transition is taken up across disciplines and used within the literature, particularly about healthcare transition (Kralik et al., 2006; McDonagh & Kelly, 2010). The often-interchangeable use of the terms healthcare transfer and transition further complicates the confusion regarding the use of the phrase. Although interrelated, the difference between transition and transfer is distinct. Though healthcare transition is the process, transfer denotes the actual transfer of care from child-centred to adult-oriented facilities and is central to the concept of healthcare transition (Annunziato et al., 2007, 2008; Blum et al., 1993; Blum, 1995; Sarigol Ordin et al.,2017).

Kralik et al. (2006) and McDonagh and Kelly (2010) address the inconsistent use of the term transition. The use of the term transition by healthcare researchers varies across disciplines but most commonly refers to change and people's responses and adaptation to these changes (Kralik et al., 2006; McDonagh & Kelly, 2010). Similarly, McDonagh and Kelly (2010) examine why progress in transitional care is slow and identify the need to clarify both the language and terminology researchers use within transition research. Specifically, McDonagh and Kelly (2010) emphasize the need to define and distinguish the terms transition and transfer because these terms are used synonymously by authors in the literature. This variability may pose a barrier to healthcare workers' understanding of transition and how best to support transitions for their patients (Kralik et al., 2006; McDonagh & Kelly, 2010; Osterkamp et al., 2013).

Following the recommendation of McDonagh and Kelly (2010), I use the conceptual definition of healthcare transition as the purposeful and planned movement from pediatric to adult care. In contrast, the transfer will denote the termination event of pediatric care and the re-establishment of adult care (Blum et al., 1993; Blum, 1995; Brooks et al., 2009; Ferris et al., 2015; Gorter et al.; Hislop et al., 2016; McDonagh & Kelly, 2010; Rosen et al., 2003; Sattoe et al., 2017; Stabile et al., 2005). Although the transfer event is necessary for healthcare transition, a successful change must be coordinated and uninterrupted, while providing psychosocially sensitive, developmentally appropriate, and comprehensive care across adolescence and adulthood (Betz, 2012, 2013; Betz et al., 2016; Blum et al.; 1993; Blum, 1995; Clarizia et al., 2009; Chaturvedi et al., 2009; Fegran et al., 2014; Ferris & Bell, 2011; Hislop et al., 2016; Lindsay & Hoffman, 2014; Nguyen et al., 2016; Rapley & Davidson, 2010; Rosen et al., 2003; Sattoe et al., 2017). In other words, successful healthcare transition planning and care involves a process that spans several years, with support for individuals moving from pediatric-oriented to adult-oriented healthcare, expanding beyond just the medical needs of individuals but also including psychosocial, educational, and vocational needs (Beal et al., 2016; Betz, 2012, 2013; Betz et al., 2016; Bloom et al., 2012; Clarizia et al., 2009; Bomba et al., 2016; Ferris & Bell, 2011; Gorter et al., 2011; Hislop et al., 2016; Lindsay & Hoffman, 2014; Nguyen et al., 2016; Rosen et al., 2003; Sattoe et al., 2017; Suris et al., 2016). However, despite the available research on many chronic illnesses, how researchers translate this into practice to support AYAs transitioning to adult-focused healthcare and how AYAs experience transition remain unclear (Betz et al., 2016; Ferris et al., 2015; Sattoe et al., 2017). Given the chronicity of solid organ transplantation, long-term care, and potential complications, we can draw on researchers' transition work focused on other chronic illnesses. For example, previous research focused on cystic fibrosis, asthma, diabetes, congenital heart defects, and genetic disorders can further inform our understanding of the transition needs of AYAs living with a solid organ transplant (Bell et al., 2008; Betz et al., 2013; Bomba et al., 2016; Catena et al., 2018; Davis et al., 2014; Nicholas et al., 2018; Rapley & Davidson, 2010; Toft et al., 2018).

2.6.2 Healthcare Transition

Development of the concept of healthcare transition emerged in the literature in the early 1990s, defined as a deliberate and intentional movement of AYAs with chronic medical and physical conditions from the pediatric-centred to the adult-oriented healthcare system (American Academy of Pediatrics [AAP], 2011; Blum et al., 1993; Kaufman & Pinzon, 2010). The Canadian Pediatric Society (CPS) position statement authored by Toulany et al. (2022) defines successful transition as care that is continuous, coordinated, and individually adapted to development and maturity while “improving (or at least maintaining) disease control, patient satisfaction, quality of life, and social participation throughout young adulthood” (p. 300).

Transition for AYAs with special healthcare needs or chronic health conditions is a complex issue influenced by multiple interacting factors, including personal, health, and organizational aspects (Beal et al., 2016; Gorter et al., 2011; Hamdani, Mistry & Gibson, 2015; Hislop et al., 2016; Lindsay & Hoffman, 2014; Nguyen et al., 2016; Reiss & Gibson, 2002; Reiss et al., 2005; Sattoe, Hilberink & van Staa, 2017; Toulany et al., 2022). The work of McCurdy et al. (2006) on the transition from the perspective of AYAs, concludes that there is a need for better preparation of AYAs for healthcare transition, as well as a need for transition programs that aim to improve the transition process for this group, which still holds true today as summarized in the CPS position statement (Toulany et al., 2022). Through this position statement, the CPS posits that the current Canadian healthcare system configuration creates fragmented care with barriers to care continuity with a lack of integration across pediatric and adult services (Toulany et al., 2022). Consequently, these barriers can harmfully impact health engagement with detrimental impacts on health and well-being (Toulany et al., 2022).

The CPS recommends transfer to adult care that is flexible and individualized with consideration of developmental stage, maturity, and capacity, as well as individual and family needs and circumstances (Toulany et al., 2022). However, the current Canadian healthcare system directs transfer movement based on age limitations rather than the AYA's choice or developmental readiness. In Canada, the age of transfer from pediatric to adult care is not determined by developmental readiness but is instead mandated by provincial/territorial healthcare funders and ranges between 16 to 19 years (Toulany et al., 2022).

Undeniably, a holistic view is critical when considering the effect chronic childhood illness that calls for interventions, such as transplantation, has on AYAs. For example, chronic illness may interfere with children's typical maturation and impair growth or cognitive development, thereby affecting their future ability to access healthcare and sustain adherence as they enter adulthood (Annunziato et al., 2010, 2011, 2013; Beal et al., 2016; Bell, 2007; Bell et al., 2008; Bell & Sawyer, 2010; Betz et al., 2013; Bomba et al., 2016; Giarelli et al., 2008; Hislop et al., 2016; Lindsay & Hoffman, 2014; Nguyen et al., 2016; O' Sullivan-Oliveira et al., 2014; Sattoe et al., 2017). To exemplify the impact of chronic illness on AYAs, one can look at children with renal disease who have a highly demanding pre-transplant treatment regime of dialysis. This challenging treatment plan often results in school absenteeism and missed vocational and social opportunities that may reduce employability and diminish self-esteem (Bell, 2007; Bell et al., 2008; Micklos, 2014; Nicholas et al., 2018).

Betz et al. (2016) highlight a gap in the implementation of transition research into practice, concluding that the healthcare transition is at the critical stages of development because there needs to be more evidence to support the creation of clinical guidelines or standards of care. Betz et al. (2016) identify several types of healthcare transition services within the models of transition care, including:

- transfer of care, comprised of referrals to primary care providers and medical summaries;
- various services and supports for parents;
- the use of a service coordinator;
- referrals to community-based transition and adult services for employment;
- post-secondary education and training.

However, a key finding is that the transfer of care is the most prominent intervention, which is problematic, because the transition process should begin long before the transfer of the AYA's care to the adult facility (Amaria et al., 2011; Betz et al., 2013; Binks et al., 2007; Reiss & Gibson, 2002). However, arguably most importantly, Sattoe et al. (2017) identify the challenge to researchers to transform the definition of transition into more holistic indicators because those most used by researchers are medically focused and do not address the psychosocial and participation outcomes. Expanding beyond a medical focus is vital because transition involves more than just the transfer event.

Successful healthcare transition from pediatric to adult-focused services involves the AYA, family/caregivers, the pediatric team, and the adult-centred health team (Beal et al., 2016;

Betz, 2013, 2016; Bloom et al., 2012; Bomba et al., 2016; Catena et al., 2018; Clarizia et al., 2009; Chaturvedi et al., 2009; Fegran et al., 2014; Ferris & Bell, 2011; Hislop et al., 2016; Kralik et al., 2006; Lerret & Stendhal, 2011; Lindsay & Hoffman, 2014; Nguyen et al., 2016; Rapley & Davidson, 2010; Rosen et al., 2003; Sattoe et al., 2017; Suris et al., 2016; Toulany et al., 2022). Reviewing the literature, researchers often focus on identifying and addressing individual and organizational factors to support the transition. The frequent attention on developing skills and knowledge to manage disability, increase family support for youth self-management, or improve procedures for the transfer event to adult-focused care, to address the process of transition from pediatric to adult care for youth with chronic conditions and disabilities exemplifies this focus (Annunziato et al., 2010, 2011, 2013; Beal et al., 2016; Bell et al., 2008; Bell & Sawyer, 2010; Betz et al., 2013; Clarizia et al., 2009; Giarelli et al., 2008; Gorter et al., 2011; Nguyen et al., 2016; Rapley & Davidson, 2010).

2.7 Transition Research Methodological Strengths and Limitations

Many studies in the domain of healthcare transition are largely exploratory or descriptive reviews or syntheses (Bailey et al., 2020; Betz, 2009; Betz et al., 2013; Betz et al., 2016; Chu et al., 2015; Gabriel et al., 2017; Kerr et al., 2017; Kim & Marks, 2014; Kralik et al., 2006; Lewis & Slobodov, 2015; Micklos, 2014; Miloh et al., 2017; Parfeniuk et al., 2020; Schmidt et al., 2020; Stevens et al., 2021; Varty et al., 2020), and originate abroad, for the most part from American or European centres (Aldiss, 2015; Beal et al., 2016; Betz et al., 2016; Bomba et al., 2016; Burra, 2012; Chu et al., 2015; Feinstein et al., 2005; Ferris et al., 2015; Hislop et al., 2016; Kim & Marks, 2014; Lerret & Stendahl, 2011; Lewis & Slobodov, 2015; Micklos, 2014; Miloh et al., 2017; Oswald et al., 2013; O'Sullivan-Oliveira et al., 2014; Sattoe et al., 2017; Szalda et al, 2015). Although earlier work was heavily reliant on research methods that aimed to quantify adherence and transition success, such as chart review, questionnaires, or immunosuppressive blood levels (Feinstein et al., 2005; Sattoe et al., 2017; Rutishauser et al., 2011) that helped to frame the importance of understanding the transition experience, the opportunity to explore participant perceptions was limited. Conversely, qualitative studies have provided a voice to patients, families, and healthcare providers and enhanced our understanding of their experiences, needs, and opportunities for support (Catena et al., 2018; Clarizia et al., 2009; Ferris et al., 2015; Gabay & Tarabeih, 2020; Giarelli et al., 2008; Li et al., 2020; Lerret & Stendahl, 2011; Lerret et al., 2017; Reiss et al., 2005; Szalda et al., 2015; Wright et al., 2017; Wright et al., 2019; Young et al., 2009).

Sattoe et al. (2017) who use a web-based questionnaire survey and a review of patient medical files rather than qualitative methods to understand the importance of the healthcare practitioner’s role in supporting adolescents with their transition. From their analysis, Sattoe et al. (2017) proposed that the indicators for successful transition show some degree of positive healthcare-related transition outcomes but not independence in youth involvement. Despite the value added to our knowledge of transition, speaking directly with participants would allow for the exploration of their thoughts, feelings, and experiences beyond what the answers from a standardized survey can offer.

Similarly, Rutishauser et al. (2011) used a cross-sectional design and questionnaires for participant data collection in AYAs with chronic illnesses who had not yet transitioned to adult care. From their work, it is apparent that a gap remains in our knowledge as how best to implement transition support for patients in practice, despite available descriptions of the importance of collaborative relationships among patients, families, and the healthcare team in facilitating a successful transition (Rutishauser et al., 2011). However, using standardized or quantitative approaches limits the descriptive scope of participant experiences. Standardized questions that provide limited opportunity to expand on answers or develop a theory of AYA transplant recipient transition to adult healthcare may make it difficult for researchers to capture the subjective experiences of AYA transplant recipients with these methods.

The work of Bell et al. (2008) is illustrative of the researcher's typical focus on provider perspectives. In this work, Bell et al. (2008) provide a comprehensive consensus report of the

Adolescent Transition to Adult Care in Solid Organ Transplantation conference, outlining a detailed summary of care providers' recommendations and discussing solid organ transplantation to support healthcare providers in guiding their care of this population. Although Bell et al. (2008) provide a comprehensive report, underrepresented is the voice of AYAs. As a result, Bell et al. (2008) may not necessarily capture the realities of AYA transplant recipients and their families.

Likewise, despite implementing a qualitative study to explore the barriers and facilitators to care for adults with childhood-onset chronic conditions, Szalda et al. (2015) only focus on the perspective of healthcare providers. The authors used purposeful and snowball sampling to identify participants and recruited twenty-seven care providers to participate in semi-structured open interviews; they included no patients or parents. Notwithstanding their valuable findings that may guide improvements to transition care for AYAs with chronic conditions, including identification of the importance of pediatric nurses in the process (Szalda et al., 2015), the lack of patient perspectives is a significant study limitation. In contrast, Catena et al. (2018) integrated patient perspectives, and Nguyen et al. (2016) and Nicholas et al. (2018) both included the perspectives of patients and parents in their research studies through qualitative interviews. This approach aligns with the broader principles of patient engagement, emphasizing the importance of empowering patients to be active participants in their care.

The focus on the patient’s voice represents a shift in the traditional approach to healthcare, moving away from a top-down model where providers make all decisions about patient care to embrace a more collaborative model, empowering patients to play an active role in their care (Waterman et al., 2020). This approach gives patients a voice in their care and involves them in decision-making processes that affect their health and well-being (Waterman et al., 2020). There are various approaches to involving patients in their care, including patient-centred care, shared decision-making, patient-reported outcomes, and experience measures (Waterman et al., 2020). This may be particularly relevant for AYA transplant recipients transitioning to adult-focused care, as they face unique challenges related to managing their chronic condition. Similarly, the use of Patient-Reported Outcome Measures (PROMs) and Patient-Reported Experience Measures (PREMs) have become increasingly important tools for assessing the impact of care programs on patients' well-being and satisfaction, providing valuable information about the patient's perspective on their health and the care they receive, allowing for a more patient-centred approach to care (Churruca et al., 2021). These measures have improved patient engagement, increased trust between patients and healthcare providers, and improved health outcomes (Churruca et al., 2021).

2.8 Independence and Self-Management

Confidence in self-management ability and feelings of personal preparedness are concepts closely linked to AYA development and transition. The development of self-management is of great importance in the nursing care of AYAs with chronic conditions as these AYAs prepare to transition to adult care (Chick & Meleis, 2010; Fegran et al., 2014; Matsuda-Abedini et al., 2022; Rea et al., 2021; Schumacher & Meleis, 2010; Toulany et al., 2022). One can describe independence as an individual's ability to demonstrate self-sufficiency without relying on others, specifically parents, for daily care and life management (Micklos, 2014; Wright et al., 2019). Furthermore, AYAs should be encouraged to develop self-advocacy to lead their care and promote their well-being (Amaria et al., 2011; Betz et al., 2013; Clarizia et al., 2009; Modi et al., 2012; Nguyen et al., 2016; Nicholas et al., 2018; Rapley & Davidson, 2010; Wright et al., 2019). Some authors suggest that to achieve this goal, the medical community must support AYAs to navigate and manage their medical conditions and the adult healthcare system by independently communicating with care providers and developing problem-solving and decision-making skills (Amaria et al., 2011; Beal et al., 2016; Betz et al., 2013; Bomba et al., 2016; Catena et al., 2018; Clarizia et al., 2009; Gorter et al., 2011; Lindsay & Hoffman, 2014; Modi et al., 2012; O'Sullivan-Oliveira et al., 2014; Nicholas et al., 2018; Nguyen et al., 2016; Rapley & Davidson, 2010; Sattoe et al., 2017; Toulany et al., 2022; Wright et al., 2019).

Based on these findings, researchers recommend that AYAs with chronic or special healthcare needs develop the skills and competencies expected to manage their lives as adults, with the recommendation for better transition preparation and planning (Catena et al., 2018; Toulany et al., 2022; Wright et al., 2019). Consequently, researchers recommend encouraging AYAs to assume responsibility for managing their health and daily lives to the best extent possible (Catena et al., 2018; Toulany et al., 2022; Wright et al., 2019). To achieve this goal, parents and caregivers must be supported in the gradual transfer of care responsibility to the AYA (Amaria et al., 2011; Beal et al., 2016; Betz et al., 2013; Bomba et al., 2016; Catena et al., 2018; Clarizia et al., 2009; Giarelli et al., 2008; Gorter et al., 2011; Nicholas et al., 2018; Rapley & Davidson, 2010; Sattoe et al., 2017; Toulany et al., 2022; Varty et al., 2020; Wright et al., 2019). Nurses are in a critical position to help support this goal (Disabato et al., 2019; Gabay & Tarabeih, 2020; Ladores, 2015; Lerret et al., 2016; Varty et al., 2020).

A factor influencing the successful transition to adult life for AYAs with chronic health conditions as they assume responsibility for managing their health and daily lives and to adult-focused healthcare is the extent and quality of support provided by parents and other family members. Oswald et al. (2013) support the significance of parental efforts in their finding that maternal education impacts transition success. The position of the CPS reflects the recommendation for AYAs to develop autonomous and independent consumer skills (Kaufman & Pinzon, 2007; Toulany et al., 2022). Similarly, the AAP (2011) points out that AYAs with special healthcare needs and chronic conditions are at higher risk for unnecessary dependency. Dependency can be reduced by enhancing AYAs' sense of autonomy and personal responsibility. However, Binks et al. (2007) caution that independence does not mean without assistance and that a level of self-management and independence is achievable through taking responsibility to collaborate with others to help manage and direct their care. Thus, although independent self-management may not be possible for all AYAs with special healthcare needs or chronic conditions, shared management can be achieved (Amaria et al., 2011; Beal et al., 2016; Giarelli et al., 2008; Hamdani et al., 2015; Hislop et al., 2016; Lindsay & Hoffman, 2014; Nicholas et al., 2018; Nguyen et al., 2016; Reiss & Gibson, 2002). Nguyen et al. (2016) contribute to the knowledge about transitions for AYA with chronic illness by highlighting the importance of supporting self-management by parents and healthcare providers through semi-structured telephone interviews eliciting experiences about their roles, needs, expectations, concerns, empowerment and enabling self-management during the transition process.

A shared management model is grounded in the idea that there are shared roles and responsibilities among AYAs, family members or caregivers, and healthcare providers. Researchers recommend this model to support caregivers, to foster a gradual shift in responsibility from healthcare providers to caregivers, and then to the AYAs themselves (Amaria et al., 2011; AAP, 2011; Betz et al., 2015; Bloom et al., 2012; Giarelli et al., 2008; Hamadi et al., 2011; Reiss & Gibson, 2002). The relationship between AYAs, parents, and caregivers is essential for healthcare providers to support the shift in autonomy, independence, and self-management. For example, Amaria et al. (2011) highlight that in Canada, AYAs often remain in their family homes longer due to demographic, economic, and societal changes, thereby maintaining parental involvement in their daily lives, including their interactions with adult healthcare.

The importance of relationships, amplified for AYAs living with special healthcare needs or chronic illness, involves a shift in autonomy that also requires the support and involvement of family members (Amaria et al., 2011). Given the long-term nature of a chronic disease or special healthcare needs, many of these individuals are dependent on their parents or caregivers to assume an active role in managing their health conditions and coordinating their care and services (Giarelli et al., 2008; Hislop et al., 2016; Nguyen et al., 2016; Nicholas et al., 2018; Rapley & Davidson, 2010; Suris et al., 2016). Thus, through a shared management model as described above, best practices guiding transitions generally follow the recommendation that healthcare providers support parents, caregivers, and AYAs, with the gradual shift in responsibilities to the AYAs themselves, to the greatest extent possible (Amaria et al., 2011; Betz et al., 2013; Catena et al., 2018; Giarelli et al., 2008; Gorter et al., 2011; Hamdani et al., 2015; Hislop et al., 2016; Nguyen et al., 2016; Nicholas et al., 2018; Rapley & Davidson, 2010; Reiss & Gibson, 2002).

From the review of the literature, we can see that the transition for AYA transplant recipients of importance to nursing (Chick & Meleis, 2010; Fegran et al., 2014; Schumacher & Meleis, 2010). Expanding our understanding on how best to support this population is crucial due to the specific physiological, psychological, and social factors that impact healthcare transitions and AYAs' interactions with families, friends, and the healthcare team (Bell et al., 2005; Dobbels et al., 2005; Lerret & Stendahl, 2011; McCurdy et al., 2006). Although some researchers recommend that family members provide support and encouragement to AYAs to help achieve the gradual development of autonomy and responsibility for health and disability management (Betz et al., 2013; Binks et al., 2007; Clarizia et al., 2009; Giarelli et al., 2008; Nguyen et al., 2016; Nicholas et al., 2018; Rapley & Davidson, 2010), there is also an emphasis on promoting learning within a shared management model. However, much of the cited literature seemingly assumes a healthcare system that is receptive and responsive to AYAs navigating their care. Yet, these scholars predominantly operate within a biomedical model that prioritizes medical outcomes, possibly at the expense of other equally important psychosocial aspects of AYA development and transition. Additionally, systemic barriers, including healthcare accessibility, fragmented services, and uncoordinated care, can significantly hamper AYAs' transition journey. Thus, a more holistic approach that considers the multifaceted challenges faced by AYAs — including social, psychological, and emotional aspects — with consideration of systemic changes can lead to a richer understanding of their transition experiences and more comprehensive support strategies and the role of healthcare professionals in advocating for these changes. To broaden our knowledge of transition support, capturing the meaning of the AYA transplant recipients' experiences throughout the transition process is essential. This knowledge will include how best to transfer health information and healthcare management progressively to AYA transplant recipients over time throughout the transition process rather than just focusing on the transfer event (Betz et al., 2013; Clarizia et al., 2009; Hislop et al., 2016; Nguyen et al., 2016; Nicholas et al., 2018; Wang et al., 2010).

2.8.1 Developmental Readiness

Another personal component of transition success identified by researchers is developmental readiness, which is reflected in AYAs' self-determination, self-efficacy, psychological maturity, motivation, and developmental skills and traits that contribute to their preparation for the roles and behaviours required of adult life (Giarelli et al., 2008; Hamdani et al., 2015; Nguyen et al., 2016; Nicholas et al., 2018). Similarly, and as already noted, developmental tasks for AYAs include consolidation of self-identity, progression toward independence from parents, and establishment of relationships with adults and peers (Betz et al.,2013; Giarelli et al., 2008; Hamdani et al., 2015; Nguyen et al., 2016; Nicholas et al., 2018).

Accordingly, best practices identified by the authors centre around promoting these developmental skills and tasks to help facilitate a successful transition to adult life (Betz et al., 2013; Giarelli et al., 2008; Gorter et al., 2011; Nguyen et al., 2016; Nicholas et al., 2018; Reiss & Gibson, 2002; Toulany et al., 2022). In other words, AYAs need support in their progression along a developmental continuum of skills and competencies to encourage developmental readiness for transition. To help prepare AYA transplant recipients for their roles and activities associated with adulthood, they require support to modify their developmental transition pathway reflected by their circumstances and health status. This includes managing personal and health care, moving out of their family home, participating in further education or vocation, and forming intimate relationships (Amaria et al., 2011; Betz et al., 2013; Giarelli et al., 2008; Hamdani et al., 2015; Nguyen et al., 2016; Nicholas et al., 2018; Rapley & Davidson, 2010). Ultimately, traditional transition preparation and planning aims to achieve skills and competencies associated with a typical developmental trajectory and requires a shift in responsibility to achieve autonomy.

However, the concept of a successful transition is somewhat reductive, based on a normative understanding of what constitutes adult life and roles. This can neglect the fact that adulthood is diverse and complex and that success may look different for different individuals. For example, not all adults will move out of their family home, pursue further education, or form intimate relationships. This normative approach could potentially marginalize AYAs who, due to their circumstances, may have different life paths or may achieve these milestones at a different pace. Additionally, there seems to be an implicit assumption in the literature that AYAs are essentially moving from a position of dependency (in the pediatric healthcare system) to one of autonomy (in the adult healthcare system). However, this overlooks the fact that all people, regardless of their age or health status, exist in a web of interdependencies. The insistence on a shift in responsibility could inadvertently place undue pressure on AYAs to be self-sufficient and may overlook the ongoing need for support in managing their chronic condition. Moreover, the focus on skills and competencies can underestimate the systemic and structural barriers that AYAs may face in transitioning to adult healthcare. These barriers could include a lack of continuity in care, differences in care philosophies between pediatric and adult healthcare systems, or financial and logistical challenges related to healthcare access. Lastly, the emphasis on transition preparation and planning could potentially neglect the importance of resilience and adaptability; AYAs with chronic conditions are likely to face unanticipated challenges and changes in their health status, and their ability to adapt to these changes could be just as important, if not more so, than their preparation for a pre-determined set of skills and competencies.

Accordingly, Hamdani et al. (2015) identify the notion of typical development as a dominant theme underpinning best practices related to transitions, along with becoming as independent as possible and approximating distinct adult roles and milestones. From the review of four fundamental best practice documents reflecting both international and Canadian transition recommendations, Hamdani et al. (2015) identify that although a generally accepted aim of transition is the achievement of developmental progression toward adult roles, this may not be an appropriate goal for AYAs with special healthcare needs, disabilities, or life-limiting conditions. Therefore, Hamdani et al. (2015) caution healthcare practitioners to reflect on their underlying assumptions that guide their understanding of the development and, indirectly, developmental readiness for transition to adult healthcare.

2.8.2 Transition Preparation

In addition to the personal and interpersonal factors described above, there are also organizational and institutional factors that influence the success of the transition from pediatric to adult services for AYAs with special healthcare needs or chronic illnesses (Amaria et al., 2011; Betz et al., 2013; Clarizia et al., 2009; Gorter et al., 2011; Lindsay & Hoffman, 2014; Nguyen et al., 2016; Nicholas et al., 2018; Reiss & Gibson, 2002). It is well established that the preparation for transition and transfer to adult services should begin as early as possible or even at the time of diagnosis (Amaria et al., 2011; Betz et al., 2013; Binks et al., 2007; Lindsay & Hoffman, 2014; Nguyen et al., 2016; Nicholas et al., 2018; Reiss & Gibson, 2002; Toulany et al., 2022).

Doucet et al. (2022) make valuable contributions to the discussion by providing policy and guideline recommendations in the areas of practice, education, and research based on their scoping review. Practice recommendations include enhancing integration and coordination among healthcare, education, social service sectors, and community partners, with suggestions for interdisciplinary teams with a designated coordinator to facilitate the transition process. Furthermore, Doucet et al. (2022) advocate for the integration of digital tools during the transition for self-monitoring. In the domain of education, Doucet et al. (2022) recommend improving knowledge and training for care providers regarding the transition process and adult healthcare services, whereby emphasis is placed on developing provider-patient relationships to ensure a smooth transition to adult care. Lastly, Doucet et al. (2022) recommend that research include providing resources for program development, such as conceptual frameworks that can guide the design and implementation of transitional care programs. Additionally, Doucet et al. (2022) highlight the need to build capacity in evaluation research to assess effectiveness.

2.8.3 Transfer Process

Transitioning AYAs from pediatric to adult care should follow a coordinated transfer process. This transition process may include a written plan for transition; transfer of health and other information to adult-focused health services; and communication between AYAs, their families, and child and adult providers (Binks et al., 2007; Lindsay & Hoffman, 2014; Nguyen et al., 2016; Nicholas et al., 2018; Rapley & Davidson, 2010; Reiss & Gibson, 2002; Toulany et al., 2022; Wang et al., 2010; Wolfstadt et al., 2011). Recommended strategies to help achieve these goals include combined visits and team meetings with the AYA, family, pediatric, and adult providers to bridge the transfer between child and adult service providers (Amaria et al., 2011; Nguyen et al., 2016; Nicholas et al., 2018; Reiss & Gibson, 2002). Also, many recommend implementing a dedicated nurse or transition coordinator to help smooth the process of transfer and transition between pediatric and adult providers and adequately prepare AYAs for transition (Annunziato et al., 2013; AAP, 2011; Betz et al., 2013; Doucet et al., 2022; Nguyen et al., 2016; Nicholas et al., 2018; Oswald et al., 2013; Rapley & Davidson, 2010; Toulany et al., 2022).

2.9 Conceptualizing Adherence

Adherence is considered a primary determinant of treatment success, defined by the WHO (2003) as the degree to which the person’s behaviour corresponds with the agreed recommendations from a healthcare provider. The common language used to address fulfillment of treatment regimens includes the use of the terms adherence and compliance focused on tasks such as taking medications at the prescribed dose and time (Bissonnette, 2008). The definition of adherence within the literature is “the extent to which patients follow the instructions they are given for prescribed treatments" (Bissonnette, 2008, p. 636) with an expectation that the patient agrees with the healthcare recommendations rather than passively obeying them. The language of compliance and adherence are often used synonymously, focused on identifying risk and improving obedience, with strong undertones of blaming the individual. This can be seen through Bissonnette's (2008) study, using Rodgers' evolutionary method for concept analysis, finding that adherence and compliance are used interchangeably and that they are directly associated with obedience, observance, conformity, acceptance, cooperation, mutuality, and therapeutic alliance (Bissonnette, 2008). Accordingly, adherence is meant to assume that healthcare plans result from mutual goal setting and treatment planning and reflect choice on the part of the patient. Through this mutual goal setting and planning, it is thought that patients internalize treatment recommendations and can choose to either adhere or not (Bissonnette, 2008).

A shift from compliance to adherence recognizes that "factors such as illness acuity, patients' social and financial support, their healthcare beliefs and healthcare providers' communication approaches operate concurrently to influence adherence rates" (Bissonnette, 2008, p. 635). Thus, adherence is dynamic and subject to social influences (Bissonnette, 2008). Accordingly, this shift in adherence discourse arises from the assumption that patients agree with the prescribed treatment plans rather than passively follow orders (Bissonnette, 2008), acknowledging that patients should not simply be blamed for not obeying what is dictated by the healthcare team. However, when considering adherence, one must consider the language used and be aware of the underlying and inherent paternalism, power, values, and overt subtle messages. To address these concerns, the WHO (2003) guided the change in language from compliance to *adherence* in 2003 to diminish the blame and power imbalance associated with the term compliance. Yet, Fawcett (2022) highlights that although the definition of adherence emphasizes agreement and in conjunction with, it remains unclear how adherence is less paternalistic than compliance, as the expectation for the patient to obey the healthcare team's care recommendations remains.

Although the intent for the uptake of the term adherence over compliance was to provide a more holistic perspective, Bissonnette's (2008) analysis of adherence found no distinct difference between the concepts of adherence and compliance, and unfortunately, there is no agreed-upon definition of adherence that reflects a patient-centred approach. Furthermore, although adherence implies that patients accept healthcare plans, the criticism remains that adherence does not reflect a patient-centred approach or the dynamic nature of patient behaviour, and that power imbalances inherent with the term persists (Bissonnette, 2008). This implies that the undercurrent of patient blame remains. In response to similar concerns raised in 1977, the Royal Pharmaceutical Society of Great Britain developed a working group to explore alternative conceptions of adherence that would be more supportive and inspiring of an alliance between patients and healthcare providers based on realistic expectations, rather than misunderstandings, distrust, guilt, and blame (Bissonnette, 2008). Through this work, the concept of *concordance* emerged.

The concept of *concordance* "implies the development of an alliance between patients and healthcare providers based on realistic expectations as opposed to misunderstanding, distrust and concealment" (Bissonnette, 2008, p. 637). The suggestion that patients and the health care team collaboratively develop mutually agreed treatment plans through a process of negotiation and shared decision-making renders concordance theoretically different from adherence and compliance. By shifting language and discourse from compliance and adherence to concordance, there is an attempt to address the power imbalance between the patient and the healthcare team and remove blame by equally valuing the patient's and the team's treatment expectations (Bissonnette, 2008). Concordance aims to resolve power issues through a patient-centred approach focusing on shared decision-making and agreement (Snowden et al., 2014).

There has been limited uptake of concordance within the nursing and chronic illness discourse, and concordance is still being used interchangeably with adherence, and even compliance, with adherence and compliance remaining the dominant words used within healthcare literature (Bissonnette, 2008; Snowden et al., 2013). The critiques as to why concordance has not been widely adopted are similar to that of adherence and compliance, in that healthcare researchers have not convincingly demonstrated that patient alliance, negotiation, or shared decision-making impacts behaviours (Bissonnette, 2008). To help move concordance forward as the dominant discourse and broaden the understanding of how best to support patients' treatment decisions, Snowden et al. (2013) developed a Rodgers' evolutionary concept analysis of concordance, exploring the different uses of concordance in nursing, pharmacology, psychiatry, and medicine. Snowden et al. (2013) suggest that the shift to concordance from adherence has been unsuccessful because concordance remains poorly articulated, and the distinction between concordance and adherence remains unclear. Fawcett (2020) again questions, despite the intention of the emphasis of concordance to spotlight partnerships between the patient and care providers, the level of patient input into the agreed treatment remains unclear.

Despite the WHO's efforts at shifting the mindset of healthcare providers, there is a lack of a theoretical framework to help operationalize and conceptualize adherence and a lack of supporting research findings that reinforce the notion that patient agreement with treatment plans results in more adherent behaviour (Bissonnette, 2008; Gardner, 2015; Vrijens et al., 2012). This lack of a shared conceptual and operational definition results in ambiguity, as seen in the many ways the term adherence is used by researchers within the literature (Aujoulat et al., 2010; Bissonnette, 2008; Gardner, 2015; Vrijens et al., 2012). For example, adherence is about behavioural outcomes, such as taking medication and attending appointments and decision-making outcomes underpinned by psychosocial considerations that ultimately affect behavioural outcomes (Aujoulat et al., 2010; Vrijens et al., 2012). Thus, there is a need for a well-articulated conceptual definition and theoretical framework that can be used to guide healthcare workers and empower patients to be active contributors to their health and care (Bissonnette, 2008; Vrijens, 2012).

2.9.1 Exploring the Significance of Adherence for Patients with a Solid Organ Transplant

Adherence, compliance, and concordance are the terms most used by researchers within the transplantation and transition literature to address the fulfilment of treatment regimes, specifically focused on tasks such as taking medications at the prescribed dose and time (Amaria et al., 2011). With solid organ transplantation as a prevailing treatment option for pediatric patients with organ failure, such as end-stage renal disease, fulminant liver failure, or severe lung disease in cystic fibrosis, there has been much focus on treatment adherence, particularly in the AYA population. Looking at a snapshot of chronic illness (Fegran et al., 2014; Giarelli et al., 2008; Harrop, 2008; Reiss et al., 2005) and transplant literature (Burra, 2012; Coyne et al., 2017; Gilleland et al., 2012; Lerret & Stendahl, 2011; Miloh et al., 2017; Modi et al., 2012; Ordin et al., 2017), it is clear that one cannot dispute the significance of adherence; the effects of non-adherence results in increased healthcare costs and poor health outcomes for patients.

Given the tremendous economic and personal factors associated with transplantation, it is not surprising that this has become a dominant focus of researchers in improving AYA patient outcomes. However, nurses are aware of the multiple barriers that may impede a patient's resources, support, ability, or willingness to achieve their healthcare plans and goals. These barriers may be related to the determinants of health, and psychosocial considerations, such as lack of knowledge and skills, conflicted family relationships, social isolation, or insufficient medical health coverage or financial resources. Further complicating the use of terminology to capture non-adherence is the researchers' varied use of tools and measures to depict these rates. For example, depending on the study design, instruments employed, type of transplant, and responsibility of medication administration, researchers may describe and define adherence differently. The differing ways in which Annunziato et al. (2013) and Bosma et al. (2011) measure medication adherence in liver transplant recipients exemplifies this point. Annunizato et al. (2013) measure adherence by the Standard Deviation of Tacrolimus Blood Levels (Tacrolimus SD), whereas Bosma et al. (2011) instead use the Medication Event Monitoring System (MEMS) to measure Tacrolimus intake to determine adherence prospectively.

Regardless of the differing adherence rates identified, it is clear that post-transplant medication regimens and follow-up are essential to graft and patient survival and must be improved to reduce rejection, graft loss, and death. Non-adherence with post-transplant immunosuppressive medication protocols and regimes can lead to physiological ramifications, including episodes of rejection of the transplanted organ requiring hospitalization and stabilization, significantly increasing healthcare costs, and diminished quality of life, along with the potential for non-adherence that may lead to organ graft loss. Nonetheless, medical complications secondary to non-adherence should not be the only concern for nurses, especially in the transition to adult care. As such, focusing on holistic nursing care, encompassed within adherence, considering the impact of chronic illness and invasive medical treatments on child and AYA development, specifically related to the transition to adult care, is imperative.

Despite the varied terms used for compliance, adherence, and concordance within the healthcare literature, healthcare practitioners have a characteristically shared goal to help facilitate positive outcomes and survival for patients, regardless of what that process is labelled. The commitment to supporting patients in their health pursuits is fundamental to nursing practice, and this shared care and concern for patients and their well-being guides nurses in their approach to patient care. Through this support, nurses aim to help patients accept and adjust to the impact of the illness experience by fostering cooperative, patient-centred relationships to enhance adherence. As such, for this study, I adopted the term *adherence* to mean the successful communication and shared decision-making between individuals and the healthcare provider to achieve healthcare goals.

2.10 Differing Philosophies of Care in Child and Adult Healthcare

Despite the best attempts at smoothing the transition from pediatric to adult-focused healthcare, there remains an underlying difference between the philosophy of care underpinning pediatric and adult healthcare. Pediatric healthcare, based on a family-centred and holistic care model, is different from adult-focused care underpinned by a patient-centred care model (Amaria et al., 2011; Betz et al., 2013; Clarizia et al., 2009; Nguyen et al., 2016; Reiss & Gibson, 2002; Rapley & Davidson, 2010). Researchers attribute the negative experiences of AYAs and their families, described as unsatisfactory due to abrupt changes in their care after transition, to the differing care philosophies of pediatric and adult care (Amaria et al., 2011; Betz et al., 2013; Binks et al., 2007; Fegran et al., 2014; Nguyen et al., 2016; Rapley & Davidson, 2010; Reiss & Gibson, 2002). As a result, AYAs with chronic or special healthcare needs report that they do not receive the services and support they require and sometimes feel rejected by adult-focused care (Amaria et al., 2011; Betz et al., 2013; Catena et al., 2018; Fegran et al., 2014; McCurdy et al., 2006; Nguyen et al., 2016; Rapley & Davidson, 2010; Reiss & Gibson, 2002).

However, researchers argue that healthcare providers within the service cultures of both child and adult-focused care contribute to barriers to transition to adulthood (Amaria et al., 2011; Clarizia et al., 2009). For example, the focus on family-centred care may impede the shift in health and daily life management responsibilities from parents to AYAs. The change in responsibility may manifest in the parents’ difficulty in letting go of their roles and responsibilities to their children, thereby hindering AYAs’ development of self-management skills (Amaria et al., 2011; Blum, 1993; Clarizia et al., 2009; Fegran et al., 2014). In contrast, some argue that healthcare providers guided by a patient-centred care model within adult-focused care may be insufficient for addressing complex and chronic conditions (Amaria et al., 2011; Clarizia et al., 2009), particularly those conditions of childhood onset. Consequently, many suggest that high-quality relationships represented by feelings of trust and connectedness and a strong rapport with healthcare providers, regardless of the model of care, can have a significant effect on the experience of transition to adulthood for adolescents and their families (Clarizia et al., 2009; Fegran et al., 2014; Hislop et al., 2016; Lindsay & Hoffman, 2014; Nguyen et al., 2016; Nicholas et al., 2018; Oswald et al., 2013; Reiss et al., 2005).

Another common perception by AYAs and their families is that adult service providers lack training and interest in childhood disability, further complicating AYAs' relationships with adult-focused care providers (Amaria et al., 2011; Binks et al., 2007; Reiss & Gibson, 2002). In response, researchers recommend that pediatric healthcare training should include skills and knowledge for supporting the development of shared management and that training for adult healthcare providers should expand to include learning about developmental conditions with physical, cognitive, and communication impairments (Amaria et al., 2011; Binks et al., 2007). However, the proposed solution of cross-training pediatric and adult providers seems rather simplistic. While this could indeed be beneficial, it assumes that the main issue lies in the knowledge and skills of individual providers rather than in larger systemic issues such as care coordination, communication, and continuity of care. Thus, it might be more beneficial to address these larger systemic issues in order to facilitate smoother transitions.

2.11 Research Implementation into Practice

Through a review of the literature, significant learnings can be appreciated and considered for implementation into practice. Nguyen et al. (2016) use an interpretive phenomenology study design to explore the meaning of lived experience and perceptions of AYAs, parents, and providers about the transition to adult care. Nguyen et al. (2016) identify three key phenomena through this study: increasing AYA's independence, parents as safety nets, and healthcare providers as enablers and collaborators. Also significant is the finding of the importance for healthcare providers to adopt a gradual and developmental perspective when working with AYAs preparing for the transition. However, Hislop et al. (2016) conclude that a single approach to supporting transition is impossible. Accordingly, healthcare providers should strive to discuss the transition with those with lived experience to understand their preferences to help facilitate engagement with adult care (Hislop et al., 2016). Moreover, healthcare providers must advocate for transition support to be individually tailored (Hislop et al., 2016).

Although there is beginning work by healthcare providers to investigate ways to improve the preparation and process for AYA transition from pediatric to adult care, there is an overrepresentation of integrative reviews and researchers attempting to understand or explain transition without the direct engagement of transplant recipients in their research (Betz et al., 2013; Chu et al., 2015; Doucet et al., 2022; Fegran et al., 2014; Hamandi et al., 2015; Lerret et al., 2012; Lewis & Slobodov, 2015; Micklos, 2014; Oswald et al., 2013; Rapley & Davidson, 2010). Consequently, we see a reliance on provider perspectives rather than the recipients themselves (Betz, Lobo & Nehring, 2013; Bell et al., 2008; Ferris et al., 2015; Lerret et al., 2012; O'Sullivan et al., 2014; Szalda et al., 2015), using predominantly quantitative methodologies, standardized questionnaires, or measurement tools (Beal et al., 2016; Feinstein et al. (2005); Hislop et al., 2016; Mavis et al., 2015; Sattoe et al., 2016; Suris et al., 2016).

Despite the identified importance of the transition process from pediatric to adult care for AYAs with chronic health conditions, disabilities, or other special healthcare needs, such as organ transplantation, the research in this field remains primarily descriptive. In systematic reviews by Betz (2004), Betz et al. (2013), and also Betz et al. (2016), the authors conclude that transition research remains at an exploratory stage of model development. Furthermore, in the review by Betz et al. (2016) of literature from 2004 to 2013, they conclude that the quality of studies is poor and is hindered by a lack of rigorous research designs or use of tools with poor psychometric properties and provide incomplete intervention descriptions thereby inhibiting opportunity for replication. Similarly, the predominant findings to inform transition policy and practice focus on identifying barriers and facilitators to transitioning from child to adult-focused services. However, there remains no accepted or tested model to guide transition care and planning.

Recognizing that research findings from other chronic health conditions may not hold for this unique population, the work of Nguyen et al. (2016), Nicholas et al. (2018), and Hislop et al. (2016) underscores the importance of understanding the experiences of AYA transplant recipients. Nicholas et al. (2018) parallel this research study in many ways; for example, the authors use qualitative interviews with AYAs with chronic kidney disease and their parents to identify how they transition to adult-focused healthcare and explore their experiences. Continued work needs to be done to understand the broader social contexts that shape how the transition to adulthood is constructed and experienced by AYAs from differing cultural and socioeconomic statuses.

As demonstrated by Nguyen et al. (2016), and also Bailey et al. (2022), Beal et al. (2016), Betz et al. (2013), Bomba et al. (2016), Catena et al., 2018, Clariza et al. (2009), Ferris et al. (2015), Hislop et al. (2016), Lindsay and Hoffman (2014), McCurdy et al., (2006), Nicholas et al. (2018), Korus et al. (2011), and Reiss et al. (2005), when considering the process of transition, it is important to consider the voice of AYAs and how they experience transition. Acknowledging this gap, I explore the meaning of AYA transplant recipients' experiences with the transition, informed by their parent's and healthcare providers' experiences, to help understand how best to support self-management in the transition process. Hislop et al. (2016) identify that a successful transition is likely influenced by how AYAs view the transition process and that young people do not have a single view of transition. Additionally, Hislop et al. (2016) highlight the value of the voice of the AYA in their study. Thus, drawing on the work of these researchers, I included patients, parents/caregivers, and healthcare providers in my study to develop a more holistic and robust understanding of the transition experience for AYA transplant recipients.

2.12 Chapter Summary

The available literature on healthcare transition provides a beginning focus on understanding AYA transplant recipients' unique experiences and how to provide care and support. The transition experience is challenging to assess due to the subjective and multidimensional nature of the concept. The variability in the transition assessment may limit the validity of study findings due to the lack of a theoretical model. Similarly, there are many different developmental theories, each with a distinct focus. As such, I have offered an overview of the literature on healthcare transition and AYA development with specific attention to Erikson and Arnett’s developmental theories, illustrating the gaps in knowledge and the need for a greater understanding of the perspective of AYA transplant recipients and their experience with transitioning to adult care.

Chapter Three: Methodology

In this chapter, I explore grounded theory (GT) methodology's theoretical underpinnings and central tenets. I begin by locating GT within qualitative research, discussing this evolving methodology's historical and disciplinary approaches, its use within nursing, and GT's philosophical and theoretical underpinnings, including post-positivist and constructivist GT. Following this review, I discuss my rationale for adopting a constructivist GT methodology. From here, I further describe constructivist GT methods, including study design, data collection, and analysis considerations. I describe the research procedures I used to conduct this study, details of my study and strategies for data collection and analysis, beginning with the inclusion and exclusion criteria for participants, recruitment and sampling, and data sources. I describe data analysis methods, including memoing, constant comparison, and coding. Specifically, I detail the strategies employed for data collection and ethical considerations related to researcher-participation relationships, confidentiality, consent, rigour and reflexivity, and dissemination of findings. Through this discussion, I explicate how I developed a meaningful research study of AYA transplantation experience and how they manage the subsequent transition to adult-focused healthcare to help improve care for this population.

3.1 Rationale for Choosing Grounded Theory

Grounded Theory originated in the 1960s, a time dominated by the discourse of quantification and when qualitative researchers were diligently working to develop methods respected within the scientific world (Denzin & Lincoln, 2000). During this time, positivism was the dominant philosophy, wherein researchers and scholars strongly valued the scientific method, objective knowledge, generalizability, and the replication of research (Charmaz, 2014; Denzin & Lincoln, 2000). From this objective approach, in which reality is believed to exist regardless of who bears witness to it, researchers value objective knowledge viewed as scientific and valid, thereby devaluing alternative ways of knowing.

Challenging these dominant ideas was difficult; nonetheless, Barney Glaser and Anselm Strauss did so in 1967. The collaboration between Glaser and Strauss was seen as an unusual pairing by some scholars, with Glaser's strong background in quantitative methods and middle-range theories and Strauss' roots in symbolic interactionism (SI) and affiliation with the Chicago School of Sociology (Bryant & Charmaz, 2007). Symbolic interactionism is a central tenet of GT methodology, viewing individuals as constructors of their realities from interactions with the symbols surrounding them, thereby creating meaning within a situation (Corbin, 1990; Cutcliffe, 2000). Through this interaction process, individuals make meaning of events, rendering knowledge relative to historical, temporal, cultural, and subjective contexts (Benoliel, 1996). As a philosophy, SI holds that the researcher attempts to determine the symbolic meanings of words, artifacts, clothing, and gestures for groups of people interacting with one another (Charmaz, 2014). Accordingly, within the philosophy of SI, the individual and society are viewed as mutually interdependent. As such, neither can be understood entirely without understanding the other and the relationship between them (Charmaz, 2014; Corbin, 1990). This makes SI particularly useful in complex situations with emerging social problems guiding the researcher to examine human nature in interaction, considering the setting and broader social processes that influence behaviour (Benoliel, 1996; Charmaz, 2014). Accordingly, researchers' epistemological and ontological assumptions influence how they engage in this process.

Despite their differing origins, Glaser and Strauss came together to develop the GT methodology through their collaborative research on dying patients (Stern, 2009). The contributions of GT methodology were embraced within early nursing research, beginning in the 1960-1970s when Glaser and Strauss offered qualitative research seminars to social scientists and doctoral students in nursing (Benoliel, 1996). The uptake of GT within the nursing discipline was spurred further by Glaser and Strauss' initial work with a multidisciplinary group, including nurses interested in chronic illness and quality of life (Stern, 2009).

Through the development of GT, as described in their seminal text, "The Discovery of Grounded Theory" (1967), Glaser and Strauss aimed to provide a foundation for systematic qualitative research. In the development of their method, Glaser and Strauss aimed to produce outcomes of equal calibre to that of the dominant statistical-quantitative methods available at that time by offering a method that allowed for new theory development based on qualitative data analysis (Bryant & Charmaz, 2007; Glaser & Strauss, 1967). In this text, Glaser and Strauss (1967) outlined GT, a methodology aimed at systematically developing theories of human behaviour derived from empirical data (Urquhart, 2012, p.14).

Consequently, as initially described by Glaser and Strauss, this approach to GT is interpreted as underpinned by positivism (Charmaz, 2000; Denzin & Lincoln, 2000). We can see this positivist underpinning in their attempts to discover an external, verifiable, and objective reality through unbiased data collection methods and descriptive technical procedures (Charmaz, 2000; Denzin & Lincoln, 2000). The differing philosophical positions of Glaser and Strauss became further evident as each researcher continued to implement and further develop their versions of GT as a research methodology reflecting their unique philosophical backgrounds. Thus, given disparate ideas on conducting GT research and different theoretical underpinnings, the distinction between the paradigms of Straussian and Glaserian GT methods evolved (Cooney, 2010). Following their partnership, Glaser and Strauss continued their work on developing GT; however, they did so separately, developing different paradigms (Bryant & Charmaz, 2007). Consequently, some scholars believe that it was, in fact, their underlying philosophical perspectives that led to their division, and this is apparent in their subsequent works (MacDonald, 2001; Stern, 1994, 2009).

The contribution made by Glaser and Strauss to social research is indisputable. Together and then later apart, they developed innovative methodological strategies that motivated generations of academics to pursue qualitative research (Bryant & Charmaz, 2007). Since the introduction by Glaser and Strauss, many versions of grounded theory have evolved

(Charmaz, 2000, 2006, 2008b, 2014; Clarke & Star, 2008; MacDonald, 2001; MacDonald & Schreiber, 2001; Schreiber & Martin, 2013), and represent the shifting prevalent ideology from positivism to post-positivism, and then to one recognizing the existence of multiple realities within the human sciences in the 1980s (Benoliel, 1996). In the following years, there was increased use of GT within the disciplines of anthropology and nursing to explore social processes present within human interactions (Corbin & Strauss, 2008; Cutcliffe, 2000; Levers, 2013).

Glaser's study of basic social processes (BSP) and his constant comparison method to allow abstract relationships between theoretical categories to emerge from the data characterize his GT work (Bryant & Charmaz, 2007; Glaser, 1978). Glaser sees himself as remaining true to his original conception in that GT is a method of discovery that follows a systematic set of processes and rules that result in a discovered reality and verifiable theory (Carey, 2013; Charmaz, 2000, 2014; Glaser, 1978). In Glaser's subsequent writing, he does not expand in much depth on the philosophical roots of Grounded Theory Methodology (GTM) (MacDonald, 2001). Yet, he purports that GTM is an approach that offers a systematic method for data collection and analysis that is rooted in quantitative analytic methods (Charmaz, 2006, 2014). Furthermore, Glaser believes in an external, discoverable reality that will emerge from careful data analysis and holds the conviction that researchers do not need to be concerned with concepts such as bias because they are only identifying patterns that exist in the data (Bryant & Charmaz, 2007; Glaser, 2002, 2016).

Glaser's independent GT work contrasts Strauss' work, both independently and in collaboration with registered nurse Juliet Corbin. Based on his academic origins of pragmatism and social interactionism, Strauss's independent work emphasizes the importance of understanding basic social processes as central to theory development (Strauss, 1995a, 1995b). The social constructionist approach to GT argues that knowledge is constructed rather than created, and researchers attempt to make sense of the social world (Strauss, 1995b). As such, Strauss moved from an approach based in positivism toward a constructionist approach to GT, shifting focus toward the need to understand the meaning and the subsequent context that shape that meaning (Charmaz, 2008b). Strauss further argues that it is nearly impossible to describe anything without at least some implicit theory guiding the researcher and the research process (Kelle, 2017; Strauss, 1995b). In other words, Strauss's approach is from the belief that researchers always bring some knowledge, experience, or both to the research process. The idea is furthered by the joint work of Strauss and Corbin, in which they aim to provide more clarity around GT and its methods, thereby developing a more social constructionist approach to GT (Strauss & Corbin, 1998). As such, the GT work of Strauss and Corbin centres on an assumption of a social constructionist approach, as they consider the impact of the researcher on the research process, data produced, participants in the study, and subsequent analysis developed.

Following the trajectory of GT came the development of a constructivist approach to GT methodology based on a constructionist epistemology (Ward, Hoare, & Gott, 2015). Kathy Charmaz, a social researcher and student of Strauss, is widely credited with articulating Constructivist Grounded Theory (CGT). Charmaz took up the term constructivism in the 1990s to distinguish her approach from social constructionism. Constructivism has grown out of a debate about the philosophical paradigms that underpin the fundamental questions surrounding the nature of research inquiry (Appleton & King, 1997; Crotty, 1998). We can view a theoretical *constructivist paradigm* as both an epistemological and an ontological perspective on the nature of scientific knowledge in natural settings (Charmaz, 2000). Epistemology is the study of knowledge and provides a way to understand and explain “how I know what I know” (Crotty, 1998, p. 3). Epistemologically, the ways of knowing in constructivism emphasize the subjective interrelationship between the researcher and participant, and the co-construction of meaning, offering insight into the nature of knowledge, thereby allowing researchers to be more open to considering other ways of interpreting the results of the research (Mills et al., 2006a, 2006b).

There is an interconnectedness between the epistemological and ontological assumptions of constructivism. Constructivists view knowledge as co-created in collaboration between the researcher and participants through interactions and relationships that develop in the research process (Carter & Little, 2007; Crotty, 1998).

An ontological perspective represents an individual's worldview (Creswell, 2007) and thus impacts what we can research. From a constructivist approach, researchers adopt a relativist ontology, believing that context influences and that reality is constructed through the interaction between the individual and their environment, which is relevant to the individual and their context; thus, multiple realities are possible based on different perspectives and experiences (Charmaz, 2006; Crotty, 2008). In other words, individuals use constructions developed from created realities to help make sense of their experiences, and constructivist researchers believe that people give meaning to reality, events, and phenomena through sustained and complex social interaction (Charmaz, 2000, 2006, 2014). Constructivism does not focus on an ontological reality that suggests reality exists regardless of the human observers but instead on a constructed reality, whereby the role of the human observer contributes to the perception of the recognized reality. Therefore, researchers appreciate and acknowledge that social reality exists as individuals experience and assign meaning to it. Through interaction with study participants throughout the research process, researchers can access multiple views of reality (Crotty, 1998). These various views render reality pluralistic with the possibility for many different interpretations. Consequently, constructivists believe that reality is pluralistic and understandable in the form of multiple, intangible, mental constructions and that other interpretations are possible within the research process (Appleton & King, 1997; Charmaz, 2000, 2014; Lincoln, Lynham, & Guba, 2011). Thus, constructivists consider meaning to be perceived and understood through human experiences and interactions with the world.

Constructivism shares the relativist idea that our understanding of reality is shaped by individual perspectives and experiences, and that multiple realities are possible based on different perspectives and experiences (Crotty, 1998; Lincoln et al., 2011). Within relativism, meaning is viewed as being constructed and co-constructed concerning historical, temporal, cultural, and subjective contexts (Crotty, 1998; Lincoln et al., 2011). In other words, reality is socially constructed (Crotty, 1998; Lincoln et al., 2011), as seen through the differing interpretations of a phenomenon at different times and places within history (Crotty, 1998). Consequently, people will have different knowledge and realities dependent upon their individually and socially constructed worlds (Crotty, 1998). As such, there is no attainable truth but rather multiple realities subject to various interpretations from a constructivist lens (Charmaz, 2014). The underlying assumption from the perspective is that meanings are temporal and dynamic and only reflect the participant and researcher at that moment. Epistemologically, knowledge is co-created in collaboration between researchers and participants through interactions and relationships that develop in the research process (Carter & Little, 2007; Crotty, 1998). The co-creation of knowledge is compatible with the philosophical views of constructivism, in which people construct meaning as they interact and engage with the world (Crotty, 1998).

From a relativist ontology, people believe that reality is a limited subjective experience (Denzin & Lincoln, 2000) and only exists within one's thoughts (Levers, 2013). Said differently, reality from a relativist perspective is consistent with an individual's subjective experience. As such, the research aims to understand the subjective experience of reality and multiple truths (Levers, 2013). Through interaction with the study participants, we can see the implications of a constructivist approach throughout the research process. For example, the researcher's influence on shaping constructions is evident in selecting a theoretical paradigm and research methodology for the research question and the study setting (Charmaz, 2000, 2006, 2014). These methodologic decisions made by researchers impact their study design, specifically what and whom they will include in their research study. Charmaz (2003, 2006) also describes creating a shared reality that evolves as a function of the mutual relationship between the researcher and participants.

Recognizing the researcher's role in the co-construction of knowledge, constructivist researchers strive to practice reflexivity by remaining self-aware throughout the process, acknowledging preconceptions, values, and beliefs. Practicing reflexivity allows understanding to emerge (Heath & Cowley, 2004), accepting that people cannot merely ignore prior understandings, knowledge, and decision-making but instead bring these experiences into the research process and analysis. Accordingly, researchers within constructivist GTM acknowledge the historical, cultural, temporal, social, and subjective circumstances and decisions the researcher brings (Benoliel, 1996).

The terms constructionism and constructivism are sometimes used interchangeably, even by Charmaz herself, which can lead to confusion and a lack of clarity in the research process (Charmaz, 2008b; Ward et al., 2015). Within constructivism, in contrast to constructionism, as described by Charmaz, there is an acknowledgment of the researcher's perceptions' role in the construction and interpretation of data. Charmaz (2000, 2014) purports that within a constructivist approach is a recognition of the complexity of social life influencing both the participant’s and the researcher’s social co-construction of reality and knowledge while acknowledging the influences that the researcher brings to the research, process, and outcomes. Charmaz (2000) sees subjectivity as inseparable from social existence and believes that her constructivist approach to GT provides an orderly inductive method that guides data collecting and analysis. Further, Charmaz contends that her GT approach allows for developing a middle-range theoretical framework to explain the data. As such, constructivist GT is within an interpretive paradigm, and Charmaz (2006, 2008a) asserts that the knowledge produced within the paradigm is situated within the context in which it is produced. By way of explanation, the subject of the research and knowledge created is contextually constructed and reflective of the cultural, historical, and social situations in which they exist (Charmaz, 2006, 2014). From this approach, Charmaz (2006, 2014) believes the researcher to be an active participant in theory development and a co-constructor of knowledge. Hence, Charmaz (2006) formally describes her approach to GT as constructivist grounded theory within an interpretivist paradigm based on the assumption of a distinct reality situated in a dynamic world with multiple different realities.

Understanding the philosophical underpinnings of a chosen research methodology is essential to recognizing how the research paradigm corresponds with one's own beliefs about the nature of reality, truth, and knowledge. Accordingly, one must make explicit one's beliefs about the nature of reality and how knowledge develops. To achieve this goal, I expand on the philosophical underpinnings of CGT, specifically constructivism, relativism, and symbolic interactionism, and the areas of congruence and methodological implications of CGT to my research study. I locate myself within a constructivist epistemology, wherein constructivism aims to understand the complex world of lived experiences from the perspective of those who live it. Constructivism resonates with my background in pediatric nursing and family-centred care, as my practice centres on striving to understand the experiences of my patients and their families. Through the constructivist lens, I can obtain first-hand knowledge of AYA transplant recipients' and families' life experiences while attending to the details, complexity, and meaning of their everyday lives through shared constructions of meaning and knowledge with participants (Charmaz, 2006).

My aim with the study was to construct a substantive grounded theory of the experience of AYA transplant recipients in their transition from pediatric to adult healthcare and how they managed the transition process. A *substantive* theory is focused on a single domain and is useful when there is limited knowledge about a topic (Glaser, 1978). The study's substantive domain of focus was how AYA transplant recipients managed their healthcare experience. I employed GT methodology to answer two questions: (a) what was the common problem experienced by participants, and (b) what did participants do to manage that problem? How participants go about resolving their problems is most often, although not always, positioned around one core conceptual process (Glaser, 1978).

The principles underpinning my philosophical position included my view that there is no single objective reality, but human perspectives, shared interactions, and attributed meanings construct our reality. Accordingly, I used a qualitative approach to explore how AYA transplant recipients viewed their world and created meaning from their diverse life experiences related to transition. Qualitative methods also enabled individuals to share their stories about their specific experience and their thoughts, feelings, needs, and desires in their own words from their perspective. However, the decision to use the GT methodology to explore AYA transplantation and transition to adult care did not come easily. Through my doctoral coursework and professional discussions in the clinical practice setting, I explored various methodologies, including phenomenology and ethnography, before embracing grounded theory as a methodology that resonated with me and was best suited to address my research question. The specific initial research question I intended to answer was: *How do adolescent and young adult kidney and/or liver transplant recipients manage the transition from pediatric to adult care?* The research question reflected my desire to understand how AYAs prepare for and engage in the transition process and how nurses and other healthcare practitioners can support the psychosocial adaptation of AYA transplant recipients through the transition process.

I defined my approach to GT as constructivist in this research study to address the issue, as outlined by Charmaz (2006, 2014). I aligned with a constructivist approach to GT, recognizing how my values and previous experiences in pediatric transplant nursing practice influenced my approach to the research process and subsequent theory development. I viewed myself as an active participant in the research process rather than an objective witness not involved in the data or emerging theory. Charmaz's (2000) constructivist approach to GT, as detailed in her text and other publications with a detailed format for collecting and coding data, was helpful for a novice researcher.

Embracing a CGT approach to examine AYA transplant recipients' healthcare transition guided the discovery of theoretically complete explanations to formulate a logical, systematic, and explanatory grounded theory of the experience for the population (Charmaz, 2014). The use of CGT allowed for the capture and understanding of healthcare experiences. It has a strong history of contributing to theory development and explanation in healthcare (Foley & Timonen, 2015). Thus, given my strong connection to nursing practice, engaging in a CGT study added to nursing knowledge of transition through the generation of a midrange substantive theory. Constructivist grounded theory methodology was directly congruent with the aim of my study. It was an appropriate and helpful approach to answering my research question, emphasizing the need to understand the context of transplant recipients to allow for an understanding of their actions and experiences. The approach helped elucidate an understanding of how AYAs manage the transition experience and the relationship between AYA transplant recipients, the healthcare environment, and the healthcare providers contributing to their transition experience.

3.2 Research Design

The goal of GT is theory development that answers the following: *What is the common problem experienced by participants*, and *how are participants trying to solve that problem?* (Annells, 1997; Charmaz, 2000; Glaser, 1978). Grounded theory guides analytic strategies to answer these questions rather than offering specific data collection techniques to generate a pattern of behaviour that is relevant for all participants (Charmaz, 2000, 2006, 2014). Despite the different methodological approaches to GT, the universal aspects of the method include: (a) concurrent collection and analysis of data; (b) an iterative data coding process; (c) comparative methods; (d) memo writing aimed at the construction of conceptual analyses; (e) sampling to refine the researcher's emerging theoretical ideas; and (f) integration of a theoretical framework (Charmaz, 2000). Furthermore, theoretical sampling is an essential component of GT directly linked to SI and intricately linked with iterative data collection and analysis. In this section, I detail each aspect of the research design, beginning with an overview of sensitizing concepts and a comprehensive discussion of participants and recruitment. Following, I outline the ethical considerations and research processes in detail.

3.3 Sensitizing Concepts

The concepts brought into the research by the researcher are considered sensitizing concepts (Schreiber, 2001). The current literature on healthcare transition provided concepts that served as a lens for interpretation during data analysis. These sensitizing concepts acted as a guide to help me make sense of the data and understand the experiences of AYA transplant recipients transitioning to adult-focused care. Using these concepts, I identified patterns, themes, and relationships within the data that would have otherwise been difficult to see. The sensitizing concepts helped me focus on key aspects of the data relevant to the research question and develop a deeper understanding of the participants' experiences. For example, the findings from previous studies suggest that fear, a lack of adequate preparation, or both may contribute to the experience of healthcare transitions for AYA transplant recipients (Begley, 2013; Fegran et al.,2014; McCurdy et al., 2006). Thus, guided by these sensitizing concepts I remained open to the data to understand how patients' and parents’ feelings about the transition process impacted their experience. However, following Schreiber’s (2001) caution that over-attention to sensitizing concepts may blind the researcher to other concepts in the data, I needed to remain open to what was presented in the data.

3.4 Setting and Research Context

The research setting is essential as it has contextual implications for the participant experience. Attending to the research location also helps ensure that the environment promotes trust and security for participants and does not add a burden with travel accommodations. An important consideration of the research setting and context is the ongoing COVID-19 pandemic and the associated global impacts on the healthcare system and the research design. In response to the COVID-19 pandemic, the Canadian government declared a state of emergency in March 2020. As a result, various cities and provinces across Canada experienced multiple lockdowns restricting individual movement and in-person activities due to resurgences of COVID-19 variants and increasing case counts (Newman et al., 2021), meaning that most research activities were paused, discontinued, or reimagined to limit face-to-face activities (Newman et al., 2021).

Adaptations were required in the context of this doctoral study to address alternative participant recruitment methods in response to people remaining at home and the hospital settings having highly restricted access with closures to students and researchers, in addition to the additional demands and responsibilities on people during the global pandemic event (Newman et al., 2021). Consequently, although I intended to engage in recruitment at pediatric and adult facilities with face-to-face interviews, the research setting for the study was shifted to an online virtual environment. However, following the shift, the virtual nature of the study design allowed for representation from two provinces, which would likely not have been possible otherwise. In Canada, the health systems are publicly funded, with specialized services, such as solid organ transplantation, limited to a network of provincial hospital networks. Thus, the necessary study redesign expanded the setting to include health systems across Canada, with participants from two Canadian provinces, Ontario and British Columbia. Additionally, by including online blogs and stories as a data source, as detailed later in the chapter, the experiences of recipients from centres within the United States enriched my reach for data collection.

3.5 Study Participants

The key informants in GT research are those participants with experience of the phenomenon under study. In this study, the sample population was drawn from three distinct groups, including AYA adult renal/liver transplant recipients (Group A), their parents (Group B), and Registered Nurses (RN) who had experience caring for them (Group C). Inclusion criteria for Group A aimed to capture participants between the ages of 12 and 28 who had been transplanted in a pediatric care centre and identified as having transitioned to adult-focused care post-transplant. Group B and C participants included caregivers of pediatric transplant recipients and healthcare professionals who identified as having experience caring for them, respectively. The recruitment of interprofessional team members was limited to those who had worked with transplant recipients for a minimum of six months, self-identified as having cared for AYA transplant recipients between the ages of 12 and 28 years, and who expressed an interest in discussing healthcare transition. Although my study was open to all interdisciplinary healthcare providers, only registered nurses participated in my research. The participant populations were enhanced by analysis of online digital stories.

Recognizing that transition is a process that occurs over time, inclusion criteria included patients who had been transplanted a minimum of six months from the time of study participation. The elapsed time from transplant was an essential criterion because it ensured that participants had adequate time on the standardized post-transplant immunosuppressive regime, thereby providing an opportunity to adapt to the transplantation experience within typical conditions and had begun to internalize their experiences. Bosma et al. (2011) and Feinstein et al. (2005) utilized a similar parameter to capture the effects of transplantation while allowing for a period of adjustment to the altered health condition and lifestyle changes.

Some individuals expressed interest in participating in the study but were not included as they did not meet eligibility criteria due to their age at transplantation and transition or having a significant developmental delay or psychiatric disorder that would impede their participation in the study and the ability to provide informed consent (Fredericks et al., 2008; Simons et al., 2008). The complete exclusion criteria for transplant recipient participants included:

- Presence of solid malignancy;
- Actively being treated for a post-transplant lymphoproliferative disorder (PTLD);
- Diagnosed with a significant developmental delay; and/or
- Diagnosed with a psychiatric disorder that would impede participation.

3.6 Sampling of Study Participants

The sampling strategies and processes used within GT begin with an initial purposive sampling approach and then move into theoretical sampling, which continues throughout the process of theory development. For my study, I started the sampling process with purposive sampling, seeking participants based on the study's aims who identify as having experience with transplantation and transition by sending letters of introduction to key informants through social media (Instagram and Facebook). As the study progressed and I analyzed the data, I used theoretical sampling to guide data collection further, as detailed below.

Theoretical sampling is another essential component of grounded theory, intricately linked with iterative data collection and analysis. The process of theoretical sampling is intentional and a strategy I used to expand on emerging categories to develop a rich theory that accounted for the variation of participants' experiences (Charmaz, 2006; Glaser, 1978). Through theoretical sampling, I sought out participants to elaborate on and follow up on concepts emerging from the ongoing analysis to develop categories (Charmaz, 2006). I used theoretical sampling to pose follow-up questions to participants, address outstanding questions and contradictions, determine whether they belonged within the theory, and created detailed categories as the theory emerged through data analysis. As the study proceeded and data were collected and analyzed simultaneously, I followed the principles of theoretical sampling. I used concepts arising from the analysis to direct further sampling to elaborate on the developing theory (Schreiber, 2001). Additional sampling included interviewing nurses who had experience caring for AYA transplant recipients in the pediatric or adult setting. Consequently, sampling, data collection, and data analysis continued simultaneously until I reached data saturation or the point at which no further data provided any other properties of the categories, and no new theoretical insight occurred.

3.6.1 Description of Study Participants

I attempted to recruit participants in Group A as young as 12. However, the youngest participant was 18 years old at the time of the interview, as summarized in Table 2 below.

Table 2

Socio-Demographic Characteristics of Participants

Participant's Characteristic Pseudonyms	Sex	Age at Interview	Age at Transplant in Years	Type of Transplant
Group A: Adolescent and Young Adult Transplant Recipients				
Jane	Female	28	11, 17	Liver
Leila	Female	24	4months, 20	Liver
Nancy	Female	27	14	Liver
Riley	Female	26	12	Liver
Sarah	Female	26	17	Liver
Andrew	Male	26	14	Liver
Bruno	Male	28	3, 23	Kidney
Josh	Male	18	16	Kidney
Online Story	Female	n/a	8	Kidney
Online Story	Female	n/a	12	Liver
Online Story	Female	n/a	12	Kidney
Online Story	Female	n/a	17	Kidney
Online Story	Male	n/a	7	Kidney
Online Story	Male	n/a	10	Liver
Online News Article	Male	n/a	3	Kidney
Group B: Parent				
				Child's Transplant
Poppy	Female (mother)		13	Liver
Donna	Female (mother)		12	Liver
Bryon	Male (father)		17	Liver
Online Blog	Female(mother)		7	Kidney
Group C: Pediatric Healthcare Professionals				
			Years of Experience	**Education**
Kelly	Female	34	8	BScN
Ariya	Female	43	16	BScN, MN
John	Male	38	18	BScN, MN (in progress)

Similarly, I aimed to recruit HCPs across disciplines at pediatric and adult care centres. Yet, I did not interview anyone outside of nursing or the pediatric centre who had experience caring for this patient population. Eight interview participants in Group A represented transplant recipients, including three cis-males and five cis-females, and an additional seven online digital sources, including stories and news articles represented a total of fifteen participants. Participants received either a liver or a kidney transplant while in pediatric-focused care. Three participants in Group B (Parents of Transplant Recipients), including one cis-male and two cis-females, were enhanced by one digital online blog for a total of four participants. Group C, Transplant Healthcare Professionals, included three participants comprised of 1 cis-male and two cis-females with a range of experience as baccalaureate pediatric nurses, two who were master's prepared and the third in progress. The participants ranged in age from 34 to 43 years old, with an average age of 38.3 years of age, a range of 8 to 18 years of nursing experience, and an average length of 8.7 years in nursing practice.

3.7 The Recruitment Process

Ethics approval was received before initiating the participant recruitment process. I used various methods to recruit study participants, mainly focusing on social media platforms, including Facebook and Instagram, and posting recruitment posters to provide information about the study (Appendix B). Although my primary focus was on AYAs who had received a renal and liver transplant and their families, healthcare member stakeholders with experience caring for transplant recipients were also key informants in helping to develop a robust grounded theory. I engaged stakeholders with knowledge of the patient population and transition as participants to facilitate increased trust and credibility. I also collaborated with administrators of social media sites to gain access to private Facebook online transplant groups to identify potential research champions to facilitate recruitment. After initiating contact and establishing preliminary information, I provided an introductory letter (Appendix C) and a study overview (Appendix D), including the purpose, process, and patient participant recruitment goals, and answered questions. Once identifying potential participants, I engaged in private online chats, providing my contact information and study details with letters of introduction to the study detailing the research. In some instances, I initiated a private online conversation within social media to introduce myself and study to individuals sharing experiences of transplant and transition, sharing the introductory letter and summary information sheet (Appendix C & D).

3.8 Data Collection

Within GT, everything is considered data, with the emerging theory guiding the data sources (Glaser, 1978). Data generation is a simultaneous process between data collection and analysis, utilizing *constant comparative analysis* and *memo writing* throughout *theory emergence* (Charmaz, 2000; Schreiber, 2001). These concepts are discussed in more detail later in the chapter. Data sources may include participants and observation, news reports, patient charts, staff bulletins, formal written policies and procedures, or nursing reports. Interviews are a way to collect rich data, allowing the gathering of specific data and immediately pursuing emerging ideas and issues while identifying the unexpected (Charmaz, 2014). Data sources for the study included field notes, individual virtual interviews, online stories, social media posts and discussions, and online virtual chats.

3.8.1 Participant Interviews

The most common method for data collection in qualitative research is in-depth interviews (Charmaz, 2006). In GTM, we often generate data through participant interviews that usually begin with a broad question, followed by more specific probing questions to expand on ideas or concepts; however, data are only one interpretation among multiple interpretations of a shared or individual reality (Charmaz, 2000). I developed an interview guide to facilitate the interview process, drawing on other studies engaging with patients, families, or healthcare workers. Once consent for participation was received (Appendix E), we arranged a mutually convenient time to connect for the interview and prepared participants for the discussion.

The initial research guide (Appendix F) helped to guide the interviews and was modified over time, keeping the questions open-ended and supported with additional probing questions that reflected the data collected and emerging themes (Charmaz, 2014; Franklin et al., 2019; Schreiber, 2014). The interview guide with draft questions helped facilitate data collection and ensured that I met the interview objectives (Schreiber, 2001). Through participation and engagement in the interview process, I co-created a narrative with participants, with meanings focused on conversation guided by the initial questions related to my study's purpose (Charmaz, 2014). Through a constructivist lens, it was essential to recognize the co-construction of knowledge through the interview process because participants and I brought our own experiences to the interview process. It is also important to note that within CGT, participants' stories are regarded as individual interpretations of what happened related to the studied experience rather than accurate accounts of the events (Charmaz, 2006).

Traditionally, in-person interviews are considered the gold standard for conducting interviews as they allow for a natural encounter whereby communication between the interviewer and participant allows for building rapport while simultaneously observing body language and the environment (Irani, 2019). Despite face-to-face interviews prevailing as the most common way qualitative researchers engage with participants in healthcare research, interviews have shifted to explore alternative ways to engage with participants. Consequently, interviews have expanded to include virtual means due to the COVID-19 pandemic and the associated social distancing requirements, travel bans, and other restrictions posing practical implications for traditional methods (Saarijärvi & Bratt, 2021; Sah et al., 2020). Alternative solutions such as video interviews and other forms of online communication and data collection methods have expanded in use because of the quick digitization process fueled by the pandemic and recognition of the logistical and practical convenience (Irani, 2019; Saarijärvi & Bratt, 2001; Sah et al., 2020).

In response to the pandemic challenges and communication technology advancements, videoconferencing has become invaluable in health research (Irani, 2019; Saarijärvi & Bratt, 2001; Sah et al., 2020). More recently, with advancements in communication technology and the wide availability of the Internet, videoconferencing is gaining increased attention as an alternative to traditional face-to-face or telephone interviews for qualitative research. Videoconferencing as a communication technology allows for a real-time, online synchronous conversation, with the ability to send and receive audio and visual information (Sah et al., 2020; Salmons, 2012). Compared with other online methods for qualitative data collection (i.e., email interviews, surveys, or online forums), videoconferencing more closely resembles the in-person qualitative interview (Sah et al., 2020; Tuttas, 2015). Realizing the many challenges posed by the COVID-19 pandemic in connecting in person with participants, the recruitment and interviews were conducted using virtual means.

After participant recruitment, I collaborated to arrange a meeting time for a virtual interview, negotiating a convenient time for us both. At the outset of the first interview, I obtained informed verbal and written consent and permission to audio and video record the interviews via the Microsoft Teams platform. All participants were interviewed once. I conducted online interviews in a quiet, personal location, free of interruption; this gave participants a feeling of privacy, which supported thoughtful and honest responses to the interview questions. The use of video conferencing helped ensure that rich data related to body language, which is an essential component of human communication, was not lost. This aspect of nonverbal communication provided valuable insight that enhanced data analysis by providing essential context for understanding participants' verbal responses by helping to identify and interpret emotions, sarcasm, irony, and other nuances that would not be apparent from text or audio alone. Attention to non-verbal cues also improved accuracy in data collection, as body language served as a complementary source of data, allowing me to cross-check and verify the accuracy of the information collected. For example, I observed for inconsistencies between verbal and nonverbal cues, which may have indicated that a participant was not being entirely truthful or was experiencing discomfort or uncertainty. Furthermore, by observing body language, I was able to adapt my approach to better engage with participants to create a comfortable environment for data collection, leading to more in-depth and meaningful responses from participants, thereby contributing to the development of trust between myself as the researcher and the participant.

Utilizing online modalities helped to limit travel costs related to the research study and facilitated scheduling and participation, allowing for a broader Canadian sample. Additionally, the virtual nature of the study allowed participants to engage in the research interview from a setting of their choice with privacy within their control, thereby promoting participant safety, comfort, and confidentiality, as participants had the power to ensure a private meeting space while participating in the online interview. I negotiated meeting times with participants to meet their scheduling constraints and ensured their safety by eliminating the need to travel to the hospital or another site to participate.

I acknowledge personal experiences that contributed to the interview process, including my background in pediatric transplant nursing, communication skills, and theoretical and professional background. Moreover, the understanding developed of participants' stories is my interpretation of what participants disclosed during the interview. Thus, I began with a semi-structured interview format, using initial open-ended questions based on my literature review to guide the interview. Although I used an interview guide (Appendix F) to lead my questioning, the interview questions evolved throughout the research process due to theoretical sampling, reflecting concepts that emerged which was captured in my memos and reflected in future interviews.

Virtual interviews were audio and video recorded and transcribed verbatim. Following each participant meeting, I wrote reflexive field notes to capture the interview setting, tone, and any other thought-provoking comments that arose. To immerse myself in the data collection, I listened to the recording several times, noting repeated words or those with tangible expressions. Once the interview transcript was complete, I reviewed it with the recording to check for accuracy and removed any participant-identifying information. Once de-identified, I used the NVivo 12 qualitative data analysis software program to manage the transcripts. Through the iterative and reflexive process, I had the opportunity to become further immersed in the data while considering multiple perspectives of the data.

I aimed to interview each participant at least once; after reviewing and transcribing the interviews, I concluded that no follow-up interviews were required to clarify statements, provide further details, or clarify the data collected. Although I had hoped to interview at least two participants in pediatric care and then again after the transition to adult care, that was not feasible due to timing, as no participants were identified or available. I revealed and co-constructed meanings from the data through participation and engagement in the interview and data collection process. I used data sources, including individual participant interviews and unique data sources such as social media posts, blogs, and online stories.

3.8.2 Online Virtual Chats

In some instances, participants expressed interest in the study but had challenges committing to a virtual interview time. In these situations, I attempted to connect with participants on multiple occasions, setting meeting times with non-attendance by participants. These participants continued to engage with me, asking questions and providing information through the online chat function of social media platforms Facebook and Instagram. After being unable to establish a virtual meeting time with these three participants, we interviewed via online chat, allowing for participation and engagement with great success (Bour et al., 2021; Saarijärvi, 2001; Sah et al., 2020). Some participants seemed comfortable engaging, which may reflect the generational experiences of Group A participants, who have frequent opportunities to express their thoughts and feelings through these text communication means and social media presence

(Bour et al., 2021). Thus, social media complemented traditional health research strategies for participant recruitment and engagement (Bour et al., 2021).

3.8.3 Online Stories

Other sources of data were publicly posted online stories, blogs, and news articles detailing experiences of transition (Benavides, n.d.; Children's Mercy, n.d.; Cincinnati Children's, n.d.; Laucius, 2013; Novotny, 2021; Sternhagen, 2019; The Kidney Foundation of Canada, n.da.; The Kidney Foundation of Canada, n.d.b). In these rich pieces, the voices and experiences of the recipients were presented and enriched by the patient's words. These sources were coded in the same way as participant interviews, contributing to the development of the resultant grounded theory. Using these online sources to collect information about experiences, perceptions, feelings, and ideas is a method supported by Wilson et al. (2015) as a way to help enhance data collection. Additionally, these data sources helped expand the reach of the setting to include individuals from the United States.

3.8.4 Document Review

In alignment with GT methodology, I entered the research without expectations of what I would uncover in the data. However, I entered the research process with some familiarity with pediatric organ transplantation, transition to adult care, and the associated literature, given my professional practice experience in the field. Some examples of documents that furthered my understanding of the experience for participants included social media sites for AYA transplant recipients and transition experiences, such as Facebook and Instagram and other informal data sources shared by teenage transplant recipients. Through prior study and work, I was aware of and reviewed additional sources of data, including:

- SickKids Transplant and Regenerative Medicine (n.d), guidelines for the transition from pediatric to adult care
- Canadian Pediatric Society recommendations to improve the transition to adult care for youth with complex health care needs (Toulany et al., 2022)

- Canadian organ transplant information and statistics (Canadian Institute for Health Information, 2020)

A review of these documents, along with a review of social media posts, transition documents and guidelines, and online stories and blogs, enhanced the robustness of the study and the experiences shared by participants by furthering my understanding and providing context to the study data.

3.9 Data Analysis

Data analysis is a concurrent process with data collection, controlled and directed by the relevance and workability of the emerging theory, guided by theoretical sampling (Corbin & Strauss, 2008). It is important to note that we cannot separate the process of data analysis from the simultaneous process of data collection and generation. I used the tenets of GT, initially advanced by Glaser and Strauss, to develop theory, including memoing, theoretical sensitivity, concurrent data collection and analysis (Corbin & Strauss, 2008).

3.9.1 Coding

I engaged in data analysis through a process of coding, which aimed to transform raw data into theory, thereby grounding the theory in the data (Glaser & Strauss, 1998; Schreiber, 2001). Although given different terms within classical and constructivist GT, coding is primarily achieved through three levels of overlapping processes (first, second, and third-level coding) that occur fluidly. In the process, I hypothesized relationships between the concepts identified from small data sections and abstracted them into more substantial, overarching categories (Schreiber, 2001). However, it is essential to note that, despite all attempts at clearly delineating and defining coding, the actual coding process was infinitely more complex than any explanation may suggest.

According to Charmaz (2006, 2014), coding allows for scaffolding the analysis to build a grounded theory, thereby providing an essential link between the data and theory, helping to move from the transcript to theory development. Coding encouraged me to ask questions regarding code development and provided answers that were supported and grounded in the data (Charmaz, 2006). Consequently, the development of codes within CGT is not a neutral act but is open to multiple interpretations, influenced and constructed my perspective as the researcher (Charmaz, 2014). I mediated variability by validating interpretations during the research process by grounding codes in data, checking interpretations with participants, and continually returning to the data to re-examine the analysis (Charmaz, 2006). The coding within GT is an iterative, inductive, and deductive process that allows for information from each interview to be incorporated and reflected into each subsequent interview and observation.

As suggested above, data collection and analysis occur concurrently using the process of constant comparison. The simultaneous data collection and analysis distinguish GT from other qualitative approaches (Charmaz, 2006, 2014). Through the concurrent process of constant comparison, I simultaneously collected and analyzed data, examining each piece of data and comparing how it related to subsequent or different data, concepts, and then concepts back to data and categories (Glaser, 1978; McCreaddie & Payne, 2010). The process allowed for the development of emerging codes and preliminary categories early in the research process. Each participant interview then provided direction for subsequent interviews, data collection, and analysis (Bryant & Charmaz, 2007; McCreaddie & Payne, 2010).

Using constant comparison, I raised data analysis to higher levels of abstraction by comparing data to data and looking for similarities and differences (Charmaz, 2014). As these comparisons were between all new and existing data, I systematically identified the contextual conditions of the recorded data (Charmaz, 2006). Arguably, constant comparison can be considered the most crucial aspect of GT because it guides the development of a theory, allowing it to be grounded in the data.

I returned to the data at each level of analysis, altering the codes, developing categories and data sources, and adjusting future interviews to reflect the emerging theory (Charmaz, 2014). Patterns, explanations, and models emerged and were integrated into a developing theoretical framework by constant comparison. Through constant comparison, concerns about remaining at a descriptive level of the phenomenon, as Schreiber (2001) described, are addressed by facilitating the movement to a level of abstraction to produce a theory. Using constant comparative analysis, I used data analysis at increasingly abstract levels of codes to guide further data collection. The process led to theoretical coding, which Glaser (1978) describes as a process that guides the conceptualization of how the substantive codes may relate to one another. As theoretical coding proceeded, I hypothesized potential relationships between categories and linked the data to a theory (Glaser, 1978; Charmaz, 2006).

I began coding with line-by-line or *first-level coding*, which required careful study to conceptualize ideas (Charmaz, 2006; Schreiber, 2001). I used codes to conceptualize small portions of the data, using the participant’s own words (Charmaz, 2006; Schreiber, 2001). I analyzed each phrase using line-by-line coding (see Appendix G for an example of line-by-line coding), producing initial codes for the data by using the words of the participants to label the coding unit, otherwise known as *in vivo codes, and focusing* on the participants' views (Charmaz, 2006; Schreiber, 2001). To ensure the codes fit, I remained close to the data, using gerunds, or action words ending in *-ing* where possible to help focus on the analysis (Charmaz, 2006; Schreiber, 2001).

I moved to *second-level coding* or *focused coding* by separating, sorting, and collapsing the data by consolidating the first-level codes into concepts, representing a higher level of abstraction (Charmaz, 2006; Schreiber, 2001). Coding level can be considered substantive coding, in which the empirical substance of the area of research can be conceptualized (Bryant & Charmaz, 2007; Glaser, 1978). I coded and sorted data more precisely, thereby making this level of coding highly reliant on the initially identified codes during the line-by-line coding (Charmaz, 2000). I constantly compared emerging data to existing data, which allowed for collapsing first-level codes into categories (see Appendix H for an example of second-level coding), creating a coding hierarchy (Charmaz, 2006; Schreiber, 2001). In *third-level coding*, I elucidated the relationship between categories through the evolution of *theoretical codes* (Schreiber & Stern, 2001). I developed theoretical codes, hypothesizing how the substantive codes related to each other and then integrating them into a theory (see Appendix I for an example of third-level coding) (Bryant & Charmaz, 2007; Glaser, 1978; Schreiber, 2001).

Although the presentation of levels of coding is linear, coding is a cyclical, iterative, and dynamic process in which all three groups may co-occur, where I moved back and forth between substantive and theoretical codes (Schreiber, 2001). Through the process, I moved from specific incidents to higher-level abstractions by checking against the incidents (Schreiber, 2001). To achieve a higher level of abstraction, I followed Glaser's (1978) suggestion in which I continually questioned: *What is this data a study of? What category does this event indicate? What is actually occurring in the data?* Through these questions, I was able to focus on patterns to help explain what was happening in the data by using the process of *constant comparison*, looking for similarities and differences among data sources to illuminate gaps and help identify where more information is needed (Glaser, 1978; Schreiber, 2001).

3.9.2 Memo Writing

Although memoing is fundamental to GT, there is no set requirement for how memos are structured, providing freedom to record ideas and hypotheses in a personally meaningful way. In creating memos, I followed the structure Schreiber (2001) described in guiding the process, with all memos dated, titled, cross-referenced, and filed (p. 72). By recording reflections, ideas, thoughts, feelings, and impressions, I developed a chronicle of the research journey, outlining my research activities and emerging theory. Theoretical notes supported my theory generation while providing a record of ideas and reasons for directions taken in theory development and hypotheses about relationships between the categories.

Memoing is distinctly different from journaling (Glaser, 1978, Schatzman & Strauss, 1973), as memo writing helps capture ideas and reflections upon assumptions, making them explicit and tracking methodological decisions regarding the research (Schreiber, 2001). Thus, the memoing process helped establish an audit trail that supported trustworthiness and provided evidence of *reflexivity* throughout the data analysis process (Schreiber, 2001). To maintain integrity in the qualitative approach of this study, I kept an audit trail throughout the study, demonstrating evidence of a logical decision-making process (Thorne, 2016). The audit trail includes a collection of materials and documentation, including raw data such as audio and video recordings, interview transcripts, theoretical notes, working hypotheses, methodological notes, reflexive notes, and diagrams or figures used to organize evolving concepts (Polit & Beck, 2012; Thorne, 2016). Most importantly, memoing helped me to develop theoretical sensitivity by explicating my ideas, thoughts, assumptions, and beliefs about the substantive area and intentionally bringing these to the data to see if they were supported (see Appendix J for an example of an initial theoretical memo).

Furthermore, theoretical sensitivity is the ability to render something abstract or conceptual, to move to a theoretical level, and is required to find and develop a central phenomenon or core category (Morse et al., 2009; Schreiber, 2001). Schreiber and Martin (2013) equate theoretical sensitivity to what Charmaz describes as abductive logic, which is the process of "identifying all possible explanations for the actions and interactions in the data and checking them against the data to find the most feasible explanation" (p. 6).

Before data collection, I began memoing to help identify what and how I might study transition and my salient issues and experiences with AYA transplant recipients. I used a word processing program accessible across devices, including my password-protected iPhone, iPad, and laptop, to improve the ease of recording and accessing memos. Memos took various forms, including written diagrams (see Appendix K for examples of diagram memos), recorded voice memos, and maps and drawings to help visually cluster data and establish relationships within the data (Charmaz, 2006; Schreiber, 2001b).

I used recorded memos to develop conceptual categories and linkages between categories further. My memos began as accepted and rejected ideas and evolved to more theoretically based notes, suggesting relationships between categories and concepts (Schreiber, 2001). Writing memos is considered an intermediate stage between coding and writing the first draft of the completed analysis (Charmaz, 2000), allowing the theory generation by bridging the gap between lists of codes (Schreiber, 2001). The memoing process was an essential component of data analysis, which entailed making ongoing notes about ideas, observations, and questions that arose through data collection and analysis (Schreiber, 2001).

3.10 Theoretical Sampling and Saturation

Traditionally, theoretical saturation of categories occurs when new data no longer provide new theoretical insights or further elaborate on the properties of a class (Charmaz, 2006; Glaser & Strauss, 1967). Thus, concurrent data collection and analysis process occurs until theoretical saturation is achieved (Charmaz, 2006; Glaser & Strauss, 1967). In other words, when new data collected no longer provides theoretical insight or further elaboration on categories, Charmaz (2000, 2006) and Glaser and Strauss (1967) contend that it can be determined that theoretical saturation has been achieved. In contrast, Braun and Clarke (2021), Sebele-Mpofu (2020), and Thorne (2020) caution qualitative researchers from declaring that they have heard everything and have a full understanding of a topic (Hennick et al., 2017), rendering further data collection redundant. Similarly, Braun and Clarke (2021) critique qualitative researchers using saturation to conclude when they can end data collection. Rather, Braun and Clarke (2013) suggest that data collection using iterative methods would see ongoing amendments to interview guides, thereby making saturation to interview questions impossible.

Consequently, determining when theoretical saturation is achieved can be uncertain as there are no specific recommendations for establishing a sample size or the appropriate number of participants to include in a study within GT. Although theoretical saturation provides a guide to sample size selection within GT, determining when theoretical saturation has occurred is not definitive and relies on researcher discretion (Charmaz, 2006). Accordingly, Charmaz (2006, 2014) and Glaser and Strauss (1967) do not address how to determine adequate sample size in

GT, but instead, state that achievement of theoretical saturation indicates the completion of sampling.

Glaser and Strauss (1967) emphasize that participant numbers are closely linked to theory development and theoretical saturation and that it is impossible to predetermine the number beforehand. In other words, theoretical sampling continues until an emergent theory is attained. As a novice researcher, I sought guidance from the nursing research literature to help determine the sample size at the outset of my research study. However, Glaser and Strauss (1967) claim that it is impossible to know the required number of participants beforehand to achieve theoretical saturation and develop a theory that will answer the research questions. Instead, considerations for estimating sample size are related to the purpose of the study and the number of available participants (Charmaz, 2006; Sandelowski, 1993). I anticipated 20-30 participants to understand the transition experience for AYA transplant recipients.

Considering both perspectives to theoretical saturation, there are practical reasons for researchers to terminate data collection, including funding research and ethic board time limits, or deadline limitations to study (Braun & Clarke, 2021; Leese et al., 2021). Within these contexts, researchers should strive towards richness and complexity of data, rather than declaring saturation has been attained (Braun & Clarke, 2021; Leese et al., 2021). Moving through data collection and analysis, I found that I had reached an emergent theory after analysis of 22 interviews and online stories. I ended qualitative data collection when I considered the concepts and theories nearly complete because of the richness and complexity of the data collected, and no significant new data emerged from continued data collection (Schreiber, 2001). I reached this decision after an interview with a transplant recipient with a very different life course from other participants that involved a challenging childhood and did not produce any novel information about the transition experience. However, acknowledging the position of Braun and Clarke (2021) and Thorne (2020), I did not claim saturation in the study, rather I relied on the data to determine when I had answered the question to form a theory, signalling that the data collection process could end.

3.11 Establishing Rigor and the Methodological Implications

Attending to rigour in a qualitative research study is essential to promote trustworthiness and attention to the dynamic power imbalances between myself as the researcher and study participants (Schreiber & Martin, 2013). Evaluative criteria are applied to qualitative research to achieve rigour and suggestions for improving rigour in GT (Charmaz, 2006; Chiovitti & Piran, 2003; Hall & Callery, 2001; Sandelowski, 1993). Glaser and Strauss (1967) initially described fit, work, grab, and modifiability as essential requirements of GT. Fit refers to how data are applied to categories and their connection. For a theory to fit, it was vital that I did not force the data into my preconceived patterns but instead allowed the theory to develop from the data (Glaser & Strauss, 1967). I ensured fit by engaging participants to ensure my analysis and emerging theory reflected their experiences.

Conversely, if the theory is forced and does not develop from the original data, the theory will have limited validity and will not fit the data (Glaser & Strauss, 1967). The second GT requirement is work, described as the applicability of a theory across multiple domains within a substantive area. A theory that does not work is inadequate because it is not multi-dimensional enough. Grab refers to the interest anyone familiar with the phenomenon would immediately have and be drawn to when presented with a theory, attracting the reader's attention quickly (Glaser & Strauss, 1967). Thus, these concepts can be used to evaluate the integrity of a theory developed by GT.

Lastly, modifiability refers to the openness to correction and change of a theory should new data or evidence emerge (Glaser & Strauss, 1967). My theory remained modifiable until the final drafting of my findings, as I remained open to changes with the introduction of new data or evidence. Another criterion for judging GT rigour is examining the study enactment. The evaluation of the study features includes the implementation of purposive and theoretical sampling, concurrent data collection and analysis, constant comparison, and memoing (Charmaz, 2006; Chiovitti & Piran, 2003; Hall & Callery, 2001; Sandelowski, 1993).

The criteria for evaluating constructivist GT include credibility, originality, resonance, and usefulness (Charmaz, 2006; Charmaz & Thornberg, 2021). Although there is varied terminology, these suggestions by Charmaz (2006) represent the fit and work described by Glaser and Strauss (1967). Furthermore, following Charmaz's (2006) suggestion, I reflected on my decisions throughout the research process, acknowledging my influence on the process and clarifying that influence. Schreiber and Martin (2013) suggest that attending to rigour through memoing, identifying personal situatedness, and remaining open to sharing with participants equalizes power and fosters reciprocity. I acknowledged the influences I brought to the research process and reflected on it through memos (Charmaz, 2000; Hall & Callery, 2001).

3.11.1 Maintaining Credibility, Originality, Resonance, and Usefulness

Strategies I used to attend to rigour through promoting credibility within my study included using in vivo codes as category names to capture the participant's experience and to integrate their voice into the theoretical development (Charmaz, 2006; Strauss & Corbin, 1998). Thus, as suggested by Charmaz and Thornberg (2021), I maintained credibility by ensuring adequate pertinent data with ongoing comparisons throughout the research process and developing a comprehensive analysis. My credibility was also reinforced by maintaining strong reflexivity throughout the research process by explicating my assumptions through memoing (Charmaz & Thornberg, 2021).

As Charmaz (2006) described, rigour's second tenant is originality. I have offered new insights into the experience of AYA transplant recipients, enhanced by the perceptions and experiences of their parents and healthcare workers, a perspective not previously offered in the existing literature. A multiplicity of perspectives provides a novel conceptualization of transition for the AYA transplant population, thereby asserting the significance of the study (Charmaz & Thornberg, 2021).

I made several adjustments to the study proposal and the research design to capture the best data sources and meet the needs of participants to encourage engagement. The forced shift from in-person recruitment and data collection to online and virtual means due to COVID-19, had unintended benefits such as increased comfort and engagement with the AYA population. Thus, enabling the recruitment of participants who best represented the transplant recipient population, which was critical to study rigour.

The idea of resonance and usefulness, as described by Charmaz (2006), entails the success of the researcher in *c*onstructing concepts that extend beyond just the research participants' experience and also to provide insight while being useful to others (Charmaz & Thornberg, 2021). I ensured that the data collection strategies enlightened participants' experience, focusing on diverse and informative data sources with attention to data quality (Charmaz & Thornberg, 2021). Thus, by attending to these details, I am confident that the resultant grounded theory will be useful to AYA transplant recipients, their parents, and healthcare workers in helping to understand their unique experiences in transitioning to adult-focused care.

3.11.2 Reflexivity: Personal Beliefs, Assumptions, and Motivations

Attending to my philosophical assumptions was the first step in practicing reflexivity. By adopting a reflexive stance for my choice of constructivist CGT methodology, the implications of the choice, and how my position as a pediatric transplant nurse influenced my choices. I also attended to how my philosophical situatedness, values, and knowledge impacted the research process. I recognize the privilege my position as a pediatric transplant nurse afforded me when developing and conducting my research approach. Therefore, I highlight areas of consideration concerning my previous experience and knowledge within the chapter to increase rigour and transparency throughout the research process.

Reflexivity allowed me to consider the influence that the interaction between myself and the participants had on the data, lending more credibility to the study (Hall & Callery, 2001;

Thorne, 2016). Relationality examines the power and trust relationships between me and the participants (Hall & Callery, 2001; Thorne, 2016). Both reflexivity and relationality increases the rigour of GT research by exploring assumptions otherwise taken for granted. Recognizing the importance of reflexivity, I paid attention to reflexivity in the research process to enhance rigour (Charmaz, 2006; Engward & Davis, 2015; Hall & Callery, 2001; Thorne, 2016). To practice reflexivity, I engaged in critical reflection on how I influenced the research process, clearly outlining and describing decision-making related to the research process to allow readers the opportunity to judge and make decisions regarding study credibility (Charmaz, 2006; Glaser & Strauss, 1967; Engward & Davis, 2015; Hall & Callery, 2001). I also acknowledged my location as a pediatric nurse and how the experience influenced my decision to research AYA transplant recipients and healthcare transition using a GT. To further strengthen my reflexivity, I explicated my assumptions in memos, outlining what I expected I might uncover in the research process.

By developing an awareness of my preliminary assumptions, I entered the research process with openness and self-awareness of location throughout the research study and engaged in self-questioning about what I know and how I know it. For example, the decision to exclude lung transplant recipients from my sample is an example of a study decision guided by a preliminary assumption based on my personal experiences with the population. From my professional practice experience, the population has significant differences with regards to survival rates, with pediatric lung transplant recipients lagging far behind other organ groups. Earlier in my doctoral program, I discovered that the median survival rate of lung transplant recipients is 4.9 years, with survival rates greatly varied dependent on primary disease (Kirkby & Hayes, 2014), whereas the survival rates for pediatric liver transplant recipients are 94% at 1-year, 91% at 5-years, and 88% at 10-years (Ng et al., 2012). As a result, I decided to exclude lung transplant recipients from the study of concern that these differences may impact an AYA lung transplant recipient's experience post-transplant and through the transition process. The awareness also continued through data analysis (Charmaz, 2014).

Adopting a reflexive stance throughout the research process, enhanced by memoing, allowed for acknowledgement and questioning of my interpretation of the data (Charmaz, 2006). To aid with the process, I kept memos of personal reflections of observations and interviews that influenced my thinking about the data. I dated memos and documented meetings with my supervisors and committee to discuss my research and data analysis. I ensured to reflect upon questions and discussions that clarified my assumptions and biases. Thus, my reflexivity was imperative to the credibility of my theory as evaluated by the fit, modifiability, workability, relevance or resonance, originality, and usefulness of the generated concepts and ideas (Age, 2011; Charmaz, 2014; Glaser, 1978; Schreiber & Stern, 2001). In essence, the credibility of my grounded theory relates to the trustworthiness of the findings and the developed theory (Chiovitti & Piran, 2003). Thus, as Sandelowski (1993) advises, I aimed to make the research process transparent and auditable while maintaining reflexivity to achieve the goal. By remaining sensitive to potential biasing factors, including the context that may influence my thinking, I aimed to increase my credibility by remaining alert to the potential outside pressures or influences that could have impacted the direction of the study to avoid being manipulated by these demands and through practicing reflexivity (Appleton & King, 1997; Thorne, 2016). For example, I ensured that the perceptions of my colleagues and peers in my place of work did not influence my data collection or analysis, but rather I remained attuned to the study participants and experiences shared.

3.12 Ethical Considerations

In the study, I adhered to protecting human participants by receiving approval from the Human Research Ethics Board (HREB) at the University of Victoria. In this section, I discuss some common ethical considerations for qualitative research, including informed consent, confidentiality and anonymity, and the researcher-participant relationship.

3.12.1 Informed Consent

The concept of informed consent in the research study means that participation is voluntary, with all known benefits and risks openly disclosed to participants at the outset. Although it is an ongoing process, participants could withdraw consent at any time without repercussion. The entire scope of the research study was described to participants at the outset, including the purpose, procedure, requirements, and any potential risks and benefits of participating. The risk associated with participating in the study was minimal. I explained to participants that, although they may not benefit directly from the study, the information may improve the care of patients in the future. I emphasized to participants that participation in the study was voluntary with no impact on their care, regardless of participation or withdrawal from the study. I also obtained audio-recorded consent from participants at the outset of the interview.

Even though the study was about the experiences of AYA, all participants were adults reflecting on their experiences as adolescents. Given the potentially sensitive nature of the topic for participants, the risk of participant harm may have included emotional stress while completing the interview; thus, I ensured protective measures were in place before initiating the interview. If the interview appeared to be causing the participant considerable discomfort or anguish, I would have paused it. Although not required, I could have intervened as a Registered Nurse to provide immediate support and allowed sufficient time for the participant to reflect and decide if they wished to continue. Above all, the success of the interview process depended upon establishing an environment of safety and trust at the initiation of the process and maintained throughout.

A final consideration of informed consent is related to my professional code of ethics and responsibility as a nurse. Although I entered the interview as a researcher, I remained governed by my professional body and code of ethics. Accordingly, if there was any information that was disclosed by participants about intent to self-harm or caused concern for participant safety, I would have been compelled to acknowledge the incident and report it to the appropriate authority.

3.12.2 Confidentiality, Anonymity, and Protection of Participant Information

Another important ethical consideration is maintaining confidentiality and protecting participant identity. I protected participant confidentiality and anonymity by identifying participants using an alias of their choice, and only conducting interviews privately to protect their identity. The patient pseudonyms were used for documents and files and were known only to the researcher and participants.

All participant and study information has been managed electronically, including copies of data, audio and video recordings, and corresponding transcripts through storage on a secured and password-protected computer to maintain participant data security. Furthermore, as needed, access to all data has been limited to myself and my doctoral supervisor and committee. Upon conclusion of the study, I have continued to secure all electronic data and will do so for an additional five years on a password-protected computer (Polit & Beck, 2012).

3.12.3 Researcher-Participant Relationship

The relationships I developed with recipients, parents, and healthcare provider participants as the researcher was an integral part of the research process in constructivist GT because we were co-creators of knowledge (Charmaz, 2006, 2008a). Consequently, there were added ethical considerations because these relationships could have had a real or perceived power imbalance depending on the participant. In my role as a nurse, there are inherent power differences as a nurse often in a power-over position. Thus, although I was not in a formal position of power, recipients and parents may have perceived me as being in a position of power. To address these considerations, as a researcher, I participated in the process *with* participants as co-creators of knowledge, ensuring patients and families knew that their participation would not impact their care in any way, and that their identities would be protected.

Also, I emphasized to participants that their identities would be protected, and their participation in the research study would not be shared with anyone within or outside the healthcare team.

The relationships with healthcare providers differ from those of recipients and parents in that there is a more equal distribution of power based on the nature of the healthcare and interprofessional teams. However, because of my previous role as Clinical Support Nurse on the Transplant unit, I may still be seen as a leader to nurses who may believe that there is power associated with the role. Therefore, I acknowledged this position and any potential participants' perceptions. To address this, I was transparent with recipients regarding the research and process to address any perceived power imbalances. Similar to the approach taken with recipients and parents, I engaged in the process *with* participants as co-creators of knowledge, not presenting myself as an expert in their experience. I highlighted to these participants that although I had my own experiences, I wanted to hear from them about their unique experiences. I also underscored protecting their identities and confidentiality in participating in the study.

3.13 Dissemination of Findings

Grimshaw et al. (2012) highlight the importance of examining knowledge translation (KT) strategies. They suggest that KT is more likely to be successful if an assessment informs the strategy choice of potential barriers and facilitators. Most importantly, I will share the discovered knowledge to put the knowledge into action (Grimshaw et al., 2012). Thus, research findings, or knowledge translation (KT), will be disseminated through different forms, including academic publications, conference presentations, and poster presentations with three distinct sectors: healthcare organizations, educational settings, and academia.

I will share the learning from the study with participants and the broader organization of the hospitals to disseminate the information to improve patient care and experiences with transition. By engaging with practice leaders and stakeholders in my organization, including key individuals involved in patient care, hospital administrators, and healthcare providers, I can present the research findings and discuss their implications for improving patient care and experiences. I will also consider using social media platforms, such as Twitter and Instagram, to disseminate the research findings to a broader audience and engage in discussions with stakeholders in healthcare.

Disseminating the research findings in educational institutions where I am a nursing faculty member is important for my ongoing professional development. By sharing these findings with students and colleagues, I am contributing to the advancement of the field of nursing and enhancing my professional skills and knowledge. I can present the research findings in these educational institutions through various methods such as lectures, workshops, or poster presentations. The presentations can be integrated into the nursing curriculum, giving students a deeper understanding of the research process and the importance of incorporating patient experience into healthcare and research.

Sharing the research findings with the academic community through publications in peer-reviewed journals and conference presentations is an important step in advancing knowledge and promoting best practices in the field of AYA transition to adult care. Presenting the findings at conferences such as the International Transplant Nurses Society Conference or the Registered Nurses' Association of Ontario (RNAO) Pediatric Nursing Interest Group (PedNIG) yearly conference provides an opportunity to share the findings with a wide audience of healthcare professionals, researchers, and practitioners, increasing the research's visibility and providing an opportunity to engage in meaningful discussions and exchange ideas with experts in the field. Publishing the findings in peer-reviewed journals allows for wider dissemination of the results, providing valuable information to a larger audience of healthcare professionals, researchers, and policymakers. By sharing the research findings, I can contribute to advancing the field of AYA transition to adult care and ensure that the patient voice remains a central focus. In the context of research on AYA transition to adult care, it is particularly important to disseminate the findings meaningfully and impactfully. Adolescents and young adults with solid organ transplants are vulnerable, and their transition to adult care is critical to their future health outcomes. By sharing the research findings with the academic and healthcare community, I can provide valuable information that can inform best practices and improve patient outcomes for the population.

3.14 Chapter Summary

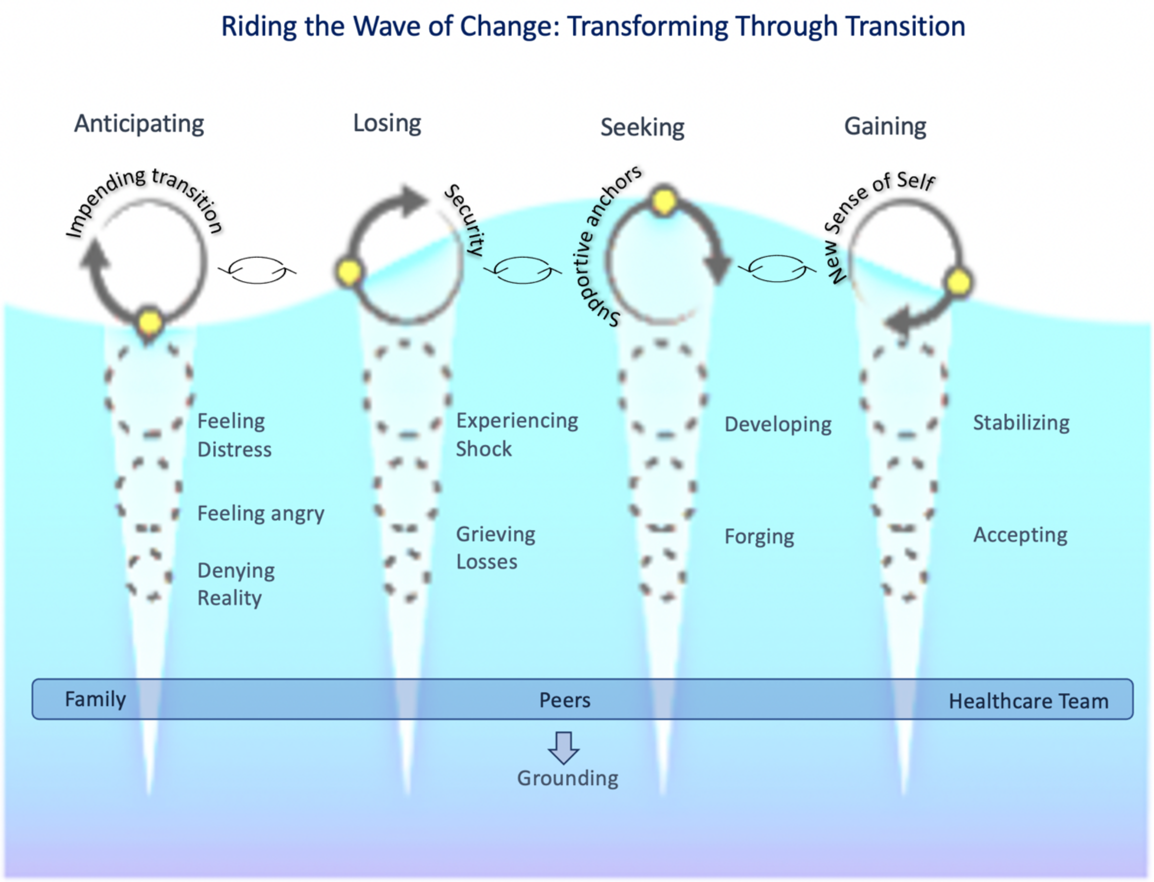
The chapter presented a detailed description of the study's research methodology. Constructivist GT was used to illustrate the phenomenon of how AYA transplant recipients manage their transition to adult-focused healthcare. To maintain CGT methodology, data gathering, and analysis were conducted simultaneously comprised of virtual interviewing, videoconferencing, online chats, social media, and online blog stories to collect data and maintain memos. The inductive process of constant comparative analysis allowed for distinctions to emerge from the data at each level of analysis (Charmaz, 2014), with a single core category ultimately emerging from the data and the subsequent development of the nascent theory. Through the study, I aimed to contribute to understanding transition experience and develop a theoretical framework representative of the population's experiences and social processes (Charmaz, 2014; Glaser & Strauss, 1967). Chapter Four presents the results, and the finding of the theoretical development of the core category, *Riding the Wave of Change: Transforming Through Transition,* is discussed.

Chapter Four: Results and Findings

In this Chapter, I consolidate and present key findings from the research data on healthcare transition and adolescent and young adult (AYA) development for AYA transplant recipients as they transitioned to adult-focused care. To address this basic social problem, participants engaged in the basic social process of *transforming through transition* in anticipation, preparation, and adjustment to the transfer to adult-focused healthcare. Excerpts from the transcripts and analyzed data illustrate various categories emerging from the data, which are presented verbatim in the quotes representing participants. The findings are organized in a resultant grounded theory, *Riding the Wave of Change: Transforming Through Transition,* as depicted by the model below in Figure 2.

Figure 2

Emergent Grounded Theory



The presentation of the findings is structured to represent both conceptual and analytical insights from the data, achieved through an iterative data analysis process. Insights are relayed by highlighting how the AYAs described their transition experience from pediatric to adult care. The findings are presented in four main categories: *anticipating the impending transition, losing security when transitioning to uncertainty, seeking supportive anchors in the swell of transition, and gaining a new sense of self* based on participant experiences and emotions.

4.1 Riding the Wave of Change: Transforming Through Transition

Participants shared different experiences of transitions, but the interviews reaffirmed that the experience of transition was not just of significance for the AYA recipients but also for their families and caregivers, highlighting the basic social problem of transitioning to adult-focused care. As explored earlier, AYAs depend on family, peers, and healthcare workers for help to manage the transition from pediatric to adult care following a solid organ transplant. Overall, as AYAs moved through the same process of transition to adulthood as their peer counterparts without medical complexities, the experience of their transition was complicated by the simultaneous healthcare transition. The basic social process of *transforming through transition* for these individuals involved a transition to adulthood and adult-focused healthcare concurrently, becoming a challenge for them as well as their entire families. The relatives and pediatric nurses were often unsure how to support the transition, creating a divide between pediatric and adult care centres. Likewise, parents and healthcare providers struggled with finding the right balance for each AYA between providing support, while letting go and promoting independence. This left AYAs responsible for managing their impending transition and seeking new ways to establish normalcy while navigating feelings of shock and grief at lost relationships. Ultimately, AYAs transitioned to adult-focused care regardless of self-assessed readiness. They gained a new sense of self through stabilizing and accepting – transforming through the transition experience.

Although this theory is depicted linearly, this is a limitation of the one-dimensional presentation of printed media. In reality, the participants voyaged through the wave of change in all directions, represented by the revolving arrows between the phases. Much like underlying currents, many forces pushed and pulled AYAs as they moved forward toward the end point of the transition to adult-focused care, with underlying feelings and experiences not always visible above the surface within each phase. Most recipients experienced a transformation as they gained strength and grounding from their family, peers, and healthcare team, depicted at the bottom of the figure, while caregivers often helped the patients make sense of the transition and moved toward transformation during the transition to adult care.

4.2 Emergent Categories for Transition from Pediatric Care to Adult Care

Through the GT process of coding and data analysis, a theory emerged that included four distinct categories of how AYAs managed or navigated the wave of change and experienced transformation through the transition: *anticipating the impending transition, losing security when transitioning to uncertainty, seeking supportive anchors in the swell of transition, and gaining a new sense of self*. Moreover, these categories are interconnected as AYA recipients moved toward achieving a new sense of self through their transition.

Within each category are sub-categories, representing participants' shared experiences that provided more insight into how they oscillated within the category before surging forward in their transition journey. For example, when *anticipating the impending transition*, participants had heightened feelings of distress, denying the reality, and anger about being made insignificant. As participants traversed along the wave, they began *losing security when transitioning to uncertainty*, experiencing shock, and grieving the loss of relationships. In response, participants began *seeking supportive anchors in the swell of transition* by developing their self-management and forging new relationships. Participants shared stories of breaking through the wave when they emerged on the other side, *gaining a new sense of self*, stabilizing through normalizing, and accepting a new reality.

4.2.1 Category One: Anticipating the Impending Transition

In the first category of *anticipating the impending transition,* recipients began with the feelings before transitioning into adult care and the impact on the participants' movement toward transformation. Beneath the surface, many emotions underpinned the anticipating phase. These sub-categories included *feeling distressed about the transition*, *feeling angry about being made to feel insignificant*, and *denying the reality*. Participants highlighted their state of mind and the process of mental preparation they undertook once they learned of the impending transition to adult-focused care. While some were ready to become autonomous, the data showed ranging views and emotions, while anticipating transition. Despite the turmoil expressed within this category, it was a necessary part of the movement toward transformation in the transition process.

4.2.1.1 Feeling Distress About the Transition. In the first sub-category, participants elucidated the complex emotional landscape during the transition from pediatric care, predominantly characterized by negative and distressing emotions, such as worry, fear, and uncertainty. These emotions notably afflicted the AYAs, as they navigated the complex terrain of transitioning to adult care. The pervasive sense of dread manifested through the heightened anxiety accompanying the transition. A noteworthy observation was the near-universal apprehension expressed by recipients at the prospect of changing care providers throughout the transition process. The move to adult care represented an uncharted and intimidating territory for these individuals, contributing to the exacerbation of anticipatory anxiety experienced by AYAs.

Interestingly, many AYAs struggled to articulate the precise nature of their emotions, suggesting a potential gap in their emotional vocabulary or introspective capacities. However, the adult-care transition was often portrayed as an abrupt and enigmatic experience for numerous AYAs recipients. Consequently, the fear of the novel and evolving environment became a salient concern. For some recipients, the prospect of assuming overwhelming responsibilities once their parents' involvement diminished proved to be a daunting challenge. The testimonial of Bruno, an AYA navigating this transition, poignantly illustrates the lack of adequate support mechanisms in place, rendering the transition to adult care a pervasive experience:

> I didn’t have family or parents to help moving into the adult program was so overwhelming for me. Learning all my meds by name and how much in mgs I had to take of each med, the hardest part for me was taking my meds in general ‘cause I always had someone giving me them. (Bruno, recipient)

This narrative invites a critical reflection on the support systems and the need for more comprehensive and individualized approaches to mitigate the emotional burden associated with such transitions. The fear of being left alone to manage their complex medical regimes, concomitant with myriad other transitional changes, was a monumental challenge for recipients. Josh's account elucidated the profound anxiety that pervaded the transitional period. His apprehension about the potential consequences of oversight in managing his care underscored the importance of adequate support during this critical phase:

> It’s a lot to figure out on my own and carry. I sometimes feel like I'm drowning with how much to remember, and then I think about the rest of the changes coming, and I get a bit panicked. I worry about screwing it up, Ya know like about my kidney and what happens if I screw up. (Josh, recipient)

The fear of change weighed heavily on recipients, and parent participants frequently expressed fear and guilt. Recipients often conveyed distress at feeling compelled to conceal their fear by feigning strength to restore equilibrium within the family. Nancy's narrative exemplifies this phenomenon:

> I think that like, I felt like I kind of had to then be strong for like, my parents who felt really so out of depth. I actually remember like, at one point, my mom had picked me up from school, and I was like, 16. And I was just like, you know, it's okay. Like, if you maybe

> need to focus on my brother, I could maybe try to live and like go live with like a really close family member, so you can like spend time to like, really take the time that you need with them. Like my, like, my mom at the time was just like, maybe surprised that I like even thought of that, like, you know, and maybe it was like a little angry at first because it was just like, no, we can handle things ourselves. (Nancy, recipient)

Even with established rapport and a positive relationship with adult care providers, these emotions persisted, rendering the transition incessantly distressing. The transition to adult care represented a significant change, engendering considerable emotional and mental turmoil for recipients. Clare's experience underscores the challenges faced by AYAs in transitioning to adult-focused care; despite familiarity with certain aspects of her care, the shift to a new healthcare team and departing from a place of comfort and familiarity proved to be an anxiety-inducing experience, “You get used to the late-night ER visits and being in pain in a familiar place with people who know you, but my health care and transplant team was never a topic of worry” (Children’s Wisconsin, 2022, para. 31).

Clare highlighted that, despite being prepared, she still worried about the shift to adult care, which required adjustment and acceptance (Children’s Wisconsin, 2022). This was a shared experience among all recipients, even those who felt they were well-prepared, as Clare did. In her situation, although she felt prepared for the transition to adult care, Clare still contended with emotional turmoil and worry about the reality of the transition and leaving the familiar pediatric care team. Thus, for all recipients in my study, the transition process caused persistent worry and uncertainty despite understanding the need for transition. This finding aligns with early research by Feinstein et al. (2005), underscoring that AYAs commonly experienced anxiety and denial as they realized that their chronic illness made them different from their peers and that despite ongoing attempts at normalization, AYAs often experienced denial as a defence mechanism against anxiety and depression.

Parents of AYAs undergoing a transition to adult care also expressed similar reflections on the emotions experienced by their children, which were amplified by the additional pressures of entering young adulthood. Parents recognized that these feelings and the added responsibilities of young adulthood could overwhelm their children. Parents also worried that there would be cascading effects of poor choices by the transitioning AYAs that could have cumulative effects, increasing their risk of adverse health outcomes. Nevertheless, recipients conveyed that the added burden of distress from the transition was inescapable, compounding the stressors already present due to their chronic illness and normal developmental changes. The situation was exacerbated by the limited availability of mental health support, a concern shared by parents and transitioning AYAs.

The scarcity of mental health support made it challenging for AYAs to maintain medication adherence, intensifying worries about suicidal ideation. In certain instances, fear was expressed on behalf of recipients. Some parents articulated profound apprehension that their children might take their own lives owing to significant mental health challenges. In other cases, recipients divulged concerns about the ramifications of their illness and the transition on their family members. Nancy's account, for example, underscores the strain on family relationships caused by her chronic illness and the transition process:

> Because as we know, chronic illness affects more than just the patient. It affects the entire family. I'd had the hardest relationship with my sibling. Like, I think he was definitely struggling, with some mental health issues at the time. And the only way I can tell you is that when I had my transplant, I was worried that my brother was going to take his life. (Nancy, recipient)

Nancy's narrative illustrates the far-reaching and enduring emotional and mental health impact that chronic illness and the transition from pediatric to adult care can have, extending beyond recipients to encompass the entire family. Nancy internalized her sibling's struggles and felt responsible for his mental health, amplifying her feelings of guilt associated with a chronic illness. Recipients commonly shared this sense of being a burden, aligning with findings in the literature concerning youth with other chronic illnesses. Recipients also noted that fear exerted a toll on their parents and other family members, “It’s a hard time for parents…they have not only to let go of a teenager, but a teen with a chronic disease” (Laucius, 2013, para. 23). Parents described fear's impact in terms of mental health and the trepidation of transitioning to adult care, compounded by the heightened risk of their children not grasping the significance of their poor choices:

> Had you asked me five years ago, I'm sure I can talk forever, but I would really just focus on the mental health piece. And the other moms that I've talked to have that had kids in that age group. That was common. Like we were terrified for their lives. After this we were literally terrified that they were going to give up. They didn't understand the importance of what was happening and their poor choices, and I can't emphasize enough the risk. And the risk that puts their life in. The mental health piece. (Donna, parent)

Donna’s account exemplifies the psychological burden experienced by recipients, parents, and family members as they navigated the challenges of transitioning their children with chronic illnesses into adult care. Parents like Donna expressed their profound fear for their child's well-being, as they worried about the potential consequences of their child's inability to comprehend the gravity of their health-related decisions fully. This fear extended beyond the immediate physical health implications; it encompassed a more profound concern for the child's mental health as, they faced the complexities of their chronic illness in a new care setting.

This exemplifies the interconnectedness of the physical, emotional, and psychological aspects of living with a chronic illness and the subsequent transition to adult care. Donna's emphasis on the "mental health piece" indicates the importance of recognizing and addressing the psychological needs of AYAs and their families during this critical period. It also underscores the need for healthcare providers to consider a holistic approach to care that encompasses medical management and provides mental health support and resources for patients and their families. Moreover, this passage highlights the shared experience among parents, as Donna refers to other mothers who expressed similar fears and concerns for their children. This commonality suggests the need for support networks and community-based interventions to assist families in navigating the challenges and uncertainties associated with transitioning to adult care.

Parents also expressed concern over supporting the entire family, feeling conflicted about how best to support the recipients that contributed to AYAs' concerns regarding their impacts on the family. Parents acknowledged that the AYAs were expected to be autonomous, while simultaneously worrying about their loss of control of the transitioning AYA once they moved to adult care:

> But I had to be very careful how I handled her, 'cause if I was too one way or too the other way she would bolt or leave, and I had to very much change and allow to trust the process and throw a lot of it to just trust. I just, I just hope I think one thing I relied on the most and that's and count on the way she was brought up, she will go back to her roots hopefully…and she did. (Donna, parent)

This statement and quote further emphasize the delicate balance parents faced as they attempted to support their AYAs during the transition to adult care. Parents like Donna faced the challenge of navigating their child's emerging autonomy while simultaneously dealing with the fear of losing control over their child's health and well-being, as their children moved into adult care. This highlights the complexities faced as parents strived to provide the right level of support without stifling their child's development or inadvertently pushing them away. It also reflects the importance of trust in the healthcare system and the values instilled in their children as they navigated this transition. This trust was a crucial element in enabling the AYAs to develop self-efficacy and confidence in managing their own health and the intricate dance between support and autonomy for the AYAs on the journey to adult care. It highlights the need for healthcare professionals to be sensitive to the unique challenges during this time and provide resources and guidance that foster trust and a sense of control for AYAs. This was worrisome for AYAs, who relied heavily on the social support provided by parents, families, and the healthcare team.

The worry was palpable as recipients described their fear of transitioning to adult care, with some describing the mounting pressure to succeed. This is exemplified by Maral (recipient):

> When I was diagnosed, I was quite scared.. When you first hear about kidney disease…you feel lost and you don't know what is going to happen to you. After the transplant, I felt I took something away from my mom and I went through depression… There are always moments of doubt and uncertainty, times that you feel lonely or sorry for yourself. (The Kidney Foundation of Canada, n.d.b., para. 2-5)

The distress experienced by recipients sometimes manifested in their pulling away from and not asking for needed help. In Maral's case, she shared that most of her friends were unaware of her illness and only discovered there was something wrong as a result of her changing appearance (The Kidney Foundation of Canada, n.d.b.). This furthered the feelings of isolation without having the support of others who knew what it meant to live through transplantation.

The development of trust between AYAs and their healthcare team was pivotal in fostering self-efficacy and confidence during the intricate transition from pediatric to adult care. This trust was essential as AYAs navigated the delicate balance between support and autonomy, enabling them to manage their health effectively. The significance of these relationships was further emphasized by the deep emotional connections AYAs often formed with their pediatric healthcare teams, which extended beyond caregiving into a support system akin to a family. The loss of these connections during the transition presented an additional layer of complexity and emotional turbulence, particularly as AYAs grappled with achieving autonomy and independence within the context of their developmental stages, as illustrated by Jane:

> I think it's because a lot of people, especially South Asian culture, they're like I guess they're not used to asking for uh, support, and they’re used to like I guess putting up like a really good really good front, So it's hard. I get how it makes sense for like their team’s point of view, and it's hard, hard, hard like since it’s somebody, like might need that support with some of that, so I think that there are some situations in which you might wanna like reach out to people like you know, even if they're like you know, not expressing interest themselves. (Jane, recipient)

Jane's quote provides valuable insight into the complex interplay of cultural factors, emotional connections, and developmental stages that shape AYAs' experiences during the transition from pediatric to adult care. In her account, she alluded to the depth and quality of her relationship with her healthcare team, which she likened to a family. This powerful emotional bond emphasized the magnitude of the loss experienced during the transition. It entailed losing a caregiving team and a vital support system deeply ingrained in her life.

This loss is particularly significant when viewed within the context of the developmental stages AYAs are navigating. The loss experienced by AYAs during the transition from pediatric to adult care is of particular significance when examined through the lens of developmental psychology and their unique developmental stages. As AYAs strive to achieve autonomy and independence, they encounter myriad emotional, cognitive, and social challenges inherent to adolescence and young adulthood. Erikson's psychosocial theory (1993) posits that during this stage, individuals grapple with the crisis of identity versus role confusion, seeking to establish a coherent sense of self while navigating the complexities of their social environment. Thus, the loss of a healthcare team, which has served as a constant source of support and guidance throughout their formative years, can exacerbate these developmental challenges by introducing additional stressors and destabilizing an essential support network. This disruption can heighten feelings of distress, uncertainty, and vulnerability, as AYAs may experience a lack of continuity in care and diminished trust in their adult care providers.

Moreover, this loss must be considered within the broader ecological systems theory framework (Bronfenbrenner, 1979), which emphasizes the interconnectedness of individuals and their social environments. The loss of the pediatric healthcare team may reverberate throughout AYAs' microsystems (e.g., family, peers) and mesosystems (e.g., connections between family and healthcare providers), potentially undermining their ability to successfully navigate the complex social and emotional landscapes of adolescence and young adulthood. Furthermore, Jane's experience underscores the influence of cultural factors on the transition process. In her case, the South Asian cultural tendency to avoid asking for support and to present a facade of well-being complicated her ability to express her needs and forge strong emotional connections with her healthcare providers. This cultural barrier may intensify the loss and distress experienced during the transition as AYAs struggle to establish the same level of trust and rapport with their adult care providers.

The anticipation of the impending transition for AYAs with chronic illnesses presented considerable challenges as they navigated the complex shift from pediatric to adult care. This critical juncture evoked various negative emotions, including worry, fear, and uncertainty, as AYAs confronted the daunting prospect of assuming greater responsibility for managing their medical regimens independently. The adult-care environment's unfamiliar and potentially intimidating nature further compounded these emotions. A salient concern from participants' experiences was the absence of adequate support during the transition process, which exacerbated their sense of being overwhelmed. This dearth of support is particularly disconcerting, considering the limited availability of mental health services tailored to address the unique needs of AYAs. Considering the high prevalence of stress, anxiety, and depression among AYAs with chronic illnesses, and the subsequent impact on their quality of life, physical health, and ability to manage their conditions, their expressions of anger with the transition process within the following sub-category were not unanticipated.

4.2.1.2 Feeling Angry About Being Made to Feel Insignificant. In the second sub-category, recipients frequently reported experiencing feelings of anger, which stemmed from a perceived sense of insignificance and isolation within the adult care system. The transition process often left these patients feeling unseen and undervalued, eliciting an emotional response characterized by anger and frustration. For instance, recipients noted that their new healthcare team often failed to invest adequate time in building rapport and understanding their unique backgrounds and experiences, leading to repetitive questioning at each visit without any indication of retention or recognition of previously shared information, such as their educational pursuits. Furthermore, participants recounted instances of extended commutes to healthcare facilities, only to be afforded brief consultation periods that adversely impacted their health outcomes. This perceived lack of attention and genuine care contributed to increased resistance to engaging with the adult care system, with some recipients ultimately disengaging from the healthcare process altogether and providing reasons for them to resist care and eventually drop out of the system:

> I used to have to go by bus 2-3 hours each way to be there for 5 mins like you're not worth their time. You're just another file that hit [sic] their desk and [they] do little to really understand what you're going through. (Bruno, recipient)

Bruno's sense of frustration and anger toward the healthcare system was a sentiment echoed by many recipients who felt that the adult care healthcare team disregarded their concerns and needs. This lack of attention is especially significant for AYAs, who typically place considerable importance on relationship-building, particularly with healthcare providers. Consequently, when these connections are absent or weakened, they may experience heightened distress during transitioning from pediatric to adult care. The need for validation and meaningful relationship with healthcare providers becomes paramount in this context. Nancy's story further exemplifies this issue. She recounted feeling invalidated by adult care providers who failed to recognize or empathize with her past experiences and their impact on her emotional well-being. Her desire to collaborate and find a mutually beneficial solution to address her anxiety was met with dismissiveness and insensitivity, exacerbating her discomfort and sense of alienation within the adult care system:

> And so when I went in I just tried to politely explain the situation of like, where that like trauma had come from and that pain, and that maybe if I was away that we could kind of compromise so that maybe I have a little bit more sleep medication or something to just make me feel more at ease because I had a lot of anxiety from it. And literally the technician like, that means then stop being a baby. And like to hear that, and like, we're like, I was kind of coming from a place where like, look, I'm, I'm not trying to make fuss, because, like, I want attention, it's simply because like, this is like how I've had my experiences, and I want to work with you, I just, I kind of need to, like, see how we can find that. So I can feel less anxious and feel more comfortable with you, like touching around my transplant area, like, you know, and that was not a very nice experience. (Nancy, recipient)

Nancy's attempt to advocate for herself and establish an understanding with her healthcare provider was met with dismissive attitudes that categorized her concerns as attention-seeking and immature, which only devalued her experience. This illustrated a more significant issue within the healthcare system, whereby the experiences and concerns of vulnerable populations, such as AYAs, may not be taken seriously or given the attention they deserve. Subsequently, Nancy communicated her longing for a deeper, more meaningful rapport with her healthcare providers, emphasizing the necessity of being acknowledged as a unique individual rather than an impersonal case file. This further accentuates the critical role that personal connections and understanding play within the healthcare landscape, particularly for AYAs navigating the complex transition from pediatric to adult care systems.

Nancy's perception of being treated as a mere number rather than an individual underscored healthcare providers' need to prioritize effective communication and cultivate meaningful relationships with their patients. In this instance, Nancy felt angry toward the adult healthcare team due to their failure to understand her as a unique person and for making her feel rushed during her visit:

> But like, maybe ask me have a conversation get to know me just for like one second, rather than throwing me out kind of in a way like how it felt like, and being like, oh, okay, you're good. Go home. Like, I would like a little bit more interaction. I like I know, you know, I don't…I don't want to feel like I'm a number is kind of how it would feel like. (Nancy, recipient)

In another example, Sarah recalled:

> It was like no one was there to like 'cause they like try to like push my parents away as well, like they really wanted me to like kind of govern and oversee my own care as much as possible so some of the transplant team weren't welcoming of my parents like being with me which was difficult as well. (Sarah, recipient)

These responses and approaches by the adult care providers contributed to recipients feeling insignificant and surged feelings of anger among participants, serving as a reminder that healthcare providers must approach their patients with empathy and sensitivity, especially when dealing with vulnerable populations. The recipients in the study experienced negative emotions and feelings of being insignificant due to the responses and approaches of the adult care providers. This indicates that healthcare providers' attitudes and behaviours can significantly impact patients' emotional well-being and overall experience with healthcare. This also implies that healthcare providers who are empathetic in their patient interactions are more likely to provide positive and effective healthcare. For example, healthcare providers who take the time to listen to their patients, understand their needs, and provide personalized care can help to alleviate negative emotions and improve patients’ overall experience.

The finding that study recipients encountered negative emotions, predominantly anger, due to adult care providers' reactions and methodologies underscores the paramount significance of sensitive healthcare provision. Patients who perceive themselves as overlooked or neglected may experience inauspicious emotions that can detrimentally affect their mental and physical well-being. As a corollary, healthcare practitioners must interact with their patients by incorporating attentiveness, esteem, and understanding to foster confidence, affinity, and constructive patient-provider associations. This concept is additionally substantiated by Nancy's portrayal of healthcare providers' disposition toward certain patients in transition:

> But with the transplant and why like, no, I know, I'm not the only one because I have thankfully been able to speak to other people who share with us when admin were so cold…oh, so that already created an experience like us from the sign in from the get go. And like, it was like, can you cheer up a bit? Like, a lot of us have been through so much. And you're just like, can you smile, like, it doesn't hurt like? And I know, like, they have so many things going on, but it was just so abrupt and like, so that already started it off, I think to say like we would come in, and you'd have to deal with that. And then like, so there's the iciness there. (Nancy, recipient)

The sentiment of anger permeated Nancy’s response and tone when recounting her experiences, and can also be seen in Leila’s experience:

> I hated [*ADULT HOSPITAL]*. I still hate it. I was lucky enough to stay with some of my same doctors, and I feel like if I hadn’t that would have made the transition so much harder. I still complain about it every time I have to go to the hospital. Which says a lot of things about adult care if I hate it that much. (Leila, recipient)

The abruptness and frigidity described by Nancy were construed as a lack of care for recipients as distinct individuals, which impeded the development of trust and new relationships with the adult care team. She went on to share more, pinpointing negativity from the adult providers, particularly in response to sharing concerns and soliciting support or more investigation. This engendered the persistent perception that she was inconsequential and that her voice was not being heard:

> But I think the negativity kind of came a bit more when I, let's say, I had concerns. And I felt like I needed to have, I wanted to feel heard. And I felt like my doctor, like the thing that really kind of kept me upset was that… if I had a concern, they would just be kind of like, yeah, okay, we'll look at it, or like it was just kind of thrown out the window, So I wasn't feeling like listened to. Every single time he would come in, he was like, maybe like really roughly looking at the notes. But like, for the amount of time I was in his care, he always thought I was stupid. And like that wasn't being very personable, again, going with bedside manners. And it felt so disconnected. And that's where I felt like, I wasn't feeling heard, because it's like, you're not even paying attention to who I am as a person, they barely even tried. (Nancy, recipient)

As divulged by Nancy and seen through the experiences of other participants, the adverse emotions, encompassing anger, frustration, and hopelessness, can detrimentally impact patients' quality of life, accentuating the importance of addressing these issues in healthcare practice. According to the biopsychosocial model, an individual's health and well-being are influenced by an intricate interplay of biological, psychological, and social factors, rendering this model particularly germane in exploring the health of AYAs with chronic health conditions (Crosby et al., 2015). The biopsychosocial framework posits that an amalgamation of these factors contributes to the overall health trajectory of patients, necessitating a holistic and comprehensive approach to healthcare provision (Engel, 1977). In the context of AYAs with chronic conditions, addressing emotional experiences becomes paramount to mitigate the potential deleterious effects on their physical, mental, and social well-being. Healthcare practitioners must acknowledge and address the psychological and emotional ramifications of patients' experiences in tandem with their physiological needs. In doing so, they can foster a supportive and empathetic environment that nurtures resilience and adaptive coping mechanisms in AYAs. Furthermore, adopting a biopsychosocial lens in clinical encounters facilitates a deeper understanding of the complex interrelations between patients' emotional states, their perception of healthcare providers, and the influence of these factors on their overall health and well-being.

Patients with chronic illness often confront negative emotions stemming from the physical and psychological impact of the disease, the complexities of managing treatment, and the uncertainty about the future, as illustrated by Josh:

> It’s a lot to figure out on my own and carry. I sometimes feel like I'm drowning with how much to remember. And then I think about the rest of the changes coming and I get a bit panicked. I worry about screwing it up, ya know like about my kidney and what happens if I screw up. (Josh, recipient)

These negative emotions can magnify the burden of the illness, engendering feelings of hopelessness, despair, and indignation (Engel, 1977; Lugg, 2022). The transition process can further compound these negative emotions, culminating in patients expressing anger and frustration toward the process (Crosby et al., 2015). Leila’s statement exemplified this, “I hate that the transition even exists. Like, I get it, but I hate it” (Leila, recipient). By embracing a system-oriented biopsychosocial approach to AYA care, we can unveil factors surpassing the mere exchange of healthcare teams or care, thereby offering valuable insights to inform the formulation of transition programs for AYA, as suggested by Leila:

> As much of the medical team that can stay the same, do that. These transitions are easier if there’s at least one familiar face. If adult care team members can start being introduced during the teenage years so its less of a shock, I recommend that. Get the child involved in their own medical care as early as possible, in age-appropriate ways of course. If possible, have coordination between the pediatric and adult teams as much as possible. And for the love of God can someone please paint the walls in the adult wards because no one wants to stare at that much grey. (Leila, recipient)

Consequently, it is crucial for healthcare providers to acknowledge the influence of chronic illness and the transition process on patients' emotional well-being and to provide appropriate support and resources. Providers can use a patient-centred approach to understand the patient's experience, identify their needs, and develop a personalized care plan that encompasses their physical, emotional, and social needs. This approach can help patients feel more engaged in their care, improving their experience and outcomes. By addressing the emotional needs of patients with chronic illness and supporting them through the transition process, healthcare providers can help patients better manage their condition, improve their quality of life, and promote positive health outcomes.

Utilizing a patient-centred approach enables providers to comprehend the patient's experience, ascertain their requirements, and devise a tailored care plan addressing their physical, emotional, and social needs. This approach empowers patients to feel more invested in their care, enhancing their experience and outcomes. By attending to the dynamic necessities of patients with chronic illness and assisting them through the transition process, healthcare providers can facilitate improved management of patients' conditions, augment their quality of life, and foster positive health outcomes.

Owing to the demanding nature of the transplant, the underlying disease of recipients, and the time dedicated to seeking treatment, some patients articulated their anger through expressions of surrender and resentment regarding the transition process. Analogous to the experiences shared by Nancy, recipients grappled with relinquishing pediatric care and establishing new foundations in adult care, underscored by an apprehension that their concerns were not duly acknowledged. As recipients contended with the anger encapsulated in this sub-category, they frequently resorted to denial of reality as presented in the following sub-category, perhaps as a coping mechanism to persevere and advance along their trajectory.

4.2.1.3 Denying Reality. In the third sub-category, recipients were reluctant to embrace the transition process and the responsibility that came with it. Some participants used denial as a coping strategy in which they felt they could continue receiving care at the pediatric hospital if they denied the necessity for transition to the adult centre. However, in some instances, the support provided to participants that did not encourage independence or self-management inadvertently left them feeling ill-equipped for the transition, impeding their autonomy. Sometimes, the feelings were deemed justifiable when comparing the care provided at the different facilities, alluding to the treatment in adult care being very harsh and grim in comparison to pediatric care, where the treatment of the patient in pediatrics was described as welcoming and therapeutic:

> Like I said, if I could go back to peds I would. Working with adults, people generally aren’t as nice. There’s more expectation that you just deal with it. There are no bright, fun colours, and I have yet to experience a therapy animal or clown come to the adult ward, which I’m actually mad about. Why do we stop bringing dogs to people when they turn 21? I would like stickers and puppies and popsicles, thank you very much. But just in general, it seems like a far harsher environment. (Leila, recipient)

These juxtapositions between pediatric and adult care were broadly shared between participants in all groups. For instance, another participant depicted adult care as brief and devoid of the numerous supplementary supports to which they had grown accustomed, either from their parents or the pediatric hospital. Yet, participants recognized that support ought to be provided in moderation, as an overabundance of support in certain instances obstructed their autonomy and resulted in AYA feeling ill-prepared for transition: “They probably tried to get me ready, but at that point, everything around my health was taken care of the group home, so I never took it seriously” (Bruno, recipient). The tensions and complexities that arose in the transition from pediatric to adult care can be seen in the experiences shared by participants. On the one hand, they noted that adult care lacked the ancillary supports that they had come to expect from their parents or pediatric hospital, such as truncated appointments with adult healthcare providers or a dearth of resources in adult care. Simultaneously, however, participants conceded that excessive support might undermine their autonomy and impede their capacity to assume responsibility for their own well-being.

The tension, as mentioned above, was underscored by one participant who divulged their inability to take the transition seriously, given that their group home managed all health-related affairs. This excessive support might have engendered a deficit in preparedness for the responsibilities inherent in adult care. Analogously, Kelly's encounters as a healthcare provider revealed that certain adolescents received excessive parental support, culminating in diminished autonomy and a reluctance to assume responsibility for their health:

> But I would say if I were to pick a majority, I would say the majority of adolescents do struggle a little bit with their self-care, especially patients who have had a chronic illness. But overall, I would say that it's definitely something that I noticed. The adolescent population struggles with, especially when in the hospital, but it seems that some adolescents have a tendency once hospitalized to kind of forget about general self like activities of daily living like their hygiene. I'm often reminding kids to like brush their teeth or have a shower or change their clothes, cut their nails was another big one. So they've kind of fallen into the roles, perhaps with their family where the parents or guardians take a more active role and the patient takes a more passive role. (Kelly, RN)

Participants often felt the tension, acknowledging the necessity for self-management and independence while concurrently desiring enhanced support during the transition. Kelly’s reflection accentuated a salient issue within the healthcare system: the critical and arduous juncture of transitioning from pediatric to adult care is often neglected, despite its significance for AYAs. The deficiency of resources and attention made AYAs feel unsupported and ill-equipped for the transition, potentially adversely impacting their health outcomes. By connecting these personal accounts, the need for a balanced approach to fostering autonomy and support was evident during the transition from pediatric to adult care. A better understanding of the complex interplay between support systems, personal responsibility, and healthcare structures could inform strategies to facilitate smoother transitions for AYAs, ultimately improving their long-term health outcomes.

Nonetheless, the transition ought to be viewed as a bridge extending from one focus of care to another, necessitating dual pillars of support. Consequently, to fortify the transitional bridge more effectively, it is crucial to comprehend that the onus for a successful transition should be more than just borne by the adult side, as was commonly perceived by participants. Instead, pediatric and adult care providers must collaborate to promote a seamless transition for AYAs as they traverse the metaphorical bridge amid the undulating waves of change. Healthcare providers should prioritize communication and information sharing with AYAs and their families, providing them with clear and accessible information about the transition process, encompassing expectations, available resources, and methods of accessing them. This approach will empower AYAs and their families, enabling them to participate in the transition actively.

To help facilitate a smooth transition, healthcare providers should ensure that AYAs receive continuous support and follow-up care throughout the transition process. This can include regular check-ins with healthcare providers, access to support groups, and assistance navigating the healthcare system. Overall, transitioning to adult care can be challenging as AYAs navigate the tension between needing support and resources and developing the skills and responsibility to manage their health independently. By synthesizing these perspectives, a more comprehensive understanding of the complex interplay between support systems, personal responsibility, and healthcare structures can emerge. Such an understanding can inform strategies to promote smoother transitions for AYAs, ultimately improving their long-term health outcomes and fostering a more holistic approach to their care as they mature into adulthood.

In summary, the first category, *anticipating the impending transition*, encapsulates the emotional and psychological dimensions experienced by AYAs as they confronted the imminent shift from pediatric to adult care. This category comprises three intertwined subcategories that shed light on the various facets of the anticipatory phase. First, *feeling distress about the* *transition* involved AYAs expressing anxiety and apprehension regarding the upcoming change. They grappled with the uncertainty of adult care and how it would impact their lives. Second, *denying the reality* captured the perspective of some AYAs who employed denial as a coping mechanism, refusing to acknowledge the necessity of transition and hoping to maintain the status quo within the pediatric setting. Last, *feeling angry about being made to feel insignificant* revealed the frustration and resentment that AYAs harboured when they perceived their concerns and emotions as being undervalued or dismissed during the transition process.

4.2.2 Category Two: Losing Security When Transitioning to Uncertainty

The second category of *losing security when transitioning to uncertainty* explores recipients' figurative and literal sense of losing feelings of safety when transitioning to an uncertain place during the transition to adult care from pediatrics. This category delves into the emotional turmoil and challenges that AYAs faced as they navigated the actual transition from the familiar pediatric environment to the unfamiliar realm of adult care. Two sub-categories emerged within this context. First, *experiencing shock* highlights the initial reactions of AYAs as they encountered the stark differences between pediatric and adult care settings, often feeling overwhelmed and unprepared for the contrasting expectations and treatment approaches. Second, *grieving the loss of relationships* underscores the emotional impact of leaving behind established rapport with pediatric healthcare providers as AYAs came to terms with the necessity of forging new relationships and building trust with adult care providers.

4.2.2.1 Experiencing Shock. The transition from pediatric care to adult care frequently proved to be a shocking and challenging experience, regardless of the extent of their prior preparation. This perception of an abrupt shift and the consequential impacts on continuity of care emerged as a consistent theme among participants. Recipients felt the transition occurred suddenly, regardless of the perceived varying degrees of preparation leading up to the transfer. For instance, Sarah, cognizant of the impending transition due to her age, felt ill-equipped for the change, highlighting the need for adequate forewarning or guidance:

> Like, I knew I was going to transition at some point because I was like at the basically maximum age but or nearing there, but there wasn't really like any warnings or like. Well, this is what's gonna happen. You just like stopped going. (Sarah, recipient)

Thus, although aware of the pending transition, Sarah felt unprepared for the change, resulting in shock at the time of transition. Similarly, Jane echoed these sentiments, portraying the transition as an almost instantaneous switch to the adult system: “'cause it's basically like how do I describe it, as like one day and then you switch over to become like an adult and adult system” (Jane, recipient). Emily had similar concerns with the seemingly arbitrary transfer occurring at eighteen years:

> “It’s just an age. It’s just a number people created. It’s not really tangible. It doesn’t speak to me other than the number of days I have been alive,” she says. “I felt that age was this magical number that they pushed on you.” (Laucius, 2013, para. 17).

As a result, almost all recipients believed they were either minimally prepared or wholly unprepared to enter adult care, where independence was crucial. The introduction of medication regimens without the comforting support of their parents exemplified the shocking experiences faced by participants, as illustrated by Sarah's account:

> I remember transplant came and they like brought all these medications. And like just the volume of the meds was like so wild and you kind of just had to do it on your own like. So some of the transplant team weren't welcoming of my parents like being with me, which was difficult as well. It has it been like pretty cool to like see the growth? I mean, it was definitely like shocking out for us to just do it all on yourself. (Sarah, recipient)

As Sarah recounted her experiences, she emphasized the unwelcoming attitude of some transplant team members toward her parents' presence. This exclusionary behaviour deprived her of the emotional support and guidance from her parents during a critical and overwhelming period in her healthcare journey and intensified the shock of having to manage medications independently. In the absence of her parents, Sarah found herself suddenly confronting a multitude of drugs, each with its own dosing regimen and potential side effects. The lack of support and guidance from healthcare providers compounded this challenge, leaving her feeling isolated and unsure how to proceed. Despite their vital role in her support network, the transplant team's resistance to involving her parents inadvertently contributed to her distress and vulnerability.

Recipients underscored the abrupt transition to adult care, with many finding it startling primarily due to the perceived lack of preparation or warning. Sarah's experience serves as a poignant example of the challenges faced by many adolescents and young adults in this context:

> There wasn't there wasn't any like warning. There wasn't like a transition process, it was just suddenly like that time had ended. So, I think I pretty much said it, but leading up to that transition period there wasn't much work done. (Sarah, recipient)

Despite being aware of her impending transition, she needed more notice, guidance, or a structured process, which left her unprepared for the significant shift in her healthcare journey. This created a sense of shock and disorientation as they tried to navigate a new and unfamiliar healthcare system. The lack of clear expectations and guidance left AYAs feeling unsupported and unsure of how to navigate the adult-care transition. This was particularly challenging for those who relied on their families or pediatric healthcare providers for support throughout their healthcare journey. They felt they were suddenly expected to take on more responsibility without adequate preparation or support.

Sarah's account further highlights the absence of a coherent transition process that was common amongst most recipients, with a seemingly arbitrary cessation of pediatric care marking the beginning of her foray into adult care. Without clear communication or guidance, participants felt overwhelmed and uncertain about the changes that awaited them in the adult healthcare system. The lack of a gradual, well-structured, and supportive transition left Sarah and others like her feeling adrift, emphasizing the need for a more comprehensive approach to address these challenges. Sarah's experience is a testament to the importance of crafting a well-designed transition process that includes clear communication, thorough preparation, and adequate warning to ensure a smoother and less daunting shift from pediatric to adult care.

Moreover, the impact of this shock was further magnified by the timing of these transitions, which frequently coincided with critical and intense periods in the patient's healthcare journeys—these crucial moments, often punctuated by normative developmental changes and heightened emotional vulnerability, added a layer of complexity and stress to an already challenging transition process. Most participants felt trepidation about the apparent disconnect between pediatric and adult care, expressing concern over the lack of continuity and support during this pivotal period. All participants shared this trepidation about the disconnect between pediatric and adult care. When asked about the setup of pediatric to adult care transition, healthcare providers were worried about the non-prioritization of transition education in the health facilities. Concerns and worries about the lack of continuity from pediatric to adult care were shared by healthcare providers as well. A pediatric nurse described the breakdown of care from pediatric to adult care as affecting the health outcome of transitioning patients:

> I think something that would help me support this population is I feel that there's a need for more continuity between pediatric and adult… because I feel like we, you know, as a pediatric nurse, I kind of live in my world in my hospital in what we do there and how things are done at the in the pediatric facility, and then once the patient is gone to the adult health care, I really don't know how it's going for them, and I feel that we lose a little bit of the continuity of care. So I feel that there needs to be some strengthened connections and more opportunity for continuity between pediatric and adult facilities, especially you know or specifically between transplant units, so whether that's a more you know, a more comprehensive team that's made up of into professionals from both facilities to help facilitate that care, or it's even just like a few transition more transitional meetings between facilities, but I think that that would really help. (Kelly, RN)

Kelly's comments address a more significant issue surrounding the transition from pediatric to adult healthcare: the uncertainty and lack of clear expectations that AYAs experience. Healthcare providers also voiced worry and unease about the apparent non-prioritization of transition education in health facilities. The inadequacy of resources, training, and attention devoted to facilitating a seamless transition compounded the difficulties patients and providers face. The need for a more comprehensive and gradual approach to the transition process emerged as a critical reflection, highlighting the necessity for enhanced communication, preparation, and support to ensure a seamless passage from pediatric to adult care. This would enable recipients to navigate the complex healthcare landscape better and develop the requisite autonomy and self-management skills to thrive in the adult care setting. The insufficient support for transition for healthcare providers directly translated into inadequate support for AYA recipients during their transition to adult care. This resonated with the distress shared by recipients and families who felt underinformed or uninformed about the expectations and timelines for the transition, subsequently contributing to their feelings of unpreparedness and shock when the time arrived to transition to adult care.

The pediatric nurse participants postulated several reasons for the disconnect between pediatric and adult care during the transition process:

> We received some education about transition, but again, it's really hard to implement that and inpatient side when we don't know what has been taught to them already and like what the expectations are…And transition has been highlighted by a few of our nurses as areas of importance and shared in education… Maybe a policy or something that ensures consistency in practice would help.
>
> (John, RN)

Systemic factors, including the lack of a standardized transition protocol or guidelines within the healthcare system, were key contributors to the varied transition processes they had witnessed. This absence of a unified approach resulted in inconsistent transition processes, which could contribute to confusion and fragmented care. Other potential contributors centred around individual factors such as healthcare providers' lack of awareness, knowledge, skills, and communication barriers between pediatric and adult care teams. Organizational factors were also identified, including inadequate resources, training, or prioritization of transition-related education and support within healthcare facilities. This was evident when Kelly noted the removal of transition-based programs within their pediatric organizations due to a lack of funding:

> I also know that our hospital did have some sort of its own program… that the purpose of that program was to again help support adolescents become more independent with their care and transition to the adult healthcare world unfortunately, that particular program I believe didn't have enough funding, so we no longer have that. (Kelly, RN)

John also noted the change in services related to both funding and COVID-19:

> …Transition has been highlighted by a few of our nurses as areas of importance and shared in education sessions in our yearly nursing caravan sessions, I believe we had a transition committee at one point that was running Transition support nights for teens currently admitted to the hospital, but that type of support has stopped either due to funding or COVID or both. (John, RN)

The elimination of transition services had cyclical impacts on individual factors. Reduced funding and resources resulted in less access to training and support for healthcare providers, leading to gaps in knowledge and skills. This, in turn, could further contribute to communication barriers and decreased collaboration between pediatric and adult care teams, exacerbating the challenges transitioning patients face. Additionally, Kelly shared that the deprioritization of transition services at the organizational level sent a message to healthcare providers that this area of care was not a critical concern, which may have inadvertently contributed to a lack of motivation or engagement in her organization addressing these issues.

The transition to adult healthcare represented a significant challenge for emerging adults already experiencing a period of instability and in-betweenness. It required them to navigate a new and unfamiliar healthcare system, take on more care responsibilities, and establish new relationships with healthcare providers. This added a layer of complexity to an already challenging developmental period. This is seen in the experience shared by Poppy in which she reflected on the impacts of the transition on her daughter, “and then suddenly go into adult care right at a time where everything is getting more intense in terms of her health… Obviously, she's a teenager, there's mom and mom and daughter dynamics there” (Poppy, parent). This kind of experience was not uncommon. Many AYAs found the transition to adult care challenging, especially during a time of significant health challenges or stress, as was the case for several participants. The shock of the transition and the challenges of managing a complex medical condition made it difficult for AYAs to navigate the transition process and led to frustration, anxiety, and fear. The transition from pediatric to adult healthcare can significantly disrupt an AYA's sense of security and stability, mainly if they have established strong bonds with their pediatric healthcare providers and have relied on their family for support throughout their healthcare journey.

The pediatric healthcare system is often characterized by a family-centred approach, in which parents or other family members are involved in the AYA's care and actively engage in decision-making. This can create a sense of security and stability for the AYA, as they have a familiar and supportive network to rely on during a challenging and uncertain time. However, transitioning to adult healthcare often requires AYAs to navigate a new and unfamiliar healthcare system, take on more responsibility for their care, and establish new relationships with healthcare providers. This can disrupt the sense of security and stability provided by the family-centred approach of pediatric care and can leave AYAs feeling shocked, vulnerable, and uncertain.

Participants' unclear expectations intensified the feelings of experiencing shock as to what to expect from adult care for parents and patients once they left the pediatric facilities. Healthcare providers believed that patients experienced shock once they transitioned to adult care due to the different approach to healthcare administration. Parents also recognized that the transition to adult care meant reduced access to their child's medical records, decision-making, and determining the course of medical treatment. This lack of support exacerbated the transition process and affected the adolescent's ability to develop self-care. Also, the complexity of recipients' medical histories and their impact on extended or frequent hospitalizations were identified by healthcare workers as having adverse effects on adolescents' development of self-management and self-care. In addition to the disruption of the family-centred approach, the transition to adult healthcare may also represent a broader disruption of the AYA's sense of identity and self. As they move from adolescence to young adulthood, AYAs undergo significant developmental changes and explore their identities and values. The transition to adult healthcare can represent a substantial challenge to this process, as it requires them to establish a new sense of identity within the context of a new and unfamiliar healthcare system.

4.2.2.2 Grieving the Loss of Relationships. The final sub-category of losing security when transitioning to the unknown was characterized by recipients and parents expressing feelings of grief and sadness over the termination of relationships with their pediatric healthcare providers. The sudden absence of familiar and trusted healthcare teams was a considerable challenge for individuals moving from pediatric to adult care. Recipients and parents reported experiencing a sense of loss and grief in response to the dissolution of these meaningful relationships, which provided critical support and guidance throughout their healthcare journey. This loss of connection was particularly impactful for individuals who relied heavily on their healthcare team for help and guidance throughout their medical journey. For some, the abruptness of the transition compounded these feelings of grief, leaving little time for individuals to process their emotions or prepare for the change. This made the transition to adult care even more daunting, as individuals felt overwhelmed and inadequately supported during this crucial period. According to Riley, the suddenness of the transition did not provide her with adequate time to process her emotions and ready herself for adulthood and adult care. Similarly, Andrew noted that he found it challenging to leave pediatric services as he had come to view the healthcare team as an extension of his family:

> Ah. I don't know how I prepared exactly…Uh. They told me that I had to move to [ADULT HOSPITAL] because I was turning 18 and I couldn't be at [PEDIATRIC HOSPITAL] anymore. Uh, it was difficult, uh, so the transition was hard. [PEDIATRIC HOSPITAL] was like my family and it was hard to leave. I was happy coming back to visit… And I was nervous. (Andrew, recipient)

As Andrew, Brendan, and numerous other participants shared, the relationships between pediatric patients, parents, and their care team were unique due to their development over time and the genuine care and connection they embodied (Children's Mercy, n.d.). Brendan (recipient) states "My experience at [*ADULT HOSPTIAL]* was incredible. My relationships with the people there are amazing. They quite literally saved my life. I'll always remember them and will stay in contact with them" (Children's Mercy, n.d., para. 50).

Such relationships were grounded in trust and familiarity, with patients and their families depending on their healthcare providers for support and guidance throughout their medical journey, often starting in infancy. Conversely, transitioning to adult care often seemed impersonal, offering limited opportunities to forge the same level of trust and connection with healthcare providers. Participants observed that doctors in adult care often changed frequently, making it challenging to establish the kind of long-term relationship typical in pediatric care. Jane illustrated this when she mentioned that the connection had been formed over her entire lifetime:

> Especially when you go to like a new hospital in new team that you're not really aware of and you've been used to like them since you were like how like three years old and all of

> a sudden when you're 17, you're changing so um. Yeah. I guess that was, uh, that was kind of like something that I needed to get used to and adjust and everything, so yeah. Uh, sure I guess like just uncertainty thinking about like how I would build trust with the new team if they know if they like they have -- they always need time to get to know you and your system, everything, so that was probably the biggest thing that I was thinking about. (Jane, recipient)

Jane's account highlights the emotional and psychological impact of transitioning from pediatric to adult care. The change in healthcare teams introduced unfamiliarity and uncertainty and challenged the patients' trust and connection with their providers. Jane's reflection underscores the significance of adapting to a new environment, especially when a new team of healthcare providers suddenly replaced longstanding relationships built since childhood. The transition also raised concerns about establishing trust with the new team, as they would require time to familiarize themselves with the patient's medical history and unique needs. This adjustment period further intensified feelings of uncertainty and anxiety, as patients were left to wonder how well their new healthcare providers would be able to understand and support them. The loss of these relationships significantly impacted recipients as they navigated the challenges of transitioning to adult care. Participants reported feeling lonely and disconnected, which affected their overall well-being and made it more challenging to manage their medical conditions effectively. Recipients expressed feelings that resembled grief as they mourned the loss of normative developmental tasks and/or experiences. These feelings of missing out and falling behind were significant for many recipient and parent participants.

The loss of relationships with pediatric healthcare providers during the transition to adult care can be understood through attachment theory, which posits that early experiences with caregivers can shape an individual's capacity for forming and maintaining relationships throughout their lifespan (Bowlby, 1982; Gill et al., 2016; Hill et al., 2019). Through establishing relationships, individuals develop a secure base with a main attachment person who provides consistency over time. Thus, in this regard, patients may see members of their healthcare team as attachment figures who offer consistency.

In pediatric care, individuals developed strong attachment bonds with their healthcare providers, who served as primary supports during intense medical needs. For example, Bruno illustrated the unique nature of the recipient relationship with the pediatric team: "When you spend 18 years at one hospital with the type of care I got from *[PEDIATRIC HOSPITAL],* there is nothing that can compare." Bruno alluded that these relationships were built over time and characterized by a sense of security, trust, and emotional connection. When recipients transitioned to adult care and left behind these established relationships, they experienced feelings of loss, grief, and abandonment. This impacted their emotional well-being and made it more difficult to manage their medical conditions effectively. Furthermore, the loss of these relationships was particularly impactful for transplant recipients with complex medical needs, who relied heavily on their healthcare providers for emotional support and encouragement. Without this support, individuals struggled to find the motivation and resilience to manage their conditions effectively.

Given the substantial impact of these transitions on patients' trust, connection, and overall well-being, there was a clear need for a more structured and gradual transition process that facilitated the development of trust and rapport between AYAs and their new adult care providers. This may include opportunities for open communication, joint meetings between pediatric and adult care teams, or a more comprehensive support system to help patients navigate this challenging period. Implementing such measures could ease the emotional burden and promote a smoother transition, ultimately improving the overall healthcare experience for AYAs moving from pediatric to adult care.

In the face of these changes, the losses were particularly challenging for AYAs who had established strong bonds with their pediatric providers. In some instances, recipients highlighted missing the morale and support they received from their pediatric healthcare team. Pediatric healthcare providers often provided emotional support and encouragement to their patients, critical to their overall well-being and coping with their medical conditions. This support was difficult to replicate in adult care, where the focus was often on managing medical conditions rather than providing emotional support:

> I think the social support is a big one and kind of like, 'cause it's basically like how do I describe it as like one day and then you switch over to become like an adult and adult system. So I think it could have been more of like an easier transition even like if you were accepted to [*ADULT HOSPITAL*] with like the team and stuff like that and more getting to know the system and everything like. (Jane, recipient)

Jane's statement highlighted the significance of social support during the transition from pediatric to adult care. She described the transition as abrupt, likening it to switching to adulthood in a single day. This sudden change can be disorienting and emotionally challenging for AYAs, who must adapt to a new healthcare environment with little preparation or guidance. Jane suggested that the process could have been eased through a more gradual transition, which could include opportunities to familiarize oneself with the adult care team and system before the actual transfer. This would allow AYAs to establish rapport with their new healthcare providers, fostering trust and support during this critical period. The lack of such opportunities for a gradual transition and relationship building underscores the need for improved continuity of care, focusing on easing patients into their new healthcare environment, promoting social support, and enhancing their overall well-being.

Given the positive feelings and memories recipients carried with them from pediatric care, it was not surprising that they expressed a desire and need for more connection to the new adult team, longing for the relationships established in pediatric care. Consequently, some participants were indifferent when asked about their relationship with their new team. When feeling alone, recipients had increased feelings of isolation in their transition to adult care. Participants described missing the extended support that pediatric care provided beyond personal relationships and highlighted missing the morale and support they received from their healthcare providers, peers, and parents. Due to the relationships formed between the patient and the healthcare team, patients felt that they would be losing already established trust with their pediatric team and would have to start again in building those relationships with their new team.

This underscores the critical role that relationships play in supporting AYAs through the transition to adult care and the grief they experienced due to the loss of those connections. As observed, AYAs who established strong relationships with their pediatric healthcare providers found it challenging to transition to adult care, where they did not have the same level of emotional support and encouragement. Jane's concern about building trust with a new healthcare team was a common sentiment. For them, the shift to adult care was a difficult and uncertain time, filled with worries about losing the bonds formed with their pediatric providers and feeling anxious about establishing new relationships with adult care providers. As a result, they felt isolated and unsupported, struggling to manage their medical conditions effectively.

Furthermore, the absence of peer support and someone to assist recipients after transferring to adult care intensified the feelings of isolation and loneliness experienced by AYAs in grieving their lost relationships. Lacking these essential support systems made it harder for AYAs to cope with the challenges of transitioning to adult care. Donna's account resonated with this as she mentioned that the lack of peer support and someone to support her daughter after her transfer to adult care made the situation even more difficult, leaving the patient feeling increasingly alone and isolated in her experience:

> But as a teenager, she needed peer support badly. 'Cause that's who they're going to listen to. They're going to identify with other peers, and there was nobody,…uh, and by the time we did finally meet the odd person in the waiting room, she was just like, well, I'm not sick like them. (Donna, parent)

Donna's statement highlights the importance of peer support for AYAs during the transition to adult care, as they naturally sought connection with others in their age group and could identify with and listen to their peers. This need for peer support became even more crucial during this challenging period. However, Donna's account revealed a lack of available peer support for her daughter, which left her feeling disconnected from others experiencing similar medical situations. Additionally, when her daughter finally encountered other patients in the waiting room, she felt disconnected from them, believing that her condition was not as severe as theirs. Thus, AYA's isolation was accentuated by the realization that they were unlike many of the patients they would encounter in adult care. The age difference between newly transitioned patients and the existing adult care patients seen in the waiting room during clinic visits made patients more aware of the transition and missed pediatric care:

> Yeah, it was a little different cause everyone around me was much, much older than I was, well, which is fine. And I think it's against a lot of the patients that I met were much younger than me. Uh. Well, yeah. It's definitely different. Uh, it was just it was different, like it's like a different sort of community, and it was nice that I was older, but also I missed [*PEDIATRIC HOSPITAL*]. (Riley, recipient)

Riley's statement emphasized the difficulties AYAs face when transitioning to adult care, where they often found themselves in a new environment surrounded by individuals who were significantly older than them. This unfamiliar setting and the absence of peers who shared similar experiences made it challenging for AYAs to feel a sense of belonging or to find emotional support. Riley’s experience resonates with Donna’s above, highlighting the importance of peer support for AYAs. Both narratives demonstrate that transitioning AYAs need connections with others going through similar experiences and challenges to feel understood and supported. The lack of a familiar environment and peer support can exacerbate feelings of isolation, loneliness, and even nostalgia for their previous pediatric care setting. Recognizing this gap, Maral (recipient) stated “If I had peer support when I was a teenager, I would have asked so many questions about transplant because although doctors and nurses would tell me things, they were older, and I didn't know them. I wish I'd had someone my age who could tell me: you're going to get through this" (The Kidney Foundation of Canada, n.d.b., para 7). This further emphasizes the need for a more structured and accessible peer support system to help AYAs build connections with others who share similar experiences and challenges. Such support systems could alleviate feelings of isolation and loneliness while providing a sense of camaraderie and understanding during this vulnerable time in their lives.

This highlights the need for a more structured and gradual transition process that facilitates the development of trust and rapport between AYAs and their new adult care providers. This may include opportunities for open communication, joint meetings between pediatric and adult care teams, or a more comprehensive support system to help patients navigate this challenging period. Such measures could potentially ease the emotional burden and promote a smoother transition, ultimately improving the overall healthcare experience for AYAs moving from pediatric to adult care.

In summary, the second category explored the complex way recipients experienced losing security when transitioning to uncertainty, encompassing the emotional challenges AYAs faced when moving from pediatric to adult care. This category consisted of two sub-categories: *experiencing shock* and *grieving the loss of relationships*. *Experiencing shock* referred to the abruptness of the transition, which often left AYAs feeling unprepared and overwhelmed. They struggled to adjust to the new expectations, routines, and responsibilities in adult care, leading to increased stress and anxiety. *Grieving the loss of relationships* highlighted the emotional distress AYAs and their families felt as they lost the familiarity and comfort of their long-term relationships with pediatric healthcare providers. This sense of loss was particularly impactful for those who relied heavily on their healthcare team for support and guidance throughout their medical journey. As AYAs navigated through these challenges, they entered the next category, seeking supportive anchors in the swell of transition.

4.2.3 Category Three: Seeking Supportive Anchors in the Swell of Transition

The third category of *seeking supportive anchors in the swell of transition* refers to how recipients navigated the challenges and changes that came with the transition process. This involved *developing self-management* strategies to help them take control of their healthcare and adapt to new environments and routines and *forging new relationships* to help them feel more secure and anchored during the transition process.

4.2.3.1 Developing Self-Management Skills. During the healthcare transition process, AYAs were faced with the task of taking on greater responsibility for their own healthcare needs. This required developing self-management skills, such as advocating for themselves and making informed decisions about their care. Learning to advocate for themselves and relinquish parental guidance was crucial to developing self-management skills. By doing so, AYAs gained a sense of control and agency over their healthcare journey, which was particularly important for AYAs navigating a time of change and uncertainty in their lives.

To successfully navigate the healthcare transition, AYAs also sought out supportive relationships, such as healthcare providers willing to listen to their concerns and provide guidance and advice. These relationships helped to build confidence and provide the necessary support to manage the challenges of this period. Yet, not all AYAs were ready to take on this responsibility at the same time, as some were more prepared for transition and able to advocate for themselves. In contrast, others still depended on their parents or caregivers for support. Recipients who had early experience and help developing self-care and advocacy during their pre-teen years were better equipped to manage their healthcare needs. This could be seen in the experience of Leila and the way her early practice in self-care helped to prepare her for assuming more independent roles post-transition:

> My parents had me preparing my own cornstarch doses and doing my own g-tube feeds since I was a pre-teen. I'd been taking care of the day-to-day activities for years, so that didn't feel like much of an adjustment. It was more weird than anything to now be the

> one answering phone calls and booking my own appointments and having to keep track of papers…Luckily my parents were still very hands on and supportive in keeping me organized, and if I needed anything, they were only a phone call away. (Leila, recipient)

The passage posits that the success of Leila's self-advocacy was strongly influenced by her parents' guided support. Similarly, Michel (recipient) reflected insight in that his parents would not be able to continue holding his hands and that his parents intentionally prepared him for that change (Laucius, 2013). These observations align with previous research that indicates that a more comprehensive preparation in self-management during childhood helps young individuals better navigate the challenges of advocating for themselves in the adult healthcare setting (Nguyen et al., 2016; Nicholas et al., 2018; Toulany et al., 2022). Conversely, those individuals who do not receive anticipatory guidance and support may find the transition process more difficult and struggle to enact their independence and meet their needs effectively (Toulany et al., 2022). This may lead to a lack of agency over their healthcare journey, ultimately negatively affecting their health outcomes (Toulany et al., 2022). Nancy’s experience highlighted the difficulties that some individuals faced when learning to advocate for themselves in the healthcare system, as it took a while to learn how to advocate for herself without feeling as though she was being seen as a complaining patient:

> I wanted to feel competent that, like, you know, in the future, if there was another situation that, we could have a better process in place for that. But I was never given that again… But that would be kind of like the thing where it would set me off to think, okay, well, wow, I really have to advocate for myself, I really have to, like, be assertive… And I think that was hard. Because I guess, like, I'm the type of person that, like, you know, I've learned along the way how to speak up when I feel like I need to, but I guess it's like, it's his own context of being a female, but like, sometimes, like, I don't want to seem like I'm a pain or something. When I say something. And like, I think as a patient, it was always like, finding that balance. (Nancy, recipient)

In this passage, Nancy elucidated her aspirations to feel competent in navigating future situations and emphasized the necessity of developing a more effective process. Notwithstanding, she conveyed her disappointment in never being granted the opportunity to demonstrate her competence again. Leila shared similar concerns in which seeking care felt like a burden:

> I feel adult care is also far more hands-off than pediatrics. Like my coordinator used to call me weekly just to check in, now I have to call them and every time I do it feels like I'm a bother. (Leila, recipient)

The excerpt accentuated her struggle with self-advocacy and assertiveness, which she perceived as arduous due to her inherent disposition and the societal implications of her gender. Moreover, she expressed apprehension about being construed as a nuisance when voicing her concerns, especially in the context of being a patient. Nancy's experience demonstrated that self-advocacy is a skill that needs to be practiced and supported by the healthcare team.

Similarly, research has shown that having opportunities for comprehensive preparation in self-management during childhood can be instrumental in helping young people develop the necessary self-advocacy skills to navigate the adult healthcare system effectively (Nguyen et al., 2016; Nicholas et al., 2018; Toulany et al., 2022). By working collaboratively with recipients and their families, healthcare providers can help cultivate the necessary self-management skills and provide opportunities for AYAs to practice self-advocacy. John's description of recipients who had an extended period before transition reinforced that providing a practice ground for communicating in adult care benefited AYAs, their families, and their healthcare providers:

> I think because of this long process leading up to his transplant and transition to adult care; the family had a lot of practice with communicating with the team and allowing him to come to his hemodialysis treatments on his own before transplant. This helped them to start transferring responsibility to him before transition, with practice for him asking appropriate questions, updating his mom after treatments about the plan, and following

> up with booking future appointments. This patient and family also developed strong relationships with the care team. (John, RN)

The notion of self-advocacy in healthcare is a concept that has been described as requiring a learning process whereby individuals develop and refine their advocacy skills over time (Nguyen et al., 2016; Nicholas et al., 2018; Rapley & Davidson, 2010; Wright et al., 2019). This highlights the challenges that individuals face in the patriarchal structure of the healthcare system, where patients are often expected to be passive recipients of care rather than active participants. Thus, despite attempts at self-advocacy, individuals encountered obstacles when care providers interpreted their efforts negatively. This may have been due to the need for patients to proactively coordinate their health issues in the adult healthcare setting, which differed significantly from the passive role traditionally adopted in pediatric care.

These challenges suggested the need for a more patient-centred approach to healthcare, whereby patients were empowered to be active partners in their care to advocate for their needs effectively. However, recipients frequently felt like their advocacy was interpreted negatively by care providers, as they needed to actively reach out and coordinate their health issues in the adult setting, which differed from the practice in pediatric care. The examples shared by the nurses suggested that parents played a crucial role in helping their children learn how to advocate for themselves in healthcare settings. The nurses' examples indicated that parents acted as strong advocates for their children, empowering them to become more active participants in their health management. For example, John highlighted the importance of parents allowing their children to take control of their healthcare, observing that parents who supported their children in taking control of their healthcare needs were more likely to raise children who could advocate for themselves in healthcare settings effectively.

Through improved communication and empowering children to take charge of their healthcare needs, parents instilled confidence and independence, which in turn helped them become more effective self-advocates. Overall, parents played a critical role in helping their children learn how to advocate for themselves in healthcare settings, underscoring the importance of parental support in helping children develop the skills and confidence needed to become active participants in their health management. By providing this support, parents allowed their children to navigate the complex and often challenging healthcare system effectively, ensuring their needs and voices were heard.

Parents were a critical factor in empowering recipients to feel more in control of their health, supporting their transition into adult-focused healthcare. When parents exhibited confidence in their children's abilities and provided them with the necessary tools and resources, they fostered an environment conducive to developing self-efficacy, autonomy, and self-management skills. These attributes were instrumental in facilitating a successful transition into the adult healthcare system, as they enabled recipients to navigate their care independently and effectively. However, there were instances where the opposite was seen, and self-advocacy was hindered by parents who would not allow the recipient to assume responsibility for their care:

> But if you can identify that, you know it might be a barrier for that challenge in the future, like if I notice that I have a 17-year-old patient that I'm caring for and they don't have any idea about their medications and they're not answering any questions when I ask them and that their father maybe is answering all the questions, I can kind of identify there that maybe we might need to do some teaching with this family and identify you know what it is that they understand about the illness and to encourage and promote the patient to be a little more autonomous in their own health and to help them feel more empowered to do that. (Kelly, RN)

In this statement, Kelly emphasized the importance of identifying potential barriers to patients' autonomy and empowerment in managing their health. She cited an example of a 17-year-old patient who lacked knowledge about their medications and relied on their father to answer questions. Recognizing this challenge, Kelly suggested educating the family and promoting the patient's autonomy to help them feel more empowered in their healthcare journey. This highlights healthcare providers' critical role in fostering self-management skills and empowering patients to take control of their health. Overall, nurses perceived that passive recipients required additional encouragement and empowerment to prepare for their healthcare transition and cultivate autonomy effectively. They considered proactivity in establishing independence an essential indicator of a successful transition. The success of the transition was further rooted in the sense of value and competence that patients derived from their autonomy. Nurses maintained that bolstering passive patients with encouragement and empowerment was crucial for facilitating a successful transition and fostering independence. Adopting a proactive approach to nurturing autonomy was viewed as a critical component for achieving a successful healthcare transition:

> So, in this particular case, that the family, I remember specifically being in the room, and it was when we were doing Med teaching, so the patient themselves was supposed to kind of prompt me and know when to take the medications and what they were taking. And kind of doing things for them, and it seemed as if the patient felt, you know, good about that and felt empowered that he really was in control of his own health, and his parents were there, but they were there in a more supportive role versus taking control. (Kelly, RN)

Kelly recounted a specific instance where she involved the patient in their medication management, with the patient prompting her about when and what medications to take. This approach led to the patient feeling empowered and in control of their health, with their parents taking on a supportive role instead of controlling the situation. John shared a similar approach to care to help foster independence:

> I think I know what the best practices are and that we should be encouraging as much participation as possible from the adolescent. I try to encourage them to ask for their meds at the times they are due, rather than just automatically bringing them in – but

> again, this is sometimes challenging to manage when I have competing demands and need to organize my care for multiple patients. (John, RN)

This example furthers the point above about encouraging and empowering patients to establish autonomy in their healthcare transition. Involving patients in managing their treatment fosters a supportive environment, allowing nurses like John and Kelly to facilitate successful transitions and help patients develop the necessary skills to navigate their healthcare journey independently.

Nurses recognized that a patient's enthusiasm for learning and autonomy and deriving a sense of value from self-care are crucial factors in a successful healthcare transition. Consequently, despite citing shorter hospital visits in adult care in which recipients needed to be more direct in communicating their needs, recipients described finding their voice in the process of advocating for themselves, which helped them establish trust with the new care team, adding to the feeling of value in being autonomous as supportive anchors in navigating the swell of transition.

The challenges with self-advocacy extended beyond the mere ability to articulate one's needs and preferences, causing AYAs to struggle to connect with their healthcare team, further complicating their ability to navigate the healthcare system effectively. The lack of connection stemmed from various factors, including a perceived lack of control over one's healthcare journey, feeling disempowered by the healthcare system, or lacking trust in healthcare providers. For AYAs transitioning to adult healthcare, these challenges were particularly acute, as they were navigating a new system and may have been experiencing heightened feelings of uncertainty and anxiety.

4.2.3.2 Forging New Relationships. As AYAs moved into this sub-category, *forging new relationships* became critical to establishing a connection with the adult care team. When AYAs did not feel heard or understood by their healthcare providers, they were less likely to express their needs and preferences. This led to a cycle of frustration and disengagement that ultimately resulted in suboptimal health outcomes such as organ rejection. Conversely, recipients who had parental support and were encouraged to engage in self-care before the transition appreciated the autonomy they had learned and eagerly forged new relationships. Establishing trust and relationships with the new adult care team was crucial for recipients and parents. Jane shared the feeling of appreciation for the gains and development experienced throughout the course of the transition as she forged new relationships with the adult care teams:

> I guess like just uncertainty thinking about like how I would build trust with the new team if they know if they, like, they have, they always need time to get to know you and your system, everything, so that was probably the biggest thing that I was thinking about. And like I had developed like trust and relationships with my other team as well, right, so at the whole year so being able to do that. Uhm. So yeah, I think that was basically what I was thinking. (Jane, recipient)

Jane articulated her apprehensions regarding establishing trust and rapport with a new team and acknowledged the inherent uncertainty and potential setbacks accompanying such transitions. However, she reflected on her ability to connect with the team, despite the challenges as she navigated to a new system and learned to advocate for herself. Jane and other recipients recognized the importance of healthcare providers and parents to establish a supportive bridge between the pediatric and adult healthcare teams. Parents were instrumental in this process. They helped develop strong relationships between the pediatric and adult healthcare teams to ensure that their child's care was coordinated and received the support they needed to transition to adult care successfully.

For healthcare providers, their role in supporting the bridge between pediatric and adult healthcare teams was focused on helping AYAs to develop healthy behaviours and to become engaged in learning and self-advocacy. This involved providing them with information about their healthcare needs and encouraging them to ask questions and express their preferences, fostering the skills needed to be successful in adult care. By building new relationships with the adult teams, recipients had more opportunities to practice self-care with the guidance and support of parents and healthcare providers, which was valued. The appreciation of the opportunity to build relationships resonated as essential for all participants. It was heightened for families and recipients who felt the support and care received from the healthcare teams was extraordinary and significant in the movement toward independence and transition to adult care, as evidenced by Clare's (recipient) story:

> Having to say goodbye to my team and getting to know a new team is emotional and worrying, no matter how prepared you are. I know I need to just sit in this moment, accept it and then move on. (Children's Wisconsin, 2022, para. 31)

Clare recognized that the process of 'moving on' was essential to her transition and that despite missing the pediatric team, she would come to know a new team and develop supportive relationships with them as well. Jatin (recipient) expressed a similar experience in that although, in the beginning, the transition to adult care was difficult, by ensuring that he remained open and spoke up to make sure his voice was heard, he developed trust in the adult team as well over time (The Kidney Foundation of Canada, n.d.a). Jackie (recipient) also shared similar feelings, "It's scary at first, as are most big changes, but it will get easier. You will find yourself comfortable in these next steps, even if your clinic isn't painted in bright colours" (Benavides, n.d., para. 14).

The sentiments shared by Clare, Jatin, and Jackie exemplify the realization shared by recipients and parents that although the familiarity of care was changing between pediatric and adult settings, the quality of the care remained consistent. Furthermore, the transition began to signal to recipients, as it did with Jackie, that they were progressing in their transplant and transition journeys. Additionally, Jackie's quote highlights the vital role of a positive mindset in the healthcare transition. The transition from pediatric to adult healthcare was a significant developmental milestone that marked the emergence of new roles and responsibilities for recipients. Although this period can be stressful, as it involves navigating a new environment and taking on more independence in managing one's health, as Jackie noted, it was also an opportunity for growth and improvement in health (Benavides, n.d.).

Therefore, pediatric healthcare providers and families are crucial in promoting positive attitudes toward healthcare transition by emphasizing the process' potential benefits and growth opportunities. This can involve providing anticipatory guidance and education to recipients, building a supportive and trusting relationship, and acknowledging and celebrating the recipient's progress and accomplishments throughout the transition process. Ideally, healthcare providers could leverage the established relationship with AYAs to help them to develop self-management skills, such as keeping track of their medications and appointments and managing their healthcare needs to foster a sense of agency and control while nurturing the developing relationship with the new care team. Overall, transitioning from pediatric to adult healthcare required a collaborative effort between parents, AYAs, and the pediatric and adult care teams, working together to establish a supportive bridge to foster healthy behaviours and self-advocacy skills.

In summary, the third category *seeking supportive anchors in the swell of transition* revolved around the essential strategies and connections that AYAs developed while navigating the complexities of transitioning from pediatric to adult healthcare. The two sub-categories, *developing self-management* and *forging new relationships*, emphasized the critical skills and networks that patients cultivated to adapt to their new healthcare environment. Developing self-management focused on patients acquiring the necessary skills and autonomy to manage their health independently, including learning about their medications, appointments, overall health and advocating for their needs. As patients became more autonomous, they felt empowered and were able to begin forging new relationships.

4.2.4 Category Four: Gaining a New Sense of Self

In the fourth category, *gaining a new sense of self,* AYAs underwent profound personal growth and development during their healthcare transition. This category is characterized by two sub-categories, *stabilizing through normalizing* and *accepting a new reality*. Most patients lead fulfilling lives despite the potential debilitation from chronic conditions necessitating organ transplantation. The accomplishment of this feat was attributable to the patient's efforts in stabilizing their lives and normalizing their healthcare journey, ultimately leading to the emergence of a transformed self.

Stabilizing through normalizing encapsulates how AYAs adapted to the new circumstances imposed by their chronic conditions and the associated healthcare transition. As they acquired self-management skills, forged new relationships, and learned to navigate the adult healthcare system, they gradually established a sense of equilibrium and normalized their day-to-day experiences. This normalization process allowed them to integrate their healthcare journey into their identity and develop a more comprehensive understanding of their evolving selves.

Accepting a new reality refers to the AYAs' acknowledgement and embracement of the changes brought about by their chronic conditions and the transition to adult healthcare. This acceptance entailed reconciling with the inevitable adjustments in their lives and relinquishing previous expectations of their future. By coming to terms with their new reality, AYAs cultivated resilience, adaptability, and a renewed sense of purpose, ultimately fostering the development of a transformed and more mature self.

4.2.4.1 Stabilizing Through Normalizing. While transitioning from pediatric to adult healthcare, recipients experienced a stabilizing effect as they began normalizing their routines within the new environment. This entailed acclimating to the novel care team and adjusting to a different care system. Generally, patients required some time to become familiar with these changes, which ultimately led to a feeling of stability and reassurance. As they adapted to their new routines in adult care, patients employed various strategies to manage their healthcare, such as enlisting family support, utilizing technology like phone applications and alarm clocks for care organization and reminders, or seeking guidance from their care team in navigating the new setting. According to Donna, who juxtaposed the two periods in care (pediatric and adult), recipients began to stabilize when experiencing hope of survival. The original mindset observed during the teen years was described as follows:

> But at that teenage age, they don't care how much help you try and find them, they they've gone to that place. They've just shut everyone out…but she listens now, so it's she when she wasn't listening. Oh, I don't even, can't even tell you, I thought she was not going to survive because of their own stupidity. (Donna, parent)

This is contrasted against her shifted mindset of how her daughter stabilized:

> She is overall with her health and taking care of herself. She's just, uh, amazing doing a very, very amazing job. It just sort of one happened after six months. She just flipped over and just really taking responsibility for her body in herself and realize she can survive. I think when she was younger, she said I just thought I was going to die anyway. (Donna, parent)

Donna's account provided insight into the different mindsets between pediatric and adult care experiences, highlighting the importance of hope for survival in stabilization. During her teenage years, her daughter displayed an air of disinterest and disconnection, shutting everyone out, even when help was offered. Donna feared her daughter might not survive due to her reckless behaviour. In contrast, her daughter experienced a transformation in her mindset as she transitioned to adult care. After about six months, she started to take responsibility for her health and well-being, which Donna described as "amazing." This change in attitude likely resulted from her daughter's realization that she could survive her health challenges. This is mirrored in Julie's (recipient) perspective, "I have a very different outlook on life now…it matured me a lot…You can't dwell on the negative. I believe that everything happens for a reason. I just don't necessarily know all the reasons" (Cincinnati Children's, n.d., para. 8-9). Acknowledging the possibility of survival played a crucial role in Donna’s daughter and Julie’s stabilization process, which enabled them to take an active role in managing their health and fostering a more positive outlook on their futures.

Both parents and the healthcare team played vital roles in supporting transition and patient transplant success. AYAs received parental guidance to become autonomous and stabilizing in their care, with their parents simultaneously letting go of control and coaching them toward self-management. Thus, there was a shared responsibility between recipients, healthcare providers, and families to guide recipients toward stabilization and support their success in the adult-focused care system. According to Kelly, nurses helped the patient during the vital stages of pre- and post-transplant:

> So, helping them manage things like taking their medications, managing symptoms, whether it might be fluid overload or maybe dialysis, uh, for kidney patients, but really helping them manage their illness both pre- and post-transplant. (Kelly, RN)

The successful transition of AYA recipients to adult-focused care requires a collaborative effort between healthcare providers, recipients, and families. Grounded in the theoretical model of family-centred care, an integrative approach to healthcare is essential for comprehensively addressing patients' needs, acknowledging the pivotal role of families and caregivers in patient care, and underlining the imperative for close cooperation between medical professionals and parents in attaining optimal outcomes for patients. In transplant care and healthcare transition, AYAs depend on nursing support during the critical pre- and post-transplant phases. The pre-transplant stage encompasses meticulous evaluation of the patient's health status and transplant suitability, in addition to preparatory measures and education to assist the patient and their family in comprehending the transplant procedure and its implications. Nurses collaborate extensively with patients and their families throughout the post-transplant phase to ensure that patients can effectively manage their health and adapt to the novel care system. This entails providing educational resources and support concerning medications and other care facets and coordinating care across many providers and settings. Therefore, by collectively adopting a family-centred approach to care, nurses contribute to stabilizing and achieving favourable patient outcomes in their new care system, ultimately enhancing this vulnerable population's health and quality of life.

The significance attributed to parents and the healthcare teams, particularly within pediatric settings, was prominently demonstrated throughout the experiences shared by all participants. As recipients acclimated to their new care environments, they attained a renewed sense of normalization about their experience and care. By establishing routine access to healthcare following the transition to adult care, patients achieved a sense of stability. According to Riley, although normalizing self-care practices post-transition necessitated a period of adjustment, perseverance would ultimately render the pursuit of post-transplant healthcare more manageable:

> I guess after a while, I sort of get so used to it that I just, I guess, I would do it myself, but I knew that they were always in sort of one place, and I still do that now; I still keep it in the cupboard at home. Yeah, it's just it's easy in it, and they're all there. And I've learned to mention with medication to ask for refills and things, like when I see these people in person or now on the phone, because I know that they're very, very busy people, and for some, it can be challenging to get refills, prescription refills. It really can; definitely, something that I've learned over the years. (Riley, recipient)

Patients found a sense of stability by normalizing their experiences and care after transitioning to adult healthcare systems. Riley's example demonstrated how she became accustomed to managing her medications and refills independently over time. However, it is essential to consider that not all participants may have reached this normalization stage similarly. It is also necessary to recognize the variety of ways individuals might attain normalization. For instance, Bruno achieved normalization through his wife's active involvement in managing his healthcare, which differed from the other recipients’ normalization. According to Bruno, he required ongoing support and encouragement from family members to encourage self-care due to his history of not being consistent with care:

> I still don't fully take control of my health. I do what the doctor ask and hope nothing comes back negative. And still, my wife pushes me to take care of myself for her. I have a lot of mental problems because of my childhood. (Bruno, recipient)

Transitioning to adult-focused care for AYA recipients was complex and multifaceted. While achieving full autonomy in managing their care was a vital transition goal, as discussed in the last category, it was not always possible or immediately achievable for all patients. In some cases, recipients required significant support from their families or healthcare providers to maintain stability and manage their care effectively. In the case of Bruno, for example, he had not yet achieved full autonomy in taking responsibility for his care but has stabilized in his ability to manage his self-care and independence through the support of his family. This is a testament to the importance of a collaborative approach to AYA care. Healthcare providers, parents, and other family members work together to support the patient in achieving their goals and maintaining stability. The dynamic between Bruno and his wife was an interesting example of how family support was critical in achieving stabilization. By working together to manage Bruno's care, they established a new normal that allowed him to maintain a sense of control and autonomy over his health while also receiving the support he needed to manage the challenges of his condition. This collaborative approach was essential to AYA care and helped support positive health outcomes and greater well-being for patients and their families.

The progression of transitioning to adult-oriented care for AYA recipients was a complex undertaking that frequently entailed an extensive adaptation period and a demanding learning trajectory as patients endeavoured to acclimate to the new system and assume greater responsibility for their care. Nevertheless, as recipients attained stability within the system, they often experienced favourable health outcomes and a feeling of accomplishment. One crucial stabilization component was the capacity to accomplish healthcare milestones, such as proficiently managing medications, attending appointments, and adhering to care plans. For many AYAs, these milestones held particular significance, as they were occasionally the first of their age to survive into adulthood with their condition. This presented challenges in finding relatable peers, yet also rendered attainment of these milestones increasingly important and gratifying. As AYAs gained stability and grew more at ease with the new system, they also tended to exhibit increased independence and self-guidance in their healthcare management. This encompassed seeking access to care without reliance on their parents and embracing a more significant role in managing their care. This was a considerable source of pride and accomplishment for many recipients, who felt a sense of competency and control over their health for the first time, as shared by Jackie:

> Transitioning from a pediatric to adult health care provider shouldn't cause anxiety. It's a sign you're getting older and maturing along the way. For me, it signalled stability and improvement in my health. [*PEDIATRIC DOCTOR*] believed I was ready for the real world and able to handle anything coming my way. (Benavides, n.d., para. 14).

Jackie's experience demonstrated that although adult healthcare can be initially daunting, the movement ultimately symbolized growth, maturity, and stabilization for patients. Stabilizing through normalizing involved adapting to the new environment and care team. Despite the initial apprehension often accompanying significant changes, patients gradually became more comfortable and confident in navigating their healthcare journey, demonstrating the importance of this stabilizing process in their overall well-being. As part of stabilizing, some recipients, such as Jackie, had a positive attitude towards taking responsibility for their health care and being autonomous. In contrast, others, such as Bruno, as discussed above, still needed immense support to maintain health and normalize receiving external support.

The stabilization concept was important in AYA care, as it represented how the patient maintained a sense of control and consistency in their healthcare management. Stabilization was not a static state but an ongoing process that required continuous adaptation and adjustment as the recipient's needs and circumstances changed. However, achieving stabilization was an important step in the journey toward gaining a new sense of self by assuming greater independence and self-sufficiency. It was a key indicator of favourable health outcomes and overall well-being for AYA recipients. By accepting the changes and the differences between adult care and pediatric care, recipients adjusted to and stabilized through normalizing their new practices of self-care and autonomy after the transition:

> But at first, it can be a lot because it's a lot of blood, where it's very frequent. Uhm? You have to wait a little bit longer than it [*PEDIATRIC HOSPITAL*] for blood work, so I try and get there early, and it's usually like a full day or so… I think maybe [*PEDIATRIC HOSPITAL*] took a little bit quicker, this is, I think maybe they see less patients, and I don't think just see transplant patients either, and I think some of them wanted to hopefully see some of the blood work come in before they saw you. (Riley, recipient)

Here, Riley compared the new routine in adult care to pediatric care by stating that, while it took more time, she adjusted by learning to arrive earlier for the tests. This may suggest that recipients with positive attitudes and proper moral support succeeded in stabilizing self-care and becoming autonomous. The concept of attitude in this context refers to the recipient’s mindset and approach to their care, whereby a positive attitude facilitated greater motivation and commitment to self-care. Conversely, a negative attitude hindered progress and led to decreased engagement with healthcare providers. In adult care, Riley's comparison to pediatric care highlighted the importance of attitude and moral support for patients in stabilizing their self-care and achieving autonomy. However, this required a significant investment of time and effort on the part of the recipient, as evidenced by Riley's adjustment to arriving earlier for tests. Yet, according to Kelly, there was minimal support from health facilities to create support to build capacity to improve the environment for transplant patients transitioning to adult care.

Stabilizing through normalizing their care was crucial to managing chronic illnesses and conditions for transplant recipients. It involved achieving consistency and predictability in managing the recipient’s health, including medication management, symptom control, and self-care practices. However, achieving this stability level was challenging in transitioning from pediatric to adult care. As highlighted by Kelly, healthcare facilities did not always provide adequate support for patients during this transition, making it difficult for them to build the capacity to stabilize their care. This lack of support often made recipients feel overwhelmed and unsure about how to manage their care effectively, leading to adverse outcomes such as medication non-adherence, missed appointments, and increased healthcare utilization.

Moral support was identified as a factor that played a critical role in helping recipients stabilize their care. It involved emotional and psychological assistance provided by family, friends, and healthcare providers, allowing patients to cope with the challenges of their care and improve their overall quality of life. For instance, receiving encouragement and motivation from loved ones helped patients maintain their medication regimen, attend appointments regularly, and engage in self-care practices that contributed to stabilizing through normalizing their care. Moreover, healthcare providers played a critical role in providing moral support by establishing trust and rapport with their patients, addressing their concerns and questions, and providing education and resources that empowered recipients to take an active role in their care. By doing so, healthcare providers helped patients stabilize their care, reducing the likelihood of adverse outcomes and improving their overall health and well-being.

4.2.4.2 Accepting a New Reality. In the last sub-category, *accepting a new reality pertaining to the transition from pediatric to adult care* was a complex psychological and emotional experience that involved recognizing and internalizing the implications of the change. This process involved a fundamental shift in the patient's identity and sense of self as they moved from a dependent role in pediatric care to assume greater responsibility for their health in adult care. At the heart of accepting a new reality was recognizing the transition itself and the responsibilities that came with it. Patients acknowledged that they were no longer children and needed to be more active in their care. This involved assuming responsibility for medication management, self-care practices, and decision-making related to their health:

> Most important to me at least, is the realization that it comes to the transplant person that it's their health and no one else can do it for them. Everyone can give you the tools and advice all they want, but if you don't take their health in their own hands, nothing will help. But we have to remember that they are only 17-18 and just starting to be adults with a lot to learn. Need the adult doctors to take more time with new patients. (Bruno, recipient)

Here, Bruno emphasized the importance of realizing that after a transplant, it was ultimately the individual's responsibility to manage their health. While others could offer advice and support, taking ownership of one's health was critical to success. In the case of Bruno, he recognized that despite having all the tools required, he needed to accept responsibility for his health and well-being. This involved accepting his autonomy, organizing his life to match post-transplant expectations, and accepting his new reality by learning to live with his health condition.

From a theoretical perspective, acceptance can be viewed through self-determination theory, which emphasizes the importance of autonomy, competence, and relatedness in promoting healthy behaviour change (Stephens et al., 2021). By accepting responsibility for their health, recipients developed a greater sense of autonomy and control over their lives, contributing to improved self-efficacy, greater engagement in self-care behaviours, and acceptance of their new reality. Leila's decision to work in the healthcare field can be seen as an example of accepting her new reality:

> Growing up, my life and what I did was very much dictated by my illness. Now, as an adult, post-transplant, I'm healthier and less of my daily decisions are dictated by my illness, but I still choose to work in healthcare…There are also the little things in my brain I think can only be explained by having grown up in the system. I still have weird

> habits for sleeping and counting carbs and how my brain operates when my phone rings. (Leila, recipient)

Leila's reflection on the lasting impact of growing up with a chronic illness highlighted her illness identity (Van Bulck et al., 2019). Illness identity refers to how a chronic health condition becomes integrated into someone's sense of self, including not only how someone views the disease and treatment but also how much the disease has affected the way they think about themselves (Van Bulck et al., 2019; Wicks et al., 2019). Illness identity comprises four constructs: engulfment, rejection, acceptance, and enrichment. In the context of this study and the transformation through transition, AYA's identities encompassed how the transplant was a core aspect of self-concept, thereby shaping behaviours, emotions, and relationships as AYAs moved towards accepting their new reality (Van Bulck et al., 2019; Wicks et al., 2019). Leila's experience demonstrated how her illness identity persisted even after her physical health improved, influencing her habits and ways of thinking, ingrained as part of her being and part of her experience. This is consistent with the findings of Wicks et al. (2019), in that AYAs endeavour to accept their illness and experience adolescence regardless of their illness.

In summary, the final category, *gaining a new sense of self*, delved into the complex and transformative journey patients embarked on as they transitioned from pediatric to adult healthcare. This process comprised two essential sub-themes: *stabilizing through normalizing* and *accepting a new reality*. Stabilizing through normalizing highlighted the patients' process of adapting to their new healthcare environment and care team. As patients familiarized themselves with the adult care system, they established routines, developed relationships with their new care providers, and gradually gained a sense of stability and comfort. This stabilization enabled them to navigate the challenges and responsibilities associated with adult healthcare more effectively, contributing to improved health outcomes and overall well-being. Accepting a new reality emphasizes the psychological aspect of this transformation as patients came to terms with their health conditions, the necessary lifestyle adjustments, and the responsibility of managing their care independently. This acceptance involved a shift in perspective and developing coping strategies to deal with their new reality. As patients embraced their new circumstances, they became more resilient and better equipped to handle the challenges in their healthcare journey. Together, these sub-themes illustrate the multifaceted nature of patients' experiences as they adapted to and grow within their new healthcare settings. By stabilizing through normalizing and accepting their new reality, patients ultimately gained a renewed sense of self, characterized by increased independence, confidence, and self-efficacy in managing their health and navigating the adult healthcare system.

4.3 Chapter Summary

In this chapter, I have presented an in-depth presentation and elucidation of the findings constituting the emergent substantive theory, *Riding the Wave of Change: Transforming Through Transition.* This substantive theory delineates the adaptive processes and management strategies employed by AYA transplant recipients during their transition to adult-focused care. The derivation of this theory is rooted in data emerging from various sources, including interviews with liver or kidney transplant recipients, parents, and healthcare providers, as well as virtual chats, blogs, and social media.

The theory consists of four categories: *anticipating the impending transition, losing security when transitioning to uncertainty, seeking normalcy and stability, and gaining a new sense of self*. Each category is further delineated by additional sub-categories, informed by a range of experiences, and shaped by the support and guidance recipients' family members, peers, and healthcare team provide. The *anticipating the impending transition* category highlights the distress about the transition and denial of reality experienced by adolescents during the transition, leading to feelings of anger about being made to feel insignificant.

The *losing security when transitioning to the uncertainty* category encompasses experiencing shock and grieving the loss of relationships and connections. The *seeking supportive anchors in the swell of transition* category encompasses developing self-management skills and forging new relationships. Finally, the *gaining a new sense of self* category defines the adolescents' journey toward stabilizing through normalizing and accepting a new reality.

Overall, this theory provides insights into the experiences and challenges faced by adolescent transplant recipients during the transition to adult care. It also emphasizes the importance of support from various sources in facilitating a positive transition. These findings are situated within the broader literature in Chapter Five's discussion and study implications.

Chapter Five: Discussion

Since I began this study, there has been a growing focus by healthcare practitioners and researchers on trying to improve the transition experience for adolescent and young adult (AYA) transplant recipients (Anton et al., 2019; Catena et al., 2018; Matsuda-Abedini et al., 2022; Rieger et al., 2019; Schmidt et al., 2020; South et al., 2022; Stevens et al., 2021; Wright et al., 2019). The key concepts of healthcare transition models include beginning the process early and developing a partnership between the AYA and the pediatric and adult care providers, with the inclusion of the family to help develop a relationship rooted in trust in the pediatric care team, as the trust is already established. Through this partnership, the transition can be fostered and nurtured, increasing transition readiness from pediatric care. Yet, as illustrated by the systematic review by Parfeniuk et al. (2020) of the transition readiness measures for young adults with chronic health conditions, there remains slow development in terms of achieving an established best-practice measure of transition readiness despite national transition practice guidelines and ongoing commitments to policy development in this area.

In this chapter, I discuss what the findings of my study mean in the context of what is known and the existing gaps identified in the literature reviewed in Chapter Two. I begin situating my study within this context and follow with a discussion of how AYA transplant recipients manage their transition to adult-focused care. Then, using the transition theory framework developed by Meleis et al. (2000), I explore the nature and conditions of transitions and the patterns and responses to these transitions as they emerged through the data and resultant grounded theory. The chapter concludes with a discussion of the study implications.

5.1 Summary of the Study

This study aimed to develop a substantive theory of how AYA transplant recipients manage the movement into adult-focused care to understand better how nurses can support a successful transition process and positive health outcomes. My analysis of findings revealed that *transforming through transition* was the basic social process participants had to navigate in response to the basic social problem of transitioning from pediatric to adult care. The philosophical assumptions underpinning this study were rooted in a constructivist perspective, embracing my background in pediatric nursing and family-centred care and striving to understand the experiences of participants allowing for an understanding within the context of their actions. Through this lens, I obtained first-hand knowledge of transplant recipients' and families' life experiences of transitioning to adult care after an organ transplant through shared constructions of meaning and knowledge with participants using GT methods to guide data collection and analysis. I collected data primarily through participant interviews and analysis of online stories, blogs, and social media sites. Data collection and analysis occurred simultaneously and continued in an iterative manner throughout the writing process.

Using constant comparison analysis, memoing, and diagramming allowed the movement of data analysis to higher levels of abstraction to develop the theory, *Riding the Wave of Change: Transforming Through Transition.* In this process of transforming through transition, recipients ride through waves of change that are sometimes small and easily managed, while other times of larger magnitude are difficult to traverse. Consistent within each wave of anticipating the impending transition, losing security when transitioning to uncertainty, and seeking supportive anchors in the swell of transition is the experience of challenge and readjustment, with underpinning emotions and experiences that help move AYAs toward the final point stabilizing through normalizing and accepting a new reality to gain a new sense of self.

5.1.1 Transforming Through Transition

In the discussion on *transforming through transition*, I identified four categories of experience pertinent to this study's findings. The recipients ebbed and flowed through phases like currents whereby they were aware of the imminent transition and experienced anticipatory emotions based on how they believed the transition would occur or how they would be treated in adult-focused care. These phases emphasized the changing relationships with healthcare providers, underscored by an emotional response to leaving the pediatric centre and the associated feelings as they developed self-management and began to forge new relationships. In the last phase of gaining a new sense of self, recipients moved further away from the transitioning and closer to stabilization and acceptance of their changing reality and situation. Throughout this process, relationships with family, peers, and healthcare practitioners helped AYAs become grounded through the waves of change, providing stability and propelling them toward a more stable footing as they gained a new sense of self and acceptance of their new reality. This emphasizes the need to examine the social forces that, on the one hand, create the social structures responsible for transitioning unrest in the movement from a pediatric-focused centre of care and, on the other hand, become the site for gaining new aspects of the self and supporting development in the adult-focused care environment.

5.1.2 Experiences and Processes of Transition

Meleis et al.'s (2000) transition framework can provide a useful lens for understanding and addressing the shared experiences of AYA organ transplant recipients in moving from pediatric to adult-focused care and will be used to structure this discussion. This framework parallels the findings of this study that is framed by anticipating the impending transition, losing security when transitioning to uncertainty, seeking supportive anchors in the swell of transition, and gaining a new sense of self. As shared by participants, this process represented a significant life transition that impacted their lives, including family, work, school, mental health, becoming an adult and developing independence. The recipients defined the transition issue as a challenging point in their healthcare journey underpinned by myriad emotions. In this study, I identified that collaboration and communication among recipients, healthcare providers, and families are essential to facilitate a successful transition. This is supported by previous research recommending that transition plans must be developed collaboratively, involving the full participation of the individual, their family, and healthcare teams (Catena et al., 2018; Davenport et al., 2022; McManus et al., 2017; Schmidt et al., 2020). Yet, this study showed that transition plans differed amongst participants with varying degrees of coordinated efforts and communication.

Those participants with better-established transition planning processes with ongoing peer and parental support described their transition as less traumatic and more positive. Participants also proposed that earlier and more organized transition planning would support AYAs' transition preparation and help to manage expectations. From the experiences shared by recipients, we can discern that a smooth and well-coordinated transition experience can significantly impact long-term outcomes and patient satisfaction. Participants identified areas that would have helped smooth the AYA's transition experience and continued development of life and social skills and suggested support in planning, management, and independence in the domains of vocation, finance, mental health, and healthcare was missing. The identified areas for enhanced and improved transition experience included early initiation of transition preparation and education for patients and their families. By providing ample time and resources to understand the differences between pediatric and adult care, the importance of self-management, and the resources available, AYAs and their families would have become more confident and proactive in navigating the transition process. Participants expressed a desire for individualized transition plans that catered to their unique needs and preferences with a collaborative effort to involve the patient, their family, and the healthcare team to establish specific goals, timelines, and a designated person supporting them through the transition process. Participants expressed frustration with the lack of interdisciplinary collaboration and communication between pediatric and adult healthcare teams, which could have been improved through joint appointments, shared care planning, and the use of standardized tools, to minimize care gaps (White et al., 2020). These experiences closely align with the recommendations provided within the literature.

Healthcare transition planning and support for AYAs with chronic illness is crucial to ensure that patients receive adequate care as they navigate the shift from pediatric to adult healthcare systems. Several policy elements have been recommended to facilitate this process. Firstly, healthcare institutions should establish formal transition policies and procedures that guide the transition process. These policies should be based on current best practices and evidence-based guidelines, such as those developed by the Canadian Pediatric Society (Toulany et al., 2022), the American Academy of Pediatrics, American Academy of Family Physicians, and the American College of Physicians (White et al., 2019), supported by Eniola (2023), Vittorio et al. (2023), White et al. (2019), and White et al. (2020) as detailed in Table 3.

Table 3

Summary of Transition Policy and Procedure Recommendations from the Literature

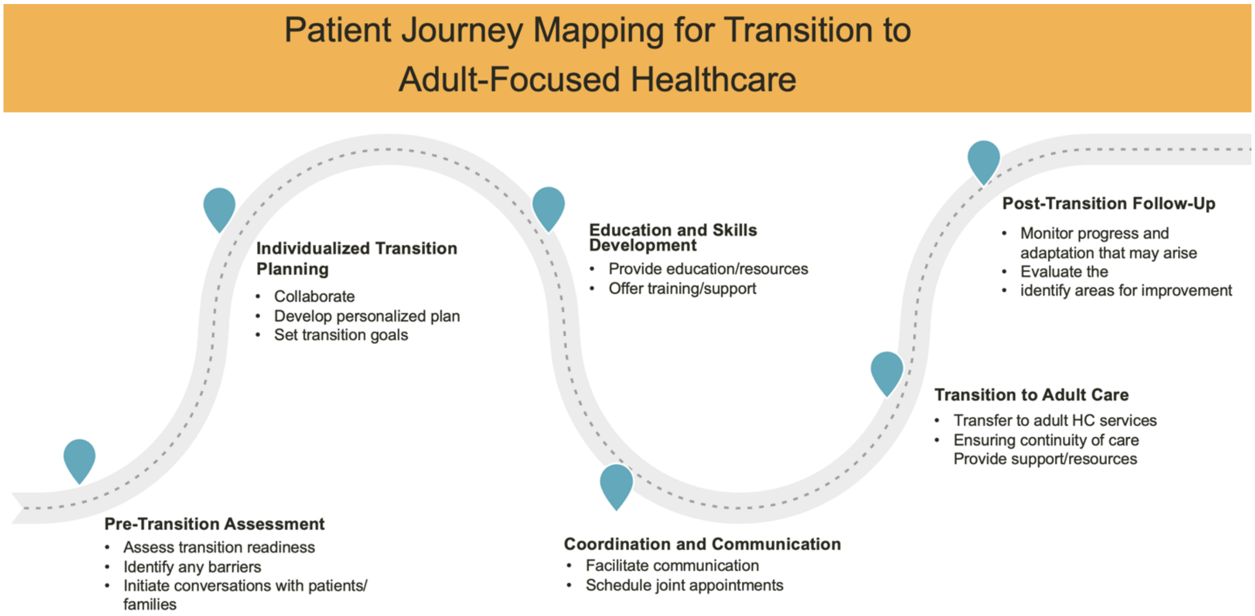
Policy Element	Description	References
Formal Transition Process Policies & Procedures	Establish evidence-based policies and procedures for the transition process, involving input from various stakeholders.	Eniola, 2023 Toulany et al., 2022 Vittorio et al., 2023 White et al., 2019 White et al., 2020
Provider Training	Provide healthcare providers with training and continuing education opportunities on transition planning and support.	Eniola, 2023 Toulany et al., 2022 Vittorio et al., 2023 White et al., 2019 White et al., 2020
Individualized Transition Plans	Develop personalized transition plans in collaboration with the patient, family, and healthcare team. Consider cultural preferences.	Eniola, 2023 Toulany et al., 2022 Vittorio et al., 2023 White et al., 2019 White et al., 2020
Standardized Tools & Assessments	Utilize evidence-based tools and assessments to evaluate transition readiness and monitor progress.	Eniola, 2023 Toulany et al., 2022 Vittorio et al., 2023 White et al., 2019 White et al., 2020
Adequate Resources & Supports	Ensure availability of dedicated transition clinics or coordinators, funding, and access to specialized adult providers.	Eniola, 2023 Toulany et al., 2022 Vittorio et al., 2023 White et al., 2019 White et al., 2020

Thus, developing transition policies should involve input from various stakeholders, including healthcare providers, patients, and families. Healthcare providers should also receive the appropriate training in transition planning and support to address the unique needs of AYAs with chronic illness or medically complexity, as well as promote interdisciplinary collaboration between pediatric and adult healthcare teams (Doucet et al., 2022: Eniola, 2023; Toulany et al., 2022; Vittorio et al., 2023; White et al., 2019; White et al., 2020). Continuing education and training opportunities should be provided to ensure that healthcare providers remain up-to-date on best practices and evolving guidelines. Transition policies should emphasize the importance of individualized transition plans tailored to the specific needs of each patient but should be developed in collaboration with the patient, their family, and the healthcare team and should include clear goals, timelines, and designated roles and responsibilities for all involved (Eniola, 2023; Toulany et al., 2022; Vittorio et al., 2023; White et al., 2019; White et al., 2020).

Additionally, transition policies should promote the use of evidence-informed, standardized tools and assessments to evaluate transition readiness and monitor progress throughout the transition process, with a specific focus on addressing various aspects of transition readiness, including medical knowledge, self-management skills, and psychosocial factors (Eniola, 2023; Toulany et al., 2022; Vittorio et al., 2023; White et al., 2019; White et al., 2020). Lastly, transition policies should ensure adequate resources and support are available to facilitate the transition process, including dedicated transition clinics, nurses, or coordinators, with funding for transition-related services and access to specialized adult healthcare providers (White et al., 2020). This process can be visualized through a proposed patient journey map outline as depicted in Figure 3 (see Appendix L for the detailed figure), outlining the comprehensive support for AYAs with chronic illness to ensure a seamless shift from pediatric to adult healthcare services (Carayon et al., 2020; Philpot et al., 2019).

Figure 3

Proposed Patient Journey Map (Outline)



Yet, despite the evidence-based knowledge that healthcare transition planning is a critical aspect of care for AYA transplant recipients as it ensures a seamless shift from pediatric to adult healthcare systems, there was a noted absence of use of consistent ways in which the participants' transition was supported. Thus, examining the reasons why transition protocols in healthcare transition planning are not standardized or universally accepted illustrates the multifaceted nature of the issue with several contributing factors.

Healthcare systems and structures differ substantially between countries, and even within different regions of the same country: for example, Canada. This variability in healthcare organization and delivery can result from differences in funding models, governance, provider networks, and insurance coverage, among other factors. Such heterogeneity in healthcare systems can create complexities and inconsistencies in care management, further complicating the development of universally accepted protocols adaptable across various healthcare settings (Martin et al., 2018). Variations in healthcare systems and structures may contribute to the absence of standardized and universally accepted transition protocols for AYAs with chronic health conditions. In Canada, healthcare systems and structures differ across provinces and territories, further complicating the development of universally accepted protocols adaptable across various healthcare settings. Healthcare in Canada is a shared responsibility between the federal government and the provinces/territories (Martin et al., 2018). Each jurisdiction's unique healthcare policies, funding models, and service delivery mechanisms can lead to disparities in the availability, accessibility, and quality of care (Cohen et al., 2019; Martin et al., 2018). These disparities can impact the availability, accessibility, and quality of care, which is further threatened for those of lower SES or indigenous backgrounds (Cohen et al., 2019; Martin et al., 2018). These differences can create complexities and inconsistencies in care management, making it challenging to develop standardized transition protocols applicable to diverse healthcare settings.

In addition to the interprovincial differences in healthcare systems, cultural and socioeconomic contexts within Canada can also influence the development and implementation of transition protocols. Canada's diverse population, comprising Indigenous communities and a substantial immigrant population, requires culturally safe and contextually appropriate transition planning that addresses the distinct needs of these diverse groups (Martin et al., 2018). Immigrant populations in Canada also face unique challenges related to healthcare access, including language barriers, unfamiliarity with the healthcare system, and varying cultural beliefs and practices surrounding health and illness (Martin et al., 2018). Although none of the study participants identified as Indigenous, it is important to acknowledge that Indigenous communities in Canada face healthcare disparities due to historical and ongoing systemic inequalities. These disparities encompass limited access to specialized healthcare services, a lack of culturally competent care, and social determinants of health that disproportionately impact these populations (Martin et al., 2018). Thus, the adoption of a standardized transition plan or protocol must consider these factors for AYAs facing barriers related to the social determinants of health to integrate appropriate strategies, such as interpreter services, cultural safety training for healthcare providers, and tailored health education, to ensure that transition protocols are effective and culturally relevant.

Cultural norms and beliefs can affect how patients and families perceive and engage with healthcare services, necessitating culturally safe and contextually appropriate transition planning. Furthermore, healthcare systems may face unique challenges related to socioeconomic disparities and access to resources, which can impact the implementation of standardized transition protocols (Gleeson et al., 2020). For example, to ensure that transition planning effectively meets the needs of Indigenous adolescents with chronic health conditions, healthcare providers and policymakers must collaborate with Indigenous community leaders and engage in culturally responsive practices that consider the unique cultural contexts, values, and preferences of Indigenous peoples. Developing and implementing flexible, adaptable, and culturally sensitive transition protocols will allow for more equitable care and improved outcomes for all adolescents with chronic health conditions, regardless of their cultural or socioeconomic background (Martin et al., 2018).

Another key aspect of this challenge is the inherent complexity of care for adolescents with diverse health conditions. This complexity demands a multidisciplinary approach encompassing various healthcare specialties (Matsuda-Abedini et al., 2022). Adolescents with health conditions may require the expertise of several specialists, such as cardiologists, endocrinologists, and pulmonologists, in addition to primary care physicians and mental health professionals. This interdisciplinary collaboration is necessary to provide comprehensive and coordinated care, addressing all patient health aspects.

However, given the heterogeneity of health conditions among adolescents with chronic health conditions, developing a one-size-fits-all transition protocol that addresses each patient's unique needs proves challenging (Eniola, 2023). Each adolescent's health condition may present distinct challenges, necessitating tailored care management and transition planning approaches. For example, in my study population alone, the primary health conditions that required transplantation included congenital and genetic conditions, cancer, and organ damage in-utero due to maternal drug use. Furthermore, varying severity and comorbidities further complicate the development of standardized protocols. Consequently, creating universally accepted guidelines must balance providing a structured framework for healthcare providers and allowing flexibility to cater to individual patients' needs. This balance becomes even more difficult to achieve when considering the dynamic nature of AYA development. Adolescents undergo significant physical, cognitive, emotional, and social changes during this crucial period, which can impact their ability to engage in self-management and navigate the complexities of the healthcare system. As such, healthcare transition planning must address the medical aspects of care while also considering AYA developmental needs and evolving autonomy, further adding to the challenge of developing standardized protocols.

The absence of standardized and universally accepted transition protocols in healthcare transition planning for AYA transplant recipients presents a significant obstacle in ensuring a seamless shift from pediatric to adult healthcare systems (White et al., 2019; White et al., 2020). This challenge raises several critical issues in healthcare ethics, equity, and patient and family-centred care. From an ethical standpoint, the need for standardized transition protocols highlights the responsibility of healthcare providers and institutions to develop and implement evidence-based practices (White et al., 2019; White et al., 2020). The principle of beneficence, a core aspect of medical ethics, entails healthcare professionals' obligation to act in their patient's best interests by promoting their welfare and minimizing harm. In healthcare transition planning, the absence of standardized protocols can lead to inconsistencies in care, which may ultimately compromise patient outcomes.

The issue of equity arises concerning the need for standardized protocols. In an equitable healthcare system, all individuals should have access to high-quality care regardless of their demographic or socioeconomic background (Martin et al., 2018). However, the absence of universally accepted transition protocols can result in varying levels of care quality across different healthcare. This variation may exacerbate health disparities and create barriers for AYA transplant recipients, particularly those from lower socioeconomic backgrounds or statuses (Fredericks et al., 2010). Hence, developing standardized protocols is essential for enhancing patient outcomes and promoting equity in healthcare access and delivery (White et al., 2020).

Interdisciplinary collaboration is crucial in successfully adopting a standardized and universally accepted transition model. Successful healthcare transition planning requires effective collaboration between pediatric and adult healthcare teams (Zhang et al., 2018), as was highlighted by the nurse participants, Kelly and John. However, communication gaps and differing care philosophies between these teams may hinder the development and execution of a comprehensive transition plan. Pediatric and adult healthcare providers often operate within separate care systems, with distinct approaches to patient management and treatment (Nguyen et al., 2016; Wan et al., 2019). Pediatric care typically focuses on family-centred approaches, while adult care emphasizes patient autonomy and self-management. The patient and family-centred care approach emphasize tailoring healthcare services to individual patients' and their families' unique needs, preferences, and values (Kokorelias et al., 2019; Nguyen et al., 2016; Wan et al., 2019). In the context of healthcare transition planning, the lack of standardized protocols may impede the ability of healthcare providers to deliver personalized care that meets the specific needs of AYAs with pediatric-onset conditions, such as transplant recipients (Marani et al., 2020; Wan et al., 2019). Thus, these differing care philosophies may lead to challenges in coordinating care and establishing a shared understanding of the patient's needs and goals during the transition process. This may be compounded by insufficient healthcare provider training, as providers may lack adequate experience in managing the unique needs of these patients during the transition process (Marani et al., 2020). This knowledge gap can result in a reluctance or inability to develop and implement effective transition plans, potentially compromising the quality of care and long-term outcomes for adolescent transplant recipients.

In the excerpt shared earlier, John mentioned the value of having a standardized transition policy to ensure consistent approaches to transition planning.

Financial and resource limitations represent significant barriers to the effective implementation of transition planning. This was underscored by Kelly and John in their reflection on the removal of a transition program at their respective healthcare agencies and how that impacted their perceived organizational support for transition care at the bedside. Healthcare institutions may face financial and resource constraints that impede their ability to support transition planning adequately. Limited funding, staff, and access to specialized adult healthcare providers can lead to suboptimal transition planning and implementation. In the Canadian context, healthcare delivery is largely a provincial responsibility, and disparities in funding allocation and resource availability can exist across provinces and territories. Furthermore, rural and remote areas within Canada may have limited access to specialized healthcare providers, exacerbating the challenges of coordinating care for adolescent patients during the transition process (Government of Canada, 2016). As discussed above, these disparities may contribute to healthcare access and quality inequities, particularly for vulnerable populations, such as Indigenous communities and individuals from low socioeconomic backgrounds.

5.2 The Nature of Transitions

Looking at the nature of the transition experiences of AYAs transition within this study, they experienced developmental transition from childhood to adolescence and young adulthood and situational and healthcare transition as they navigated their transplant and the associated changes as they moved into adult-focused care with new care providers. Meleis et al. (2000) highlight the developmental transition as the responses to the life cycle stages with particular attention to the transition from childhood to adolescence and adulthood to old age. In contrast, the situational transition was represented by the changes experienced in the transition between the two different care centres. Transition properties such as awareness, engagement, change and difference, time span, and critical points and events impact the nature of the transition

(Meleis et al., 2000). Furthermore, understanding the nature of transitions, including the type of transition and the transition patterns and properties, is important for determining the extent and type of support needed for individuals navigating change. Thus, in the context of this study, the salient dimensions of the nature of transitions are developmental theory, transition readiness, and preparing and planning for transition, as AYAs manage the simultaneous developmental and situational healthcare transitions. For the study recipients, navigating the confluence of situational and developmental transitions simultaneously, much like traversing the intersections of powerful ocean currents, was further impacted by underlying transition properties. This intricate interplay created a fluid and challenging environment that required resilience and adaptability to maintain their course and progress.

5.2.1 The Nature of Developmental Transition and Transition Readiness

Developmental theories provide important insights into the patterns of development in cognition, social interaction, and personality, attempting to explain why changes occur and how these changes relate to one another. The two key developmental theories of Erikson and Arnette, as discussed in Chapter Two, provide a framework for a holistic understanding of development across the lifespan with consideration of culture. Specifically, Erikson focuses on understanding identity development, which was a salient aspect of the transition experience for study participants. At the same time, Arnett provides insight into emerging adulthood as a distinct stage of development.

As described by Arnett (1999, 2000, 2015), the characteristics expected within Emerging Adulthood include a search for identity, a focus on self-exploration, and experimentation in various aspects of life. The expected experiences and feelings of instability and uncertainty were evident in most of this study's domains, particularly anticipating the impending transition, losing security when transitioning to uncertainty, and seeking supportive anchors in the swell of transition. As the findings show, AYA transplant recipients faced unique challenges in transitioning to adult care as they adjusted and gained a new sense of self. While recipients shared a common experience of ongoing identity exploration and instability with a significant focus on relationships with peers, healthcare teams, and family, there was minimal focus on vocational work. Rather, instability was closely aligned with the change in healthcare providers and care centres, focusing on relationships across all phases of the *Transforming Through Transition* theory. Yet, less clearly identified within the study were the expected experience of ambivalence in describing themselves as adults or perceiving various available life choices. In most cases, recipients described the transition as happening to them rather than as being active or willing participants in the process. However, the characteristic of self-reliance development was of great focus for study recipients as they sought supportive anchors in the swell of transition, regardless of their eagerness to engage in this process.

Arnett (2006) describes a shift from self- to other-focus during this period, whereby emerging adults assume more adult social roles, such as marriage and full-time employment (Arnett, 2006; Broderick & Blewitt, 2019). Arnett's theory of emerging adulthood, which posits that the period between ages 18 and 25 represents a distinct developmental phase characterized by identity exploration, instability, self-focus, and a feeling of being in-between adolescence and adulthood, has gained significant attention in the academic community (Arnett, 2000). However, there has been growing criticism of this theory, with some scholars arguing that it is an outdated construct that fails to account for contemporary socioeconomic, cultural, and demographic factors (Bynner, 2005; Côté, 2014; Parameswaran, 2020; Schwartz et al., 2015; Syed & Mitchell, 2013).

One of the primary criticisms of Arnett's theory is that it predominantly reflects the experiences of middle-class, well-educated young people from Western societies, thereby overlooking the diverse experiences of individuals from varying socioeconomic and cultural backgrounds (Côté, 2014). Emerging adulthood is not a universal experience; instead, it tends to be contingent upon access to resources, opportunities, and support systems. For instance, young people from lower socioeconomic backgrounds or those living in developing countries may be unable to delay work to explore their identities, as they are often forced to assume adult roles and responsibilities at an earlier age (Côté, 2014). Similarly, Bynner (2005) argues that the concept of emerging adulthood overlooks the variability in pathways to adulthood and the mechanisms behind these trajectories. Moreover, Syed and Mitchell (2013) emphasize the influence of race and ethnicity on the transition to adulthood, which is not sufficiently addressed in Arnett's theory.

The theory of Emerging Adulthood has faced criticism for its reliance on traditional markers of adulthood, such as marriage, parenthood, and financial independence. Scholars argue that these markers may no longer hold the same relevance in today's rapidly changing social landscape (Furlong, 2013). Factors such as shifting cultural norms, delayed family formation, increased educational attainment, and changing labour markets have contributed to a more fluid understanding of what it means to be an adult in contemporary society.

Cultural norms and values have evolved over time, leading to a reassessment of the traditional milestones associated with adulthood. For example, attitudes towards cohabitation and non-marital childbearing have become more accepting, challenging the centrality of marriage as a key marker of adulthood (Furlong, 2013; Oláh et al., 2021). Furthermore, changing gender roles and expectations have redefined the paths to adulthood for both men and women, with an increasing number of women pursuing higher education and careers before entering into marriage or parenthood (Oláh et al., 2021). The delayed family formation also complicates the traditional understanding of emerging adulthood. Young people today marry and have children later in life than previous generations, often prioritizing education and career development over family formation (Furlong et al., 2013; Oláh et al., 2021). This trend has led to a more diverse and extended period of transition to adulthood, marked by various trajectories that do not necessarily align with the traditional markers. The increased pursuit of higher education and fluctuating labour markets have also contributed to a more fluid understanding of adulthood. Today's young adults face a competitive and uncertain job market, often requiring prolonged education and training periods (Furlong et al., 2013; Oláh et al., 2021). As a result, financial independence and stable employment may be achieved later in life, further challenging the traditional markers of adulthood.

Thus, while Arnett's theory of emerging adulthood has been influential in developmental psychology, it has also faced substantial criticism for its lack of inclusivity, reliance on traditional markers of adulthood, and failure to adapt to contemporary societal changes. Parameswaran (2020) adds to this critique by providing a historical perspective on the emergence of Arnett's theory, highlighting the social and cultural roots underpinning emerging adulthood. The author argues that the theory is based on a predominantly Western and individualistic understanding of the development and may not apply to early adults from different cultural backgrounds or those facing unique socioeconomic challenges. This limitation is echoed by Syed and Mitchell (2013), who emphasize the long and complex paths to adulthood in contemporary societies and the need for more nuanced perspectives that account for diverse life-course experiences.

Yet, this was not consistent with the recipients in this study, as only two were married. Thus, in the context of this study, it is uncertain if the delay in moving into these adult roles was a result of sensation-seeking and gaining multiple experiences before assuming adult roles and responsibilities as described by Arnett (1999, 2000, 2015) and Broderick and Blewitt (2019), or rather due to focus on managing their transplant and transition to adult care and focus on educational pursuits for these participants. Also, the belief that the behaviours typically associated with sensation-seeking, gaining experiences, and risky behaviours, such as engaging in unprotected sex, substance use, or driving at high speeds or while intoxicated (Arnett, 1999, 2000, 2015; Broderick & Blewitt, 2019), was not consistent with the experiences shared by study participants. But rather, risky behaviours were more related to non-adherent behaviours.

Instead, risky behaviours in this population were more closely linked to non-adherence to medical recommendations, such as skipping medications or neglecting self-care routines crucial for their overall health and transplant success. This supports Bynner's (2005) critique of Arnett's theory, suggesting that it has limited applicability to populations, such as transplant recipients, whose transition to adulthood may be shaped by unique healthcare and educational factors. Transplant recipients, particularly AYAs, face distinct challenges as they transition to adulthood. Managing their transplant, adhering to complex medical regimens, and traversing the healthcare system as they move from pediatric to adult care presents unique hurdles that can significantly impact their priorities, behaviours, and overall experiences during this critical developmental period (Annunziato et al., 2013; Coyne et al., 2017; Cuenca & Yeh, 2019; Griva et al., 2018; Hammond et al., 2021; Fu et al., 2022; Lawrence et al., 2020).

One of the primary challenges transplant recipients face is the need to adhere to complex medical regimens, which may include multiple medications, frequent medical appointments, and ongoing health status monitoring (Anton et al., 2019; Griva et al., 2018; Hammond et al., 2021; Lawrence et al., 2020). The responsibility for managing these regimens often shifts from caregivers to young transplant recipients during the transition to adulthood, which can be daunting and stressful (Annunziato et al., 2013). Moreover, the transition from pediatric to adult healthcare systems can be fraught with difficulties, as AYAs must establish relationships with new healthcare providers, adapt to different care philosophies, and navigate complex healthcare systems (Annunziato et al., 2013; Catena et al., 2018; Fu et al., 2022). These challenges may be exacerbated by disparities in the availability and quality of transitional care services, which can vary widely between healthcare institutions and geographical regions (Stevens et al., 2021). The unique challenges AYA transplant recipients face during their transition to adulthood can influence their priorities and behaviours, leading them to focus on managing their health and navigating the healthcare system rather than engaging in the traditional emerging adulthood experiences described by Arnett (1999, 2000, 2015). As such, it is crucial to recognize the diverse experiences of individuals transitioning to adulthood and develop tailored support strategies that address transplant recipients' specific needs and challenges during this critical period.

Thus, Bynner’s (2005) critique holds for this population in that Arnett’s theory has limited application given these recipients' dependence on the period between graduation from high school and continuing education and employment opportunities. In other words, the qualities and experiences as expected by Arnett et al. (2000) were impacted by the transplant and transition experience for these recipients. As such, researchers and practitioners must be cautious in applying the concept of emerging adulthood to diverse populations and consider alternative theoretical frameworks that better account for the complexities of contemporary youth transitions.

In considering the developmental stage and cognitive development for emerging adulthood, this period presents the first-time individuals can self-govern, which is an important experience and normative part of identity development (Arnett, 1999, 2000, 2015); thus, we must consider the impacts on the simultaneous transition to adult care. Developmental readiness, reflected by self-determination, self-efficacy, psychological maturity, motivation, and developmental skills and traits, contributes to youth’s preparation for the roles and behaviours required of adult life (Giarelli et al., 2008; Hamdani et al., 2015; Nguyen et al., 2016; Nicholas et al., 2018). Recognizing these developmental attributes, healthcare transition should be considered to align planning and support. The evidenced-based recommendations to tailor transition for AYAs centred around individual readiness rather than age alone should be embraced to accomplish this goal (Pape et al., 2022; Rieger et al., 2019; Samarasinghe et al., 2020; Yassaee et al., 2019).

A federally funded program of the National Alliance to Advance Adolescent Health entitled *Got Transition Six Core Elements of Health Care Transition 3.0*, describes an approach to improve the transition experience from pediatric to adult healthcare by detailing six core elements that should be a part of a structured transition process, including transition and care policy/guide, tracking and monitoring, transition readiness, transition planning, transfer of care, and transfer completion (White et al., 2020). These elements are pervasive throughout the transition literature and were also consistent with recipients' experiences and findings within this study. However, despite this shared knowledge, the common experience shared among patients, families, and healthcare practitioners alike is that there is a gap within practice.

Transition readiness can be measured using specific tools such as the Expanded Socioecological Model of AYA Readiness to Transition (SMART) model, which offers a comprehensive framework for understanding the complex factors influencing transition readiness among adolescents and young adults with chronic health conditions (South et al., 2022). The SMART model is based on Bronfenbrenner's socioecological framework, discussed previously in Chapter Two, which posits that multiple interacting environmental systems influence individual development. The SMART model was developed through a comprehensive literature review to identify the factors influencing transition readiness, which were then mapped onto the socioecological framework (South et al., 2022). The model highlights the role of multiple levels of influence, including individual, interpersonal, organizational, community, and policy factors, in shaping an individual's readiness to transition from pediatric to adult healthcare. Subsequently, modifiable risk factors, including knowledge, abilities, self-efficacy, interpersonal connections and communication, emotional and psychosocial aspects, developmental maturity, beliefs and expectations and goals and motivation, are assessed to offer valuable insights into the development of transition preparation and targeted strategies (Schwartz et al., 2013; Schwartz et al., 2011; South et al., 2022).

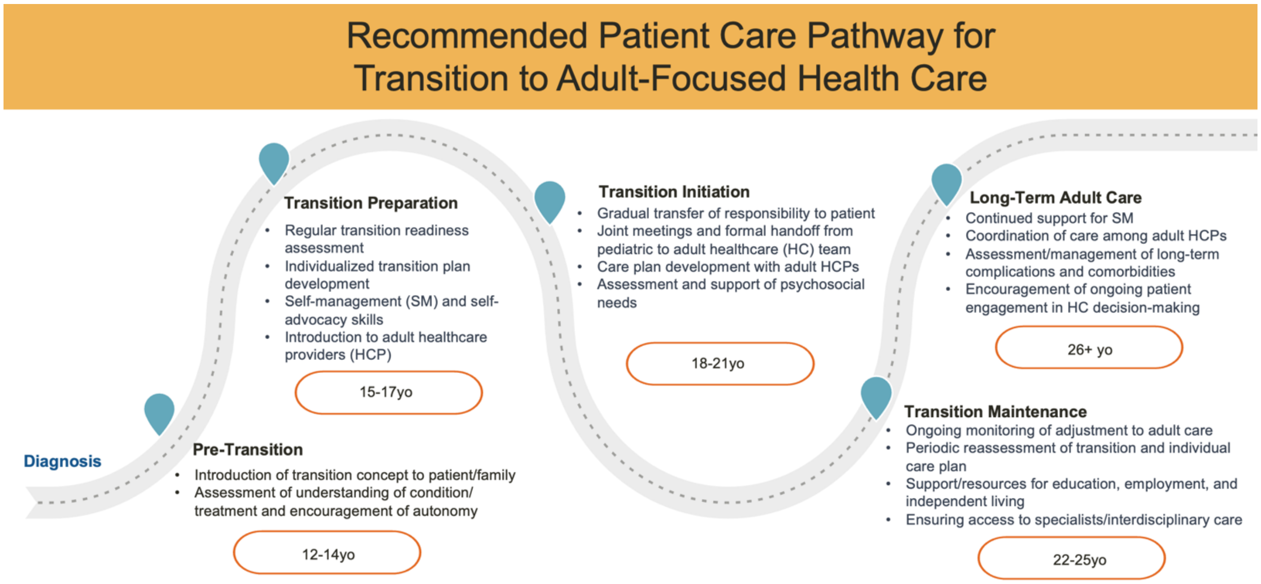
At the individual level, the SMART model emphasizes the importance of personal factors, such as self-management skills, self-efficacy, and adherence to medical regimens, which may be particularly crucial for transplant recipients (South et al., 2022). Interpersonal factors, such as supportive relationships with healthcare providers, family, and peers, can also play a critical role in fostering a successful transition experience for these individuals (South et al., 2022). Organizational factors, including the availability and quality of transitional care services, can significantly impact the experiences of transplant recipients as they navigate the healthcare system. As mentioned earlier, disparities in transitional care services across healthcare institutions and geographical regions can exacerbate the challenges faced by these individuals during their transition to adult care. At the community level, the SMART model highlights the importance of social support networks, access to resources, and culturally sensitive care in promoting a successful transition experience. Finally, policy factors, such as healthcare policies and funding for transitional care programs, can also influence the overall quality and availability of services for transplant recipients during their transition to adult healthcare.

However, although it has been identified that the use of transition readiness measures or tools can help understand when AYAs are ready to begin the transfer to adult care and can also be used to help evaluate the effectiveness of the transition preparation and process and discover obstacles (Parfeniuk et al., 2020; Stephens et al. 2021), their use is limited (South et al., 2022). Despite transition measurement tool availability, there is a lack of consensus on the most important factors impacting transition and knowledge of instrument focus (South et al., 2022). This lack of knowledge stems from the root cause of a non-standardized definition and operationalization of transition readiness or a theory that helps to guide tool research and development (South et al., 2022).

In the context of this study, the *Got Transition* approach and the SMART model offer valuable insights into the unique experiences and challenges AYAs face during their transition to adulthood (White et al., 2020). This can be visualized in Figure 4 through a recommended patient care pathway for transition to adult-focused care that emerged from my study findings, drawing upon these existing approaches, and highlighting the importance of early transition planning that begins at the time of diagnosis (Cadogan et al., 2018; Schwartz et al., 2011; South et al., 2022; White et al., 2020).

Figure 4

Recommended Patient Care Pathway for Transition to Adult-Focused Healthcare



Recommended Patient Care Pathway for Transition to Adult-Focused Health Care

Diagnosis

Pre-Transition
- Introduction of transition concept to patient/family
- Assessment of understanding of condition/ treatment and encouragement of autonomy

12-14yo

Transition Preparation
- Regular transition readiness assessment
- Individualized transition plan development
- Self-management (SM) and self-advocacy skills
- Introduction to adult healthcare providers (HCP)

15-17yo

Transition Initiation
- Gradual transfer of responsibility to patient
- Joint meetings and formal handoff from pediatric to adult healthcare (HC) team
- Care plan development with adult HCPs
- Assessment and support of psychosocial needs

18-21yo

Transition Maintenance
- Ongoing monitoring of adjustment to adult care
- Periodic reassessment of transition and individual care plan
- Support/resources for education, employment, and independent living
- Ensuring access to specialists/interdisciplinary care

22-25yo

Long-Term Adult Care
- Continued support for SM
- Coordination of care among adult HCPs
- Assessment/management of long-term complications and comorbidities
- Encouragement of ongoing patient engagement in HC decision-making

26+ yo

In my proposed patient care pathway, the key elements highlighted by the Got Transition approach and SMART model are simplified, with suggested guiding ages, with early initiation beginning at 12 years of age.

Assessing transition readiness is a critical aspect of tailoring care plans to address the unique needs and challenges faced by AYAs during the transition process (South et al., 2022; White et al., 2020). By identifying gaps in transition readiness, healthcare providers can develop targeted interventions to enhance self-management skills, foster independence, and ultimately improve long-term health outcomes. In contrast to relying solely on age as a criterion for transition, evaluating transition readiness measurements allows for a more individualized and holistic approach to supporting AYAs as they navigate the complex process of healthcare transition. However, in my study findings, all participants indicated that only age was used to determine transition readiness and emphasized the lack of proper assessment and structure in healthcare organizations to increase transition success. This finding conflicts with South et al. (2022), who advocate for assessing effective transition readiness measurements to provide personalized care for AYAs transitioning from pediatric to adult healthcare systems. Transition readiness measures assess an individual's knowledge, skills, and abilities in managing their health condition, navigating the healthcare system, and engaging in self-care behaviours. These measurements may include domains such as medication management, communication with healthcare providers, self-advocacy, appointment scheduling, insurance, and financial management, and understanding of the disease process (South et al., 2022).

Consistent with the findings from this study, Meleis et al. (2000) identify that transition engagement varies based on an individual's awareness of the change. In this study, engagement and awareness underpin the phase of anticipating the impending transition and losing security when transitioning to uncertainty. That is, all participants described feeling unaware of the transition until it was actually ‘happening’ to them. Similarly, transitions' change and difference properties underscore the nature and temporality of the transition change, with varied perceptions of change importance, norms, and expectations of the transition to adult-focused care. Consequently, the change was linked to the critical transfer event and the subsequent disruption in relationships and routines described as experiencing shock and grieving the loss of relationships and seeking supportive anchors within the phase of losing security when transitioning to uncertainty.

In the wave of seeking supportive anchors to navigate the turbulent waters in the swell of transition, recipients presented feelings of advocating, appreciating, and establishing. For emerging adults, the quest to attain self-responsibility, autonomous decision-making, and financial independence constitutes fundamental developmental tasks that are cornerstones of maturation (Arnett, 2000). However, for AYA transplant recipients, these tasks are imbued with additional layers of complexity, akin to turbulent waters, as they simultaneously grapple with the transition to adult-centric healthcare and confront the compounded challenges of achieving conventional milestones and developmental tasks characteristic of adulthood. Given this amplified intricacy, it is essential to accord particular attention to the potential emotional ramifications experienced by AYAs, including feelings of disappointment and dissatisfaction in their progress toward these goals. Failure to accomplish these developmental benchmarks may engender negative emotional and psychological consequences, such as depressive symptomatology, necessitating heightened levels of support to navigate these challenges (Arnett, 1999, 2000, 2015; Broderick & Blewitt, 2019).

Feelings of disappointment can materialize in several ways. For example, AYAs may experience disappointment in their inability to navigate the complexities of adult-centric healthcare systems effectively. This could manifest as difficulties in adhering to medical regimens, communication barriers with healthcare professionals, or a lack of autonomy in decision-making. Additionally, these AYAs might encounter disappointment in their personal lives, as the challenges of their medical condition may hinder their capacity to achieve traditional milestones associated with emerging adulthood, such as forming intimate relationships, pursuing higher education, or establishing a career. These disappointments could exacerbate feelings of isolation and lower self-esteem and increase the risk of mental health issues such as anxiety and depression (Allen et al., 2022; Huang et al., 2021; Nicholas et al., 2018).

Consequently, there is an opportunity to promote positive thinking in healthcare transitions. This is underscored by self-determination theory (SDT), which posits that an individual's beliefs and expectations about their ability to succeed with a task or goal strongly influence their motivation and behaviour (Stephens et al., 2021). Stephens et al. (2021) support using SDT to promote transition readiness among AYAs with chronic conditions transitioning from pediatric to adult healthcare settings, highlighting the importance of AYAs developing self-management skills and receiving autonomy support from their healthcare providers during this critical period. Stephens et al. (2021) conclude that future interventions to improve transition readiness among AYAs should consider using the SDT framework to promote self-management skills and provider support for autonomy, recognizing that a positive attitude and a sense of control over one's life can improve health outcomes and well-being. Thus, to mitigate these feelings of disappointment and their potential negative repercussions, healthcare providers must adopt a comprehensive, patient-centred approach that not only addresses the clinical aspects of care but also considers the psychological, emotional, and social dimensions of the individual's well-being to help promote a sense of control over their lives (Allen et al., 2022; Nicholas et al., 2018).

5.2.2 The Nature of Situational Transition and Transition Readiness

The degree of awareness that individuals exhibit during the transition process, as described by Meleis et al. (2000), is consistent with this study's findings in that recipients expressed feelings of anticipation as they prepared for and adjusted to the change, with a desire for peer support to help understand what was expected. Participants identified peer mentorship as a potential way to support the transition to the new care setting, which could help bridge the gap, provide a touch point, answer questions, and be a familiar person in the new setting. This finding is supported by the research of Dumais-Lévesque and Pomey (2020), exploring the needs of pediatric patients transitioning from a gastroenterology program and the benefit of introducing an accompanying patient program to support this transition. In this study, Dumais-Lévesque and Pomey (2020) found that once the young adults transitioned to adult care, they developed an awareness of the disease’s impact on their lives and the value of having support from a peer. In contrast, parents expressed considerable anxiety before the transition and a desire to connect with other parents earlier. This unmet need was further observed through this study, in which recipients connected through social media platforms, seeking support, guidance, and mentorship in preparation for the transition experience.

Subsequently, the degree of readiness for transition profoundly influenced the transplant recipients' perception of stability. Within the oscillating wave of anticipation for the forthcoming transition, a pervasive lack of clarity regarding their trajectory or orientation manifested, as there was no clear sense of path or direction, resulting in the cascade of emotions saturating their experience. In certain cases, AYAs found solace through the support provided by family members, peers, or healthcare professionals, which served as a stabilizing force during this turbulent period. However, for those AYAs with precarious family or peer support networks or inadequately established connections with care providers, the overwhelming nature of these emotions sometimes proved insurmountable. This underscores the significance of a comprehensive and robust support system for AYAs undergoing healthcare transitions. Insufficient support can potentially exacerbate feelings of uncertainty, anxiety, and disappointment, which may, in turn, contribute to adverse health outcomes, reduced adherence to treatment regimens, and diminished overall well-being (Huang et al., 2021).

In this way, recipients stressed how imperative support to continue with ongoing monitoring was for them, which could have been enhanced through peer mentorship or formalized transition planning by establishing a process for identifying transition-aged youth and tracking transition progression (White et al., 2020). Consequently, in most instances, participants described themselves as generally unprepared for the transition, much like being caught up in an unexpected wave, which led to losing their sense of security when transitioning to uncertainty. Recipients described feeling shocked and heartbroken over missing their pediatric care centre and team, grieving the loss of those relationships as if mourning the shoreline of a familiar coast.

Similarly, healthcare providers acknowledged a deficiency in prioritizing transition management policies at the systemic level within pediatric-oriented hospitals. Multiple factors contributed to this deprioritization, with funding constraints and excessive workloads as primary concerns (Raphael et al., 2013). Both recipients and individual healthcare providers preferred the continuous engagement of pediatric providers throughout the transition process, like a steady stream guiding them through the journey. Positive outcomes were reported in cases where this support was provided, and pediatric providers actively participated in the patient's transition preparation. As a result, recipients experienced sustained support and connection, fostering a successful transition that smoothly merged into the vast sea of adult-centric healthcare.

Nonetheless, a potential pitfall in this approach arises from an apparent bias among pediatric providers towards well-adjusted AYAs. This predisposition could inadvertently lead to the allocation of additional support to these individuals in response to their eagerness to engage in their care, while overlooking the needs of patients who may be struggling with adherence to their healthcare regimen. Such disparities in resource distribution may inadvertently exacerbate health disparities and reduce the likelihood of successful transitions for patients facing greater challenges. Addressing this issue necessitates a comprehensive reassessment of systemic priorities and the implementation of equitable transition policies that cater to the diverse needs of all AYAs, regardless of their perceived level of adjustment. This can be achieved through a combination of policy changes, increased funding, targeted education, and the development of standardized guidelines with the flexibility to be individualized based on these diverse needs to ensure a consistent approach to transition management across healthcare institutions (White et al., 2020).

Lastly, bridging the gap between pediatric and adult care requires a multifaceted approach that addresses the logistical aspects of healthcare provision and the psychological and emotional factors contributing to the perception of pediatric care as more enjoyable than adult-focused care. To level the connection, healthcare system teams must employ evidence-based interventions that foster a smoother, more engaging patient transition experience (Catena et al., 2018; White et al., 2020). One crucial aspect of this process involves promoting continuity of care and preserving the therapeutic relationships established within the pediatric setting. This can be facilitated by adopting a transitional care model that involves collaboration between pediatric and adult providers, regular communication, and joint care planning (Catena et al., 2018; White et al., 2020). Additionally, including transition coordinators who serve as a bridge between pediatric and adult care teams can help maintain rapport with patients and provide guidance through the transition process (Annunziato et al., 2013; White et al., 2020).

Moreover, to address the perceived disparity in care, adult healthcare facilities should strive to create a more patient-centred, developmentally appropriate, and welcoming environment for emerging adults (Catena et al., 2018; McCurdy et al., 2006). This could be achieved by integrating age-appropriate resources, recreational activities, and supportive services tailored to young adults' unique needs and interests (Betz et al., 2021; Betz et al., 2013; White et al., 2020). Furthermore, incorporating patient and family input in the design and implementation of transition programs can help ensure that these initiatives effectively address the concerns and preferences of those directly affected by the transition process. By involving patients and families in decision-making, healthcare systems can develop more responsive, engaging, and enjoyable transition experiences that align with the expectations of both pediatric and adult care recipients.

5.3 Transition Conditions

Within this study, the context of solid organ transplant, sexuality, gender identity, sexual orientation and transfer of care were prevailing conditions for consideration as factors shaping the Canadian transition experience for participants.

5.3.1 Solid Organ Transplant and the Transition Experience

For individuals with solid organ transplants, the presence of a transition-triggering event may be the onset of end-stage organ disease or organ failure. Still, for many pediatric patients, this diagnosis and subsequent treatment is in infancy or early childhood, meaning that they have never known a life without medical intervention. Thus, in the context of this study, the triggering event was most often related to entering adolescence and facing the transfer to adult-focused care. This event necessitated transitioning from managing symptoms and living with a chronic illness to a new reality of managing the post-transplant experience independently into adolescence and young adulthood. Negotiating this transition was often challenging, as it involved navigating a complex healthcare system, adhering to a strict medication regimen, and adjusting to the physical and emotional changes that came with transplantation. The process represents a formidable challenge in the context of healthcare transitions, comparable to navigating treacherous water. This critical period of adaptation requires an individual to navigate through turbulent currents of change involving not only the integration of newfound health status but also the negotiation of a multifaceted healthcare system, strict medication adherence, and the physical and emotional changes concomitant with transplantation (Hislop et al., 2016; Huang et al., 2021; Lewis & Slobodov, 2015; Marani et al., 2020; Samarasinghe et al., 2020).

Adolescents and young adults undergoing transplantation must also confront and adapt to the physical and emotional changes accompanying this medical intervention and lingering concerns about graft failure or death. Like patients with other chronic conditions, such as diabetes, cancer, or inflammatory bowel disease, transplant recipients face a unique set of challenges that may have a profound impact on their overall well-being, self-concept, and quality of life (Van Staa et al., 2008; McErlane et al., 2013). Physical changes following transplantation, including weight gain, skin changes, and other side effects of immunosuppressive medications, can significantly affect patients' self-image, body satisfaction, and social functioning (Clarizia et al., 2009; Fredericks et al., 2007). For instance, corticosteroids, which are commonly prescribed to prevent organ rejection but also used for the treatment of many other illnesses, can lead to an altered appearance, such as Cushingoid features, acne, or hair growth, potentially exacerbating the already challenging process of identity formation during adolescence (Stuart et al., 2005).

Comparable to other chronic illnesses, the post-transplant journey shares certain characteristics with conditions such as diabetes, cystic fibrosis, or congenital heart diseases, wherein patients must adapt to new care routines, treatment plans, and self-management expectations (Catena et al., 2018; Hislop et al., 2016; Huang et al., 2021; Lewis & Slobodov, 2015; Mackie et al., 2016; Marani et al., 2020; Samarasinghe et al., 2020). The complex interplay of biological, psychological, and social factors during this transition period may amplify the challenges faced by AYAs, potentially exacerbating the vulnerability of this population (Huang et al., 2020). For example, the need for self-advocacy and acquiring health literacy skills becomes paramount during this transition, as AYAs must effectively communicate with healthcare professionals, comprehend complex medical information, and make informed decisions about their care (Mackie et al., 2016; Sattoe et al., 2017). The emotional impact of transplantation, encompassing mood swings, anxiety, and depression, may parallel the psychological experiences of individuals with chronic illnesses, who often grapple with feelings of uncertainty, loss of control, and social isolation (Huang et al., 2022; Larouche & Chin-Peuckert, 2006).

The experience of transitioning to life after a solid organ transplant also shares many similarities with other healthcare transitions. Similar parallels can be drawn with transitions such as the shift from pediatric to adult care or the transition from hospital to home. In each case, individuals find themselves navigating unchartered waters, adjusting to new environments, and facing unique challenges along their journey towards wellness and autonomy. However, the experience of transitioning after a solid organ transplant is also unique in several ways. For example, patients may experience physical and emotional changes related to their transplant experience that are not present in other healthcare transitions. In addition, patients need to manage a complex medication regimen for the rest of their lives, which can be challenging and may impact their ability to participate in daily activities.

Through this study, recipients and families shared that their transition experiences impacted the transition's success. For example, social support, including support from family and healthcare providers, was key in helping recipients manage their transition and adjust to life after transplantation. Involving patients and families in the transition planning process and the need for ongoing communication and collaboration between pediatric and adult care providers was key for all participants. Research on other healthcare transitions has also identified the importance of social support and communication in facilitating successful transitions (Larouche & Chin-Peuckert, 2006; McAllister et al., 2006; Rumsey et al., 2004).

Overall, research on the transition experiences of pediatric solid organ transplant patients supports and extends other research findings on healthcare transitions. The importance of social support and communication are consistently identified as key factors in facilitating successful transitions, regardless of the specific type of transition or patient population. However, the unique challenges of transitioning after a solid organ transplant, such as managing a complex medication regimen and adjusting to physical and emotional changes related to the transplant experience, require tailored interventions and support to help patients and families manage this transition successfully.

In the transition following a solid organ transplant, acquiring new skills and knowledge is critical for a successful transition. This was seen with recipients in this study, who needed to learn how to manage their medications, recognize the signs of rejection, and navigate the healthcare system effectively. Additionally, they needed to learn how to manage the physical and emotional changes accompanying transplantation, such as weight gain, skin changes, and mood swings. Just as sailors acquire the knowledge and skills necessary to navigate unpredictable seas, these recipients had to acquire the necessary tools and knowledge to steer their own health and well-being amidst the complexities of life after a solid organ transplant.

This new knowledge and skill set was necessary for successfully adapting to the new post-transplant reality. Finally, integrating the new identity or status into one's sense of self was crucial to a successful transition. For individuals with solid organ transplants, this involved accepting the fact that they were now living with a new organ and the associated physical and emotional changes that come with transplantation. This process involved significant emotional and psychological adjustment as patients reconciled their pre-transplant identity with their new post-transplant reality.

5.3.2 Sexual Orientation and Gender Identity and the Transition Experience

Sexual orientation and gender identity are contextual factors that can shape the transition experience by influencing factors such as access to resources, societal expectations and norms, and individuals' beliefs and attitudes. The experience of romantic relationships and sexuality is a complex and evolving process shaped by a multitude of factors, including individual, social, and cultural influences. The experience of transition to adulthood, romantic relationships, sexuality, and gender identity is not uniform across all individuals, as diverse populations may face unique challenges and opportunities in this domain. For example, LGBTQ+ youth may encounter additional stressors related to stigma, discrimination, and identity formation, which can impact their experiences of romantic relationships and sexual exploration (Mereish et al., 2017). Additionally, AYAs with chronic health conditions may need to navigate the complexities of their health status within the context of romantic and sexual relationships while negotiating the formation and maintenance of intimate relationships. Several factors can uniquely shape the experience of romantic relationships and sexuality for AYAs with solid organ transplants.

Concerns about disclosing transplant status to potential partners may generate vulnerability and anxiety (Annunziato et al., 2013). Fear of rejection, stigmatization, or misunderstanding can hinder forming intimate connections and may lead to social isolation (Saprio & Ward., 2020). Additionally, the management of medical conditions and adherence to complex treatment regimens can impact AYAs' experiences of romantic relationships and sexuality. Medication side effects, such as weight gain, changes in appearance, or decreased libido, can affect self-esteem, body image, and sexual functioning, further complicating relationship dynamics (Pulewka et al., 2021). For example, the need for ongoing medical care and frequent contact with healthcare providers can create practical challenges for AYAs in maintaining romantic relationships, such as finding the time and energy for dating while managing the logistics of medical appointments. Furthermore, the transition to adult-focused healthcare may exacerbate these challenges as AYAs encounter new healthcare providers and systems that may not be as familiar with their unique needs and experiences (Catena et al., 2018). However, within this study, the main relationships highlighted by recipients were those with the healthcare team and peers. Beyond this, the participants did not focus on romantic relationships or sexuality within the interviews but on the transition experience and biomedical and psychological impacts of the transition.

Conversely, there were references to sex and gender by recipients, which were identified as impacting the transition experience for recipients. The intersectionality of sex and gender with the transition experience is a crucial area of consideration for healthcare providers and researchers in the field of chronic illness care. The influence of these factors on transition experiences cannot be overstated, as they impacted recipients' access to resources, societal expectations, and individuals' beliefs and attitudes.

Female AYAs shared encountering societal expectations that made them feel as though self-advocacy was perceived as being a difficult patient. Similarly, the societal expectations of masculinity may discourage male AYAs from seeking support or expressing vulnerability, negatively affecting their transition experiences. Additionally, gender identity and sexual orientation can influence access to resources available for transition. Recognizing that social and cultural expectations of gender roles and behaviours shape the transition experience of AYAs should be acknowledged.

Considering the broader social context in which transition occurs is crucial in effectively identifying and addressing these barriers. Addressing sex and gender-related issues requires a multidisciplinary and multi-level approach that involves the development of inclusive policies and practices, educating and training for healthcare providers, and involving patients and their families in the care process (Coyne et al., 2023; Lindsay et al., 2019). Overall, recognizing the influence of sex and gender on the transition experience is vital for ensuring that all patients receive comprehensive and equitable care that supports their unique needs and challenges (Alderman et al., 2019). This requires a shift towards a more patient-centred approach that considers the broader social context in that transition occurs. Healthcare providers and researchers must work to navigate these waters collaboratively to develop strategies that address these issues effectively, ultimately leading to improved outcomes for adolescents and young adults with chronic illnesses.

5.3.3 Transfer of Care and the Transition Experience

The transfer of care from pediatric to adult care providers represents important contexts framing the setting, relationships, and resources available through transition, thereby impacting participants' transition experiences. As AYAs continued through their transition journey, the transfer of care to the adult-focused setting initiated the wave of seeking supportive anchors in the swell as recipients began to establish relationships with new care providers and develop self-management, then cascading into gaining a new sense of self with feelings of stabilizing through normalizing and accepting a new reality. As shared by recipients, strategies that provided grounding and helped to achieve these goals included the involvement of family, peers, and healthcare providers. Through combined visits and team meetings with the recipient, family, pediatric, and adult providers, participants shared experiences of a smoother pathway to transfer between child and adult service providers, with meaningful support received through a dedicated nurse or transition coordinator (White et al., 2020).

In the *Got Transition* approach, introduced earlier*,* White et al. (2020) suggest supporting transitioning AYAs by offering education and resources on needed skill development as identified through a transition readiness assessment. Other suggestions presented by study participants and underpinned by the grounded theory is the suggestion of building ongoing and collaborative partnerships between pediatric and adult care providers. There should also be consideration of timing, as initiating a transfer event during medical instability contributed to feelings of worry, fear, shock, and anger. Thus, transferring the individual at a time when medically stable allows for better planning in collaboration with the parent or caregiver, whereby preparation for adult care, decision-making, self-advocacy, and self-management are better supported. Also highlighted is the importance of considering cultural differences and preferences when planning care, communicating, and interacting with the patient and family. Thus, it is clear from the literature, participant experience, and recommendations by leading transition organizations that transition planning and preparation are quintessential in transition success.

Colver et al. (2020) present the findings and implications of a 5-year research program focused on facilitating the transition of young people with long-term health conditions from pediatric to adult-focused healthcare services. The researchers conducted a series of mixed methods studies to explore the factors influencing the transition process and the effectiveness of interventions to support it. Their research identified several key factors that contribute to a successful transition, including the importance of the young person's readiness for transition, the role of healthcare providers in supporting the process, and the need for individualized transition plans. The researchers also found that a structured, developmentally appropriate approach to transition, including education and training for patients, families, and healthcare providers, can improve outcomes for young people with long-term health conditions. Thus, the transition is best supported by an organizational approach to ensure that effective transition practices are adopted in both pediatric and adult health settings (Colver et al., 2020). To achieve this, Colver et al. (2020) recommend a developmentally appropriate approach that recognizes the biopsychosocial developmental needs of young people, highlighting the importance of parental involvement, promoting the confidence of young in self-management of their health, and establishing relationships with the adult health care team before transfer. Additionally, Colver et al. (2020) suggest that pediatric and adult healthcare providers should routinely explore with patients as they approach their transition to tailor their clinical approach to their needs.

As per the recommendations of White et al. (2020) and depicted in the recommended patient care pathway for transition to adult-focused healthcare (Figure 4), this process should begin between 12-14 years and be integrated as part of ongoing care; however, as shared by participants, this is not translated into standard practice. The way in that youth prepare for the transition to adult care should be guided by an established transition policy that is developed with input from youth and their caregivers with consideration to privacy, consent, and age of transfer to adult-focused care (White et al., 2020). This policy should also reflect the developmental and cognitive stage when establishing the age of transfer. This policy should also integrate staff education with attention to the approach to transition and distinct roles of the youth, caregivers, and pediatric and adult healthcare teams in the process and reflect cultural preferences. In this way, participants stressed how imperative support to continue with ongoing monitoring was for them. It could have been enhanced through peer mentorship or formalized transition planning by establishing a process for identifying transition-aged youth and tracking transition progression (White et al., 2020).

Respondents within this study associated successful transfer of care with autonomy. While parents and families still want to remain a carer during the transition, fostering the transitioning AYA's autonomy and independence is vital to a successful transition (Rodrigues et al., 2018). According to the study findings, education, earlier exposure to decision-making, and preparation of medications helped in advocating for oneself in adult care (Rodrigues et al., 2018). After the transition, recipients with positive health outcomes reported high adherence to medication, clinical visits, and advocacy. In contrast, surviving patients with poor autonomy and negative health outcomes required more support to sustain health after transitioning to adult care (Rodrigues et al., 2018).

Yet, despite these recommendations and the positive experiences of those with the opportunity for a planned and coordinated transition, this was not the experience for most. Rather, time and ongoing experiences helped to normalize the experience and provided the opportunity to learn new ways of communicating with adult providers, ultimately leading to seeking supportive anchors by forging new relationships, developing a self-management, and gaining a new sense of self by stabilizing through normalizing and accepting a new reality. Frequently, *transforming through transition* emerged like a cresting wave when participants recognized their transition success as evidenced by their ability to attend appointments, develop relationships, exchange information with care providers, fill prescriptions, and self-administer medications independently. However, most AYA participants did not experience a coordinated and planned transition. For these individuals, time and ongoing experiences helped to normalize the process of transitioning to adult care, acting as guiding currents leading them towards smoother waters of self-care and well-being. Through these experiences, they learned new ways of communicating with adult providers and eventually established supportive relationships with their healthcare team. Furthermore, they developed adaptive self-management strategies and gained a renewed sense of self-identity, which allowed them to navigate the complex landscape of adult healthcare services with increased confidence and independence. These experiences facilitated their successful transition to adult care, despite the absence of a structured and coordinated transition program.

In the Canadian context, additional factors may complicate the healthcare transition process for AYAs, particularly for those living in rural, remote, or Indigenous communities. Access to specialized healthcare services and providers can be limited in these areas, further exacerbating the challenges faced by AYAs during their transition to adult care (Toulany et al., 2022). Moreover, the unique cultural and social factors that shape the experiences of Indigenous youth must be considered, particularly when implementing transition support programs tailored to their specific needs. Jordan's Principle, a child-first policy in Canada, aims to ensure that First Nations children receive the care and services they need without delay or denial; however, there remains a need for more robust and culturally safe healthcare transition planning and support for Indigenous AYAs (Assembly of First Nations, n.d.; Chambers et al., 2017).

The recommended structured healthcare transition is not actively implemented, thereby underserving AYAs (Schmidt et al., 2020). My findings enrich our knowledge by providing a voice to transplant recipients, engaging them directly to communicate about their transition process during adolescence and young adulthood. Understanding how AYAs manage the transition and the impact of the process is crucial. My findings suggest that current best practices and recommendations are not effectively translating into practice in the Canadian context, resulting in significant consequences for mental health, adaptation, and self-management. We must continue exploring ways to improve the healthcare transition experience for AYAs, to ensure equitable access to quality care and support during this critical life stage.

5.3.4 Transition Conditions in the Canadian Context

With its expansive geography and diverse population, Canada presents unique challenges for adolescents and young adults (AYAs) with chronic health conditions, such as those requiring solid organ transplants. These challenges become particularly pertinent when examining the transition experiences of these individuals within the context of Meleis et al.'s (2000) transition framework. This theoretical model underscores the significance of understanding the specific contexts in which transitions occur, as these can substantially influence the individual's experiences and outcomes during the process. Consequently, it is essential to consider the distinct characteristics of the Canadian healthcare landscape when exploring the complex journey of AYAs with chronic health conditions as they navigate the transition from pediatric to adult-focused care.

In Canada, access to healthcare resources, including transplant services, can vary significantly depending on the location and the size of the healthcare centers. Major urban centers, such as Toronto, Vancouver, and Montreal, have specialized transplant centers providing comprehensive care for AYAs with solid organ transplants. Pediatric transplant programs are often part of larger healthcare institutions, which may also provide adult transplant services (Table 4).

Table 4

Pediatric Transplant Centres in Canada

Pediatric Transplant Center	City
Alberta Children's Hospital	Calgary, AB
BC Children's Hospital	Vancouver, BC
Children’s Hospital of Winnipeg	Winnipeg, MB
IWK Health Centre	Halifax, NS
Montreal Children’s Hospital	Montreal, QC
Stollery Children's Hospital	Edmonton, AB
The Hospital for Sick Children (SickKids)	Toronto, ON

These centers are located in larger cities within Canada and have dedicated transplant services. Conversely, smaller cities and rural or remote communities may not have access to the same level of specialized care and resources to care for AYAs once they return to their home communities after transplantation. Consequently, AYAs outside these major urban centres might need to travel long distances to access specialized transplant centers or rely on local healthcare providers who may not have the same expertise in transplant care (Toulany et al., 2022). This geographical disparity can significantly impact the pre- and post-transplantation care and transition experience of AYAs, as the availability of resources and support can influence their ability to navigate the healthcare system and maintain optimal health outcomes.

Transitioning from pediatric to adult care can be a challenging experience for AYAs, as it involves navigating a complex healthcare system, developing new relationships with care providers, and adjusting to new care models. Various factors, including geographic and cultural diversity, healthcare system fragmentation, and limited resources for transition planning and support, can complicate the process of healthcare transitions in Canada. Thus, it is essential to consider these diverse contexts when evaluating an individual's transition experience within the Canadian healthcare system, as they can profoundly impact their ability to navigate their healthcare journey and access necessary resources.

It was clear from this study that there is a need for more consistent and coordinated approaches to transition planning and support across pediatric and adult care centres across Canada. Consequently, the size of Canada may impact the implementation of transition support, as there are varied geographical and cultural landscapes. Different regions might have unique challenges and resources related to healthcare delivery, cultural norms, and support systems, which could impact an individual's transition experience. In this sense paying attention to individual and interpersonal factors, such as cultural, social, and environmental factors, is important when considering the geographical spread of Canada.

Participants from this study were mainly from Ontario and British Columbia, but different regions might have unique challenges and resources related to healthcare delivery, cultural norms, and support systems, which could impact an individual's transition experience that this study may not have captured. For example, AYAs living in remote or rural areas may have limited access to specialized healthcare providers and resources. In contrast, those in urban areas may face long wait times and overburdened healthcare systems. Furthermore, healthcare transitions may be further complicated by cultural and linguistic barriers and differences in healthcare systems between provinces and territories and pediatric and adult centres. Similarly, the size of Canada could play a role in shaping the transition conditions and, in turn, the response patterns. Consequently, Canada’s unique size and varied healthcare systems by province may impact access to resources, cultural norms, and values, impacting an individual's ability to adapt to change during a transition.

5.4 Patterns of Response

For participants of this study, self-care, autonomy, and trauma were the dominant patterns of response identified.

5.4.1 Developing Self-Care and Autonomy

Self-care emerged as a significant response pattern for participants, reflecting the importance of prioritizing one’s health and well-being during the transition process in seeking supportive anchors in the swell transition. This finding is consistent with the growing body of research emphasizing the importance of self-care in promoting positive health outcomes (Li et al., 2021; Wright et al., 2017). The concept of self-care and advocacy aligns with the Patterns of Response dimension of Meleis et al.'s (2000) transition framework. This dimension focuses on how individuals respond and adapt to changes in their lives and surroundings.

Self-care and advocacy skills are important in helping individuals assume control of their health and well-being, particularly during significant life transitions such as transitioning from pediatric to adult care. These skills can help individuals navigate the challenges of transitioning to a new healthcare system and promote their overall well-being throughout the transition process. Autonomy was also identified as a key pattern of response, with participants describing the importance of taking an active role in their healthcare decision-making.

Autonomy is the idea that individuals have the right to make decisions about their lives and to have those decisions respected. In healthcare, autonomy means that patients have the right to participate in their healthcare decision-making and consider their values and preferences. This finding aligns with the broader literature on patient empowerment, emphasizing the importance of involving patients in healthcare decision-making to promote positive health outcomes and enhance patient satisfaction (Menschner & Maul, 2016) and transition readiness (Mora et al., 2019). The emphasis on autonomy underscores the importance of respecting individuals as rational and moral agents. By giving patients a voice in their healthcare decision-making, healthcare providers acknowledge their autonomy and treat them with dignity and respect. In the context of healthcare, this means treating patients with dignity and respect, recognizing their autonomy, and involving them in their healthcare decision-making.

5.4.2 Trauma and Impacts on the Transition

Trauma emerged as a significant pattern of response for some participants. This finding is not surprising, given the significant stress and uncertainty associated with the transition process. Trauma-informed care is an emerging approach in healthcare that emphasizes the importance of recognizing and responding to the impact of trauma on patients' health and well-being (Bargeman et al., 2021). Identifying trauma as a pattern of response highlights the need for healthcare providers to be aware of the potential for trauma in the transition process and to provide appropriate support and resources.

Trauma was a significant pattern noted throughout this study as a way in which recipients responded to changes and the strategies they used to adapt to the transition. Trauma can impact an individual's response to change and shape their response patterns. For example, individuals who have experienced trauma may have difficulty adapting to change or may use specific coping mechanisms to manage the stress associated with the transition. By understanding the impact of trauma associated with the healthcare transition for AYAs on the patterns of response, Melies et al.'s (2000) framework can be used to develop interventions that support individuals who have experienced trauma as they navigate changes in their lives.

Trauma is a deeply unsettling experience that shatters one's sense of safety, security, and stability (Bargeman et al., 2021). When an individual experiences trauma, it is as if a powerful wave has crashed down on them, altering their perception of the world and themselves. This may lead to persistent and pervasive feelings of fear, anxiety, and disconnection. When examining trauma, the literature tells us that trauma is less about what happened and more about the impact on a person. Thus, with no universal definition of trauma available, the most referenced definition is from the Substance Abuse and Mental Health Services Administration (SAMHSA) (2012): “trauma results from an event, series of events, or set of circumstances that is experienced by an individual as physically or emotionally harmful or life threatening and that has lasting adverse effects on the individual’s functioning and mental, physical, social, emotional, or spiritual well-being” (p.2). Accordingly, trauma-informed care must recognize the complex nature of trauma.

In the context of transitions and changes, trauma can significantly impact how individuals respond and adapt to these events. Consequently, the experience of trauma can create a sense of rigidity and inflexibility in an individual's response patterns (Bargeman et al., 2021). For example, they may become stuck in familiar behaviour or thought patterns, even when those patterns are no longer effective or adaptive. This can make it difficult for individuals to adapt to new situations or changes, as they may be unable to break out of their established response patterns. Moreover, trauma can also lead to the development of specific coping mechanisms that individuals use to manage stress and anxiety associated with transitions. These coping mechanisms may be helpful in the short term. Still, they can also become maladaptive if they are relied upon too heavily or prevent individuals from engaging with the changes more constructively and meaningfully.

From a philosophical perspective, the impact of trauma on an individual's response to change raises important questions about the nature of human experience and the relationship between individuals and their environment. Specifically, what does it mean to be resilient in the face of change, and how can individuals cultivate resilience in the aftermath of trauma? How do we navigate the tension between stability and flexibility, and what role do our past experiences play in shaping our response to new challenges? These questions are complex and multifaceted, but they offer valuable insights into the human condition and how we can learn, grow, and adapt in the face of adversity.

During data collection, I heard accounts of medical trauma, and the transition to adult care was triggering for that reason, or even sometimes traumatizing in and of itself. However, these cases often focused on acute physical medical care, with little or no regard for the psychosocial or psychological impacts. Themes arose in interviews with young adults in which parts of their transplant journey were traumatizing. The transition to adult care was triggering for that reason, or even sometimes traumatizing in and of itself. Additionally, recipients' experience within the health care system as a sick child could be a source of trauma, thereby impacting their subsequent transition to adult care.

According to my findings, the abrupt transition to adult care coupled with the treatment by detached healthcare providers impacted and increased the patients’ trauma experiences. Patients described being treated as customers in a fast-food restaurant where no attention was paid to them during their visits. This discouraged recipients and reduced their adherence to clinic visits and medication uptake. Subsequently, recipients lost the sense of ongoing care, which was worsened by changing faces on every visit and the paternalist nature of visits where the patient was expected to remain passive. Consequently, these experiences may manifest as altered mental health, indicating that additional focused mental health support would be important for transitioning AYAs. For example, Hendrickx et al. (2020) argue that there is a need for focused mental health care due to increased psychopathologies within the developing brains of transitioning young adults. They also posit that mental healthcare should go beyond the patient and be provided to their families as well. However, my study findings identified that there was no structured way in which adolescents were connected to mental health practitioners during the transition process, leaving a gap and increasing the risk of transition failure and the traumatic effects of an unsupported transition.

By examining the experiences of transition recipients’ trauma, we can appreciate that there may be subsequent impacts on their development and future experiences. Thus, framing their experience with the transition with a trauma-informed care lens would help practitioners to focus on how to support best, as often the focus is placed on their acute physical medical care. In a white paper by Menschner and Maul (2016) for the Center for Health Care Strategies, the importance of trauma-informed care involving both organizational and clinical practices is highlighted. Specifically, organizational policies and culture need widespread changes to become truly trauma-informed (Menschner & Maul, 2016), which includes patient empowerment, choice, collaboration, safety, and trustworthiness, which are also aspects identified within by study and underpinning the grounded theory, *Riding the Wave of Change: Transformation Through Transition*.

Thus, by recognizing AYA transplant recipients' medical-related traumas and the subsequent potential for trauma caused by the transition to adult-focused care, healthcare organizations and organizational practices can be modified to embrace trauma-informed principles to transform the culture of the healthcare setting and provide trauma-informed care to these transitioning adolescents. This is imperative for patients with previous trauma experiences, as feeling physically, socially, or emotionally unsafe may cause extreme anxiety and may cause re-traumatization (Menschner & Maul, 2016). Therefore, creating a safe environment is fundamental to successfully engaging patients in their care. Safe environments were also highlighted by participants throughout the study in the sharing of their experiences. They can be achieved through simple acts such as welcoming patients and ensuring that they feel respected and supported, maintaining consistent, open, respectful, and compassionate communication, and remaining aware to culture and how that may impact how trauma, safety, and privacy are perceived (Menschner & Maul, 2016).

The impacts of trauma extend beyond the patient and family and may also have secondary traumatic stress impacts on healthcare workers caring for these patients. Secondary traumatic stress is defined as the presence of post-traumatic symptoms arising from exposure to another’s trauma and has been found to impact many pediatric nurses related to high-stress levels compounded by caring for both the pediatric patient and their family members, often resulting in intense emotions from being with and witnessing critically ill children and their parents (Figley, 1995; Kellogg et al., 2018; Sprang et al., 2019). That is, secondary traumatic stress is “the natural consequent behaviours and emotions resulting from knowing about a traumatizing event experienced by a significant other – the stress resulting from helping or wanting to help a traumatized or suffering person” (Figley et al., 1995, p. 7). Consequently, pediatric nurses may experience a multitude of effects, such as disturbing thoughts, poor concentration, emotional detachment and exhaustion, avoidance, absenteeism, chronic fatigue, and physical illness which has significant impacts on their well-being and also hospital staffing and retention (Figley, 1995; Kellogg Et al., 2018). Kellogg et al. (2018) suggest that preventing secondary traumatic stress can improve staff morale, thereby allowing for optimal staff functioning and reducing the expense of high staff turnover rates. Thus, acknowledging secondary traumatic stress in pediatric nurses is an important step in supporting nurses' psychological health to allow for more present engagement with patients and families through their healthcare journeys and transition to adult care (Kellogg et al., 2018).

5.5 Study Implications and Recommendations

My research contributes to the body of literature on healthcare transition evidence and depth to what is known about AYA transplant recipients' experiences and management of the transition process. In the existent body of literature, the voice of healthcare practitioners dominates rather than augments. This study offers significant contributions to understanding the experience of healthcare transition for solid organ transplant recipients. The substantive theory *Riding the Wave of Change: Transforming Through Transition* represents how AYA transplant recipients move through their healthcare transition. Within this, the main theoretical category, Riding the Wave of Change, reflects the instability felt of the constant ebbs and flows, waves and swells, as they manage this process. The main concern for recipients was learning how to navigate the unsteady waters alone. Based on the study results, implications for nursing practice, healthcare organizations, research, and policy development, are presented.

The inadequate funding for healthcare transition planning and services in Canada for AYAs with chronic illnesses constitutes a multifaceted issue, necessitating an examination of the complex interplay among various systemic, economic, and socio-cultural factors. A comprehensive understanding of these factors is critical for developing and implementing effective policies and strategies to enhance the provision and quality of transitional care for this vulnerable population. One contributing factor is the decentralized structure of the Canadian healthcare system, in which provincial and territorial governments are responsible for the organization, delivery, and management of healthcare services. This decentralization can lead to inconsistencies in the provision and funding of healthcare transition planning and services across the country. Consequently, the absence of a unified national framework for transitional care results in fragmented and uncoordinated services that ultimately disadvantage AYAs with chronic illnesses who require specialized care and resources throughout their transition process (Toulany et al., 2022).

Financial constraints and competing priorities within the healthcare system can also lead to inadequate funding allocation for transition planning and services. As the prevalence of chronic illnesses in the general population rises and healthcare costs escalate, healthcare budgets experience significant strain (Marchildon et al., 2020). Consequently, healthcare decision-makers may allocate resources to acute care services that address more immediate and visible healthcare needs while overlooking the transitional care services for AYAs with chronic illnesses. Thus, public awareness and understanding of the unique challenges faced by AYAs with chronic illnesses during their transition to adult care can influence funding for transitional care services. The relative invisibility of these challenges in public discourse and policy debates can hinder the development of targeted policies and the mobilization of resources to address the specific needs of this population.

Moreover, disparities in access to healthcare services for specific populations, such as Indigenous youth and those living in rural and remote areas, further compound the challenges in securing adequate funding for transitional care services. Structural barriers, such as the inconsistent implementation of Jordan's Principle can disadvantage AYAs with chronic illnesses who require tailored transitional care services. Therefore, addressing the complex issue of inadequate funding for healthcare transition planning and services for AYAs with chronic illnesses in Canada requires a comprehensive, integrated, and evidence-based approach. Various stakeholders, including policymakers, healthcare providers, and advocacy groups, must collaborate in a concerted effort to develop and implement effective strategies that ensure the equitable provision of high-quality transitional care services not only for this population but for all AYAs with chronic illness or other special healthcare needs.

The anticipating impending transition phase was quite consuming for AYAs as they often did not have a clear picture of the future outside their familiar pediatric setting. Fear, worry, and denial may be mitigated by normalizing the transition experience and providing open and transparent information about the care transition. Additionally, through early adoption of transition care planning, parents, caregivers, and healthcare providers can help introduce change gradually, alleviating the feeling of losing security when transitioning to uncertainty by directly counteracting the shock and grief. Although the sadness associated with leaving the familiarity and meaningful relationships may still be present, increasing knowledge and understanding on managing transition may help to alleviate the intensity of heartbreak and a sense of deep loss. Through this supportive transition process underpinned with information and openness, AYAs will have more clarity on navigating transition change and facilitate the forging of new relationships. This will help with seeking supportive anchors in the swell of transition as AYAs become better equipped to advocate and appreciate, leading to new therapeutic relationships to support their care.

Transition is challenging for individuals with chronic illness as multifaceted considerations impact their experience. In response, parents and caregivers have the desire to create smooth and successful transitions but also struggle with the change in their permitted involvement and understanding of the importance of promoting self-management and autonomy. The results of this study add a unique insight into the transitional experiences of those young people living with a solid organ transplant and transitioning from pediatric to adult care. The grounded theory developed on managing transition provides an opportunity for caregivers and healthcare providers to support the transition experience of young adults by providing opportunities to practice transition strategies and verify if the theory can be generalized or is transferable to their own situation. A greater understanding of these experiences of young people may help parents, caregivers, and healthcare providers to assist successful transitions so that people youth with organ transplants can adapt to their new care providers and healthcare setting. Every individual with a chronic illness is unique. However, there are many similarities in the challenges of living with and managing ongoing healthcare requirements for transplant recipients. The grounded theory of Transforming Through Transition identifies strategies for managing the transition to attend to anticipating the impending transition, losing security when transitioning to uncertainty, seeking supportive anchors in the swell of transition, and gaining a new sense of self.

A consideration for future research aimed at improving patient care and experience AYAs transitioning from pediatric to adult-focused healthcare is adopting a quality improvement (QI) approach. This approach would systematically implement evidence-based interventions to enhance transitional care's quality, safety, and effectiveness while continuously evaluating and refining practices and processes to optimize outcomes for AYAs and their families. By integrating a QI framework, such as the Institute for Healthcare Improvement's (IHI) Model for Improvement, into transitional care research, investigators can identify areas of improvement and design targeted interventions that address the unique needs of AYAs during this critical period (Ogrinc et al., 2015). The IHI model consists of three main components: setting clear, measurable, and achievable aims; identifying evidence-based interventions to achieve these aims; and conducting iterative Plan-Do-Study-Act (PDSA) cycles to test and refine the interventions.

To implement this QI approach effectively, researchers should engage interdisciplinary teams of healthcare professionals, AYAs, and their families in identifying key challenges and barriers that AYAs encounter during the transition process. These teams can utilize various data sources, such as patient surveys, interviews, and medical records, to inform the development of targeted interventions that address the identified issues (Betz et al., 2016). For instance, investigators could examine the adoption of evidence-based practices and protocols, such as the Six Core Elements of Health Care Transition developed by the *Got Transition* initiative, which provides an approach for implementing structured transition processes in healthcare settings (White et al., 2020). This approach outlines essential components of a successful transition, including transition policy development, transition tracking and monitoring, transition readiness assessment, transition planning, transfer of care, and transfer completion.

Moreover, researchers should explore integrating patient and family engagement strategies to ensure that AYAs and their families are active partners in the transition process. This may involve examining the impact of shared decision-making, tailored education and support, and peer mentoring opportunities on the overall transition experience and health outcomes (Toulaney et al., 2022). To assess the effectiveness of these interventions, investigators should employ rigorous data collection and analysis methods, tracking key performance indicators such as the proportion of AYAs who successfully transfer to adult care and patient-reported outcomes like satisfaction with care and quality of life (Betz & Nehring, 2018). Thus, the application of a QI approach in future research endeavours focusing on healthcare transition for AYAs with chronic illnesses holds the potential to generate valuable insights and innovations that enhance patient care and experience. By leveraging evidence-based practices and engaging AYAs and their families in the process, researchers can contribute to the ongoing refinement and optimization of transitional care for this vulnerable population.

5.5.1 Implications for Nursing Practice

Nurses can play an important role in supporting AYAs and other recipients during the transition process by providing education, emotional support, and connecting them with resources to help them build self-management skills and supportive relationships. Nurses must recognize the unique challenges AYAs face during their healthcare transition, which includes adapting to a new care environment, establishing relationships with adult care providers, and navigating complex medical regimens. By acknowledging these challenges, nurses can better understand the diverse needs of AYA transplant recipients and tailor their care accordingly. Thus, nurses are pivotal in fostering patient-centred care and promoting effective communication among the interdisciplinary team, AYAs, and their families. By facilitating open and empathetic dialogue, nurses can empower AYAs to actively participate in their care and support them in developing self-management skills essential for a successful transition.

Nurses also provide stabilizing care to help transplant recipients achieve consistency and predictability in managing their health, including medication management, symptom control, and self-care practices. Moreover, nurses can play a critical role in providing moral support by establishing trust and rapport with AYAs, addressing their concerns and questions, and providing education and resources that empower recipients to take an active role in their care. By doing so, healthcare providers can help patients stabilize their care, reducing the likelihood of negative outcomes and improving their overall health and well-being.

Nurses can lead the way in supporting the transition process for AYA transplant recipients by advocating for the implementation of evidence-based collaborative care models that involve both pediatric and adult care providers that have been shown to have positive impacts on AYAs' healthcare experiences. This includes promoting structured transition plans, interdisciplinary collaboration, and ongoing assessment of AYAs' readiness for transition. By working together, nurses can help develop a shared understanding of the AYA's healthcare needs, including the skills and knowledge needed to transition successfully to adult care. In this way, nurses can support AYAs by working with patients and families to improve the transition process and ensure that AYAs receive the resources they need to manage their health successfully as they transition from pediatric to adult care.

Nurses can help mitigate the shock of transition by taking a proactive and personalized approach to the transition process, recognizing the complex developmental and psychosocial factors at play and working with AYAs to address these factors in a supportive and collaborative manner. By doing so, nurses can help to facilitate the AYA's ongoing development and transition into adulthood. Specifically, nurses caring for AYAs during the transition must be attuned to the disruption of the AYA's sense of security and stability and the broader developmental changes and challenges they are experiencing. By providing personalized and supportive care that considers each AYA's unique needs and experiences, nurses can help facilitate a successful transition and promote the ongoing development and growth of the AYA.

The experiences of AYAs during the transition to adult healthcare highlighted the need for a more coordinated and supportive approach to this process. Nurses must collaborate with AYAs, their families, and other healthcare providers to develop a personalized transition plan considering AYA's unique needs and experiences. This may include providing more information and education about the expectations and demands of adult care, as well as offering more targeted support and resources to help AYAs navigate this challenging time. Specifically, nurses must recognize the emotional impact of transition and provide support and resources to help AYAs prepare for the eventual loss of these important relationships. This may include providing access to counselling services or connecting AYAs with support groups for those who have experienced similar transitions.

By acknowledging and addressing the emotional impact of this transition, nurses can help to ease the process of moving from pediatric care to adult care and provide individuals with the support they need to thrive in their new healthcare environment. To address the emotional impact of the transition to adult care, nurses should recognize the importance of attachment relationships and work to establish meaningful connections with patients and their families by providing empathy, support, and encouragement during this challenging time to ease the transition to adult care and support individuals as they navigate this important milestone in their medical journey and life. Thus, it is crucial for nurses to work with AYAs and their families to provide anticipatory guidance and support during the healthcare transition process. By doing so, nurses can help AYAs develop the necessary self-management skills and cultivate a sense of agency over their healthcare journey, leading to better health outcomes and greater overall well-being. One way nurses can provide this support is by promoting the adult hospitals positively to help AYAs and their families develop confidence and trust in their new caregivers and lay the foundation for establishing new relationships.

Ultimately, a more critical and in-depth understanding of the experiences of AYAs during the transition to adult healthcare can help to promote a more responsive and supportive healthcare system that better meets the needs of this vulnerable and underserved population. By working together to address the challenges and barriers AYAs face during this transition, nurses can help ensure they receive the care and support they need to achieve their full potential and thrive as emerging adults.

5.5.2 Mental Health and Social Support

Mental health is a critical aspect of overall health and well-being, especially for AYAs with chronic illnesses. The burden of mental health concerns among this population is well recognized and has been identified as one of the most significant challenges faced by AYAs (Orth & van Wyk, 2022). Adolescents and young adults with chronic illnesses often experience high levels of stress, anxiety, and depression, which can impact their quality of life, physical health, and ability to manage their illness (Law et al., 2019). For example, stress and anxiety can trigger symptoms or worsen existing symptoms, making it more difficult for AYAs to manage their illness and adhere to their treatment. Additionally, the physical, emotional, and social challenges associated with a chronic illness can also have a negative impact on mental health, leading to feelings of isolation, hopelessness, and low self-esteem (Orth & van Wyk, 2022; Şengül & Kurudirek, 2022). This is also supported by the WHO (2022) findings, which estimate that mental health conditions accounted for 16% of the global burden of disease and injury for adolescents. In Canada, there has been an increase in hospitalizations for mental health for pediatric and AYAs aged 5-24, from 21% in 2019 to 23% in 2020 (CIHR, 2022b).

Similarly, the aspect of social support and mental health care was emphasized as a significant concern by participants, although it remains underrepresented within the literature. The parents in this study highlighted that mental health was challenging for the AYAs in the context of transplantation and transition to adult care. Parents and recipients were often emotional throughout the interview, and it was evident that they had many raw emotions that may not have been thoroughly explored and maybe even suppressed. There was common language around trust, abandonment, and rushed transition with the suggestion that the transition was abrupt and a transfer of care, and not actually a planned and gradual 'transition' to the adult setting as is suggested by the literature as best practice.

Many participants returned several times to the notion of mental health support and partnerships with families, peers, and mentors as potential strategies to better support young adults and foster coping in support of mental health. The importance of trust and relationship building with the adult care team, with therapeutic support provided by the pediatric care team, resonated through all the participant interviews. Yet, in most instances, participants shared that their perception was that there was a rushed transition experience rather than a planned and supported gradual process, underpinned by a tone of fear concerning the transition experience. Thus, although the need for both social support and mental health care consideration is unmistakeable (Colver et al., 2020; Dumais-Lévesque & Pomey, 2020; Hendrickx et al., 2020; Musamali, 2018; White et al., 2020), it is clear from my study that these needs are not being met in practice and there is a need to strive to do better in supporting in this domain.

In my study findings, mental health strain, anxiety, and emotions associated with losing the already established pediatric healthcare connections and security exacerbated poor transition outcomes. While recipients with strong social support reported having mental health strain, they excelled in adult care and continued to develop robust mental and physical health outcomes. However, recipients with poor mental health support reported low adherence to medication and medical follow-up routines, and for some increased risk of infection, lower motivation for self-advocating during consultations, and ultimately losing the transplanted organ, thereby needing future re-transplantation. While the transition process is expected to be efficient, planned, and patient-oriented, meeting physical health and psychosocial and educational needs (Blum et al., 1993), I have found that these needs have been largely neglected. Thus, the impact of distress in relation to transition at this already critical development stage is important to address, with attention to mental health concerns among AYAs with chronic illnesses, to ensure that they receive the support and care they need to manage their illness and improve their quality of life. Drawing on the results and suggestions from this study and my observations and findings, it would be beneficial to establish a peer support program alongside routine mental health assessment and support to meet the unmet needs of recipients in preparation for and throughout the transition.

5.5.3 Implications for Healthcare Organizations

Despite these suggestions, the interviews in this study have highlighted gaps in services concerning management, funding, and availability of services. This study provides thoughtful information for healthcare providers, decision-makers, and key policy stakeholders. The insight and information provided from this study and compiled in this dissertation can be used by healthcare organizations to evaluate their transition programs considering gaps in services and proposed suggestions for better coordination regarding transplant recipients' transitional needs. For instance, all participants said there was a lack of formalized transition programs or plans, despite the best practice recommendations that exist. Healthcare providers shared experiences of feeling unprepared or unable to support transition efforts for pediatric transplant patients due to a lack of resources and training. Hence, healthcare organizations can consider these points when evaluating programs to better support AYA transition patients and their families. The participants also identified recommendations for policy change, including mandatory mental health screening for all patients.

Thus, healthcare providers need specialized training in adolescent medicine and the intricacies of healthcare transitions, particularly for complex cases such as transplant recipients. This training should encompass medical, psychosocial, and developmental aspects of adolescent health and care coordination between pediatric and adult healthcare providers. Additionally, healthcare professionals must be prepared to address the emotional and psychological challenges that patients and their families may experience during the transition process. To enhance healthcare provider competence and confidence in managing adolescent transplant recipients, interdisciplinary collaboration and continuous professional development opportunities should be prioritized. This may include educational workshops, mentorship programs, and the incorporation of transition planning education into medical and nursing school curricula and professional development programs. Establishing a culture of lifelong learning and fostering communication among healthcare professionals across specialties and pediatric and adult-focused care will facilitate the exchange of knowledge and expertise, ultimately leading to improved transition planning and better patient outcomes.

There must also be collaboration among researchers, healthcare providers, and policymakers in Canada to develop flexible and adaptable transition protocols tailored to specific healthcare systems and contexts. This approach will enable the integration of local expertise, resources, and cultural factors, ensuring that transition protocols are effective and relevant to the populations they serve. Moreover, sharing best practices and learnings across different healthcare systems within Canada can help foster innovation and improve the quality of care for adolescents with health conditions transitioning from pediatric to adult healthcare services. Adopting standardized protocols that incorporate flexibility and customization can help ensure that transition planning aligns with patient- and family-centred care principles. Fostering interdisciplinary collaboration and communication is essential; joint meetings, shared care planning, and standardized tools can help bridge the communication gap and facilitate the exchange of vital information between pediatric and adult healthcare providers. Furthermore, interdisciplinary training programs can promote a shared understanding of the unique needs of adolescent patients and the importance of a coordinated approach to transition planning. This alignment is crucial for fostering a sense of trust and partnership between patients, their families, and healthcare providers, which ultimately enhances the overall quality of care.

5.5.4 Implications for Transition Research

This study suggests a grounded theory on the transitional process for AYA transplant recipients, proposing strategies for a successful transition. Although solid organ transplantation is a specific unique healthcare condition, this study helps others understand transitional strategies for AYAs with other chronic health conditions. Furthermore, this study can provide useful insights for future research into the transitional needs of this unique population. The importance of ongoing research on service gaps in transitional needs is also evident, and this study provides preliminary information to future prospective researchers concerning identified gaps in service. Based on the findings in this study, additional research would be beneficial to develop insights into transitions and transition care. Specifically, future research may focus on approaching transition from a trauma-informed care lens, how transitions are experienced by the entire family unit, including siblings, the effect of transition on mental health, and the unique transition experiences of those from varied cultures.

5.5.5 Implications for Policy Development

One key finding from this study is the highlighted limitation of the current policy for determining the time of transition for AYA transplant recipients. Despite our best evidence suggesting that transitions should be gradual and reflective of individual development, the current practice at leading Canadian pediatric hospitals is to terminate care at the pediatric centre at age 18. Although this age may align with developmental readiness for some adolescents, many transplant recipients are simply not yet be ready, while others may be ready earlier. Instead, there should be a shift to align with pediatric healthcare values and philosophy, initiating a family-centred and personally individualized approach to transition. This shift will ensure that adolescents and young adults receive the ongoing family support desired to reduce trauma and promote successful and healthy transitions with positive long-term outcomes.

5.5.6 Strengths, Limitations, and Delimitations of the Study

In the context of this study, several delimitations and limitations are worth examining as they may impact the interpretation of the findings. By recognizing these areas, researchers can better understand the constraints of the present investigation and identify areas for improvement in future research endeavours. The delimitations of this study warrant careful consideration, as they encompass the choices and boundaries I made throughout this study that marked the scope of the research (Theofanidis & Fountouki, 2019). One of the primary delimitations in this study is the specific focus on AYAs with liver and/or kidney transplants transitioning to adult-focused healthcare. This concentration may circumscribe the applicability of the results to other solid organ transplant groups or populations experiencing healthcare transitions, such as those with chronic illnesses or alternative health conditions. Consequently, exploring diverse populations would enhance understanding of healthcare transition experiences across various contexts.

The selected age range of 12-28 years for transplant recipients represents both a delimitation and limitation. The delimitation of the age range, particularly given that the study's youngest participant was 18, implies that younger individuals' perspectives during the transition process remain unexplored. The limitation of this is that younger participant voices are not directly captured, and participants may have different perspectives throughout the transition process. Therefore, incorporating a wider age range or including younger participants in future studies, as depicted in the proposed patient journey map outline in Figure 3 (see Appendix L for detailed figure), could yield a more comprehensive understanding of the transition experience across different developmental stages. Similarly, the geographical focus on Canadian and some American AYA transplant recipients delimits the applicability of the findings to other countries with distinct healthcare systems and cultural contexts. By including a more diverse geographical representation in future research, researchers could elucidate how healthcare transitions are experienced in different settings, thereby expanding the generalizability of the findings.

I encountered recruitment-related issues; recruitment was restricted to online methods due to COVID-19 precautions, resulting in a narrowed population to draw upon. With an awareness that recruitment limited by snowball sampling and social media would be difficult and that some recruitment issues were to be expected, I did not anticipate the significant challenges that ensued. Subsequently, recruitment for this study lasted longer than anticipated. The implications of COVID-19 restrictions also resulted in the shift to virtual data collection in which video conferencing was the primary source of participant engagement. Although initially anticipated as a limitation, this proved to increase the responsivity of young adult participants and the request for chat-based interview modalities as this was a form of communication that they were familiar with and comfortable with. However, while these methods proved effective in engaging young adult participants, they may not capture non-verbal cues and interpersonal dynamics as comprehensively as in-person interviews. The delimitation of adopting video conferencing and chat-based interviews as the primary data collection methods may have affected the richness of the collected data. Hence, considering alternative data collection methods could enhance the depth and quality of the information obtained.

Constructivist Grounded Theory (CGT), as a research methodology, holds substantial merit when applied to the study of transitions experienced by AYA transplant recipients. One of its principal benefits is the profound depth of understanding it offers. The CGT methodology facilitated the exploration of the lived experiences of AYA transplant recipients, enabling the unearthing of intricate details, nuances, and the complex interplay of factors impacting this group's transition experience. This made CGT a particularly effective tool in the pursuit of understanding the unique challenges faced by this group, thereby allowing for more tailored interventions and support mechanisms. Moreover, the participatory nature of CGT, grounded in the principles of constructivism, values the voices and perspectives of the research participants.

This led to the co-creation of a theory that was directly influenced by the experiences of the AYA transplant recipients, ensuring that the theory was firmly rooted in their lived realities. Such an approach holds the potential to render the resultant theory more relevant, applicable, and impactful for the population under investigation.

Nevertheless, the use of CGT is not without limitations. The depth and richness that makes CGT valuable also limit the generalizability of the findings. Given its focus on a specific context and population, extrapolating the results to broader contexts or other populations may be inappropriate. Similarly, the resultant theory, while grounded in the participants' experiences, was influenced by my interpretive lens as the researcher. Despite efforts to maintain reflexivity and mitigate researcher bias, the co-constructed nature of CGT means that the researcher's own experiences, assumptions, and perspectives can influence the process and outcomes of the research. Therefore, it was imperative that as a researcher using this approach, I continually engaged in reflexivity and transparently articulate my own personal situatedness within the research process. Further, the intensive, iterative nature of data collection and analysis in CGT was time-consuming and resource-intensive, which posed challenges as a doctoral student completing degree requirements with a limited timeline. Overall, the benefits of applying CGT to understand the transition experiences of AYA transplant recipients were significant, offering deep, contextually rich insights that can guide policy and practice. However, the potential limitations underscore the importance of recognizing the unique characteristics and demands of this methodology and the necessity of situating its findings within the specific context of the study.

Lastly, the Meleis et al. (2000) transition framework was used to inherently shape the interpretation of the findings. Employing alternative theoretical frameworks might offer other unique perspectives on the healthcare transition experience, contributing to an alternative understanding of the phenomenon. Thus, by acknowledging these delimitations, researchers can pinpoint areas for further exploration and expansion in subsequent studies. This recognition also aids in contextualizing the study's findings within the confines set by the researcher, thereby facilitating a more nuanced understanding of the specific population and context under investigation.

5.6 Chapter Summary

In this chapter, an in-depth exploration and integration of the findings from Chapter Four have been presented, drawing upon the existing literature, and situating the emergent theory, *Riding the Wave of Change: Transforming through Transition*, within the context of Meleis et al.'s (2000) transition framework. The study's AYA transplant recipients underwent numerous changes as they entered adult-focused care. This research serves as a guiding beacon in the sea, illuminating the nuanced experiences of AYA transplant recipients during this pivotal transition. The findings offer valuable insights into the development of self-management skills throughout this process, equipping healthcare providers with a compass to navigate the complex landscape of supporting AYA transplant recipients as they navigate the uncharted seas of adult care. The findings derived from this study hold substantial practical implications for AYA transplant recipients, their families, and healthcare teams. As delineated in the implications and recommendations section, these insights inform future research endeavours and potential avenues for enhancing the experiences of AYAs during their transition to adult care. By cultivating a more comprehensive understanding of the challenges and triumphs experienced by AYA transplant recipients, we can contribute to the ongoing development of responsive and supportive healthcare practices that cater to the unique needs of this population.

5.7 Closing Thoughts

Solid organ transplantation is a lifelong condition that necessitates continuous medical management, rendering the experiences of AYAs who navigate these transitions of utmost importance. This study has afforded a unique opportunity to gain insights into the perspectives of AYAs themselves, as well as the viewpoints of their family caregivers and healthcare providers. It is with great sincerity that I aspire for this work and the derived theory on managing transitions to make a meaningful and positive impact on the experiences of AYA transplant recipients as they venture into adult-focused care.

The existing body of literature reveals a paucity of research that directly engages AYAs to explore their perspectives on the transition and self-management processes. To foster the evolution of transition services, it is imperative to transcend the theoretical discussions surrounding transition support and actively implement change rooted in a trauma-informed care framework. By harnessing the insights gained from this study and applying them to practice, we can strive towards creating a more thoughtful, responsive, and effective healthcare environment for AYAs with solid organ transplants as they navigate the complex journey of transitioning to adult-focused care.

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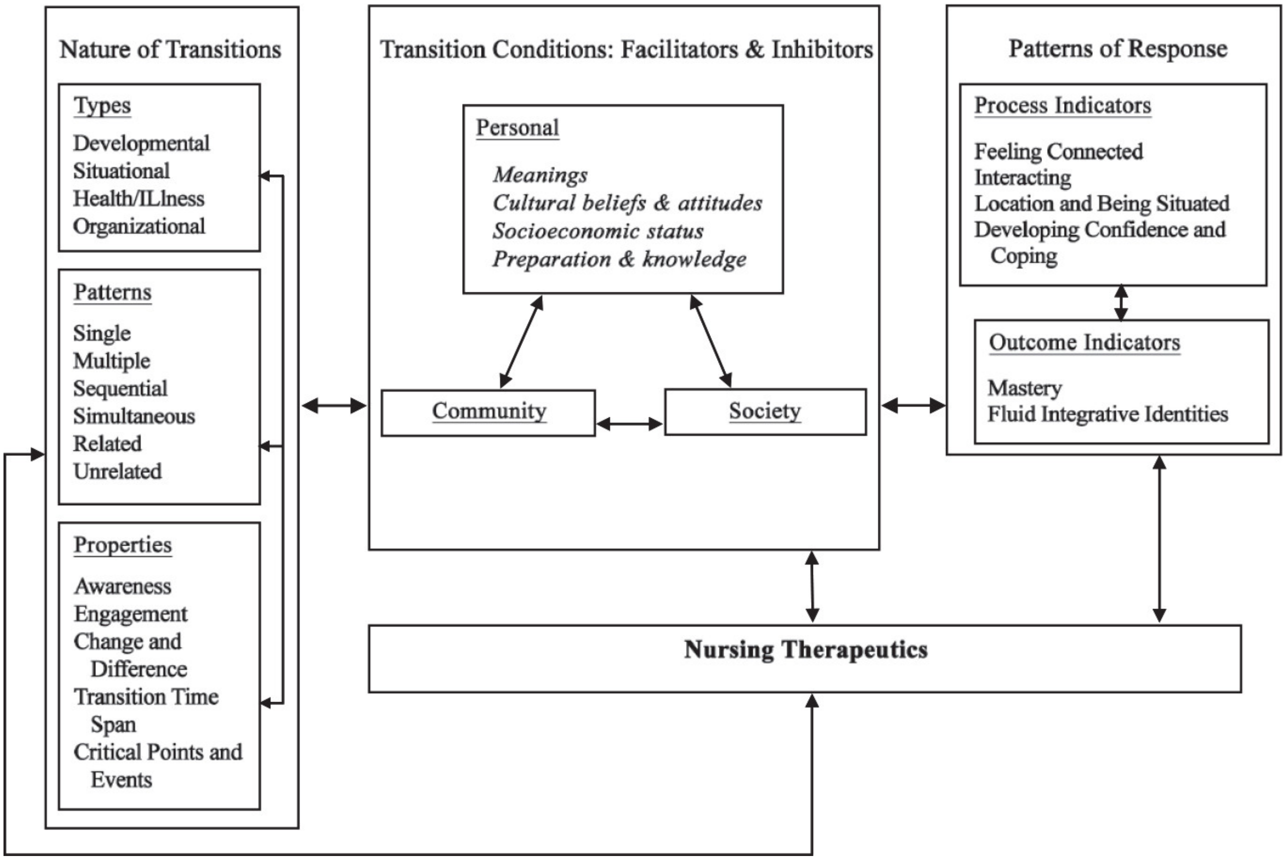
Appendix A: Transitions: A Middle-Range Theory Framework



Meleis et al., 2000

Appendix B: Information Signs for Recruitment

Join our study on Transplant Recipients' Transition to Adult Care

Study Title:
Adolescent transplant recipients' transition to adult-focused care.

Principal Investigator:

Angie Lim

Interested?

To ask questions contact:

Angie Lim, RN, PhD(c), MN, BScN (PhD Student)

angielim@uvic.ca

Lenora Marcellus, PhD, RN (PhD Supervisor)

Lenora.marcellus@uvic.ca

Deadline to enrol:
March 30, 2022

Version 3: 01-10-2022

Are you a kidney and/or liver transplant recipient between 12-28 years of age, or their parent/caregiver?

Consider participating in our study:

What is the study about?

To gain in-depth understanding of how adoelscent transplant recipients manage the process of transition to adult-focused care.

Who can participate?

We are looking for English speaking adolescents, parents, and caregivers at least 6 months from transplant, and not currently being treated for PTLD or cancer.

What's involved?

Participation in 1-2 virtual/online interviews. The first interview is about 1 hour, and the second is 15-20 minutes.

Are there benefits to participating?

There are no direct benefits to you for participating in this research, but you will help other adolescents who will be transitioning in the future.

Participants will be given an optional certificate of recognition of their contribution.

Additionally, a $15 gift card will be provided as honorarium for you time.

Appendix C: Letter of Introduction

June 16, 2021

Dear Participant,

The purpose of this study is to understand how adolescent kidney and/or liver transplant recipients prepare to move from pediatric to adult care. The results of this study will help the healthcare team better understand how we can support the transition process for other transplant recipients.

This study involves participating in an interview about your transition preparation following your transplant. It will take about 1 hour of your time to participate. Sometimes a second follow-up interview may be required – that would take 15-20 minutes virtually.

If you are interested in participating in this research study please call, text, or leave a message with Angie Lim at 437-375-2887 or email angielim@uvic.ca. You do not have to participate in the research study.

If you are interested in participating in the study, we will obtain your consent to participate. If you consent, we arrange a time for the interview (virtual) that works well for you.

Participation in any research study is voluntary. You do not have to participate in this research study if you do not want to. If you decide to participate in this study you can change your mind at any time without giving a reason.

Thank you for considering participation in this study.

Sincerely,

Angie Lim, RN, PhD(c)

Appendix D: Summary Information Sheet

Adolescent Transplant Recipients' Transition to Adult-Focused Care: A Doctoral Research Project

Primary Investigator: Angie Lim[1], RN, PhD(candidate)
Senior Investigator: *Supervisor:* Lenora Marcellus[1], RN, PhD
Committee Members: Lorelei Newton[1], RN, PhD; Hilde Zitzelsberger[2], RN, BScN, MSc, PhD
[1]University of Victoria, Victoria, BC, [2]Ontario Tech University

Purpose: To gain in-depth understanding of how adolescent transplant recipients manage the process of transition to adult focused care. Specific aims include identification of how adolescents prepare for and engage in the transition process, and how nurses and healthcare practitioners (HCP) can support the psychosocial adaptation of adolescent transplant recipients in their transition. Therefore, the overarching research question guiding this study is: *How do adolescent kidney and/or liver transplant recipients manage the transition from pediatric to adult care?*

Significance: Solid organ transplantation prevails as a leading treatment for pediatric patients in organ failure. Because transplantation is a chronic condition requiring ongoing monitoring and medication for stability and organ graft survival, solid organ transplantation is a treatment modality and not a cure. Currently, pediatric-focused healthcare systems provide ongoing transplantation care to patients 0-18 years of age, after which there is a transfer of care to the adult healthcare system. Despite the success of transplantation as a treatment option, research shows that adolescents and young adults with chronic health conditions experience adverse outcomes during the transition period from pediatric to adult healthcare, with the most common and most impactful outcome being frequent emergency room visits, increased hospital admissions, and graft failure often as a result of rejection or infection, although sometimes due to treatment non-adherence.[1, 2, 3, 4, 5, 6]

Non-adherence is a phenomenon common among adolescent transplant recipients that is well documented in the literature, with rates as high as 75% in adolescents, compared to 3-19% in children, and 15-25% in adults.[1, 2, 4, 7] Consequently, graft loss and mortality rates are highest in adolescent transplant recipients compared to all other pediatric transplant recipients, [2, 8, 9] as evidenced by adolescents' increased risk of graft loss, late acute rejection, and chronic rejection,[1, 8] and is considerably worse at the time of transition to adult care.[1, 8, 9, 10, 11, 12] Despite significant advancements in pediatric transplantation, the healthcare transition research to support this population has not progressed at the same rate and there is limited research focusing on the broader implications for adolescent transplant recipients and their families during the transition period.

Theoretical Framework: This study is based in constructivism and symbolic interactionism. Constructivism is a perspective that suggests individuals use constructions developed from created realities to help make sense of their experiences and give meaning to reality, events, and phenomena through sustained and complex social interactions.[13, 14, 15]. Constructivism is harmonious with symbolic interactionism, another perspective that views human behaviour as constructed from social interactions and inner interpretive process. [16, 17]

Design: Grounded Theory is an inductive, comparative methodology that provides systematic guidelines for gathering, synthesizing, analyzing, and conceptualizing qualitative data with the goal of constructing a theory. Grounded theory methodology[13, 14, 15, 18] guides study design.

Sample: The primary participant group is 12-28-year-old adolescent liver and/or kidney transplant recipients. Adolescents must be a minimum of six months from the time of transplantation and not currently undergoing treatment for post-transplant lymphoproliferative disorder or diagnosed with a significant developmental delay or psychotic disorder. Participants must be able to provide informed consent and cognitively able to participate with the interviews, as determined by clinical judgement. Further sampling may include interviewing participants' families or primary caregivers, or HCPs who have more than six months of experience caring for adolescent transplant recipients, either in the pediatric or adult setting. As the study proceeds and data are collected and analyzed simultaneously, I will follow the principles of theoretical sampling, and I will use concepts arising out of the analysis to direct further sampling in order to elaborate the developing theory.

Methods: Patient participant and family recruitment will begin through online social media groups with snowball sampling to identify other potential participants. Virtual in- depth interviews will explore participant perspectives on preparing for and managing transition to adult-focused care. Demographic questionnaires will allow for detailed description of participants. Analysis will occur concurrently with data collection and will be guided by the principles of constant comparison and questioning, involving methods of coding and memo writing. Use of NVivo 12 software will facilitate the analytic process.

Implications: Health care professionals play an important role in helping patients adolescent transplant recipients in managing transition to adult-focused care. In-depth understanding of transition is needed to optimize supportive care and transition preparation, and inform the development of supportive transition interventions, for adolescent transplant recipients and their families. The substantive theory developed in this study will provide a framework to inform future research and practice.

For further information, please contact:
Angie Lim
XXX-XXX-XXXX

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Appendix E: Consent Forms for Each Participant Group

Consent to Participate in a Research Study
(Participant Consent)

Study Title: Adolescent Transplant Recipients Transition to Adult-Focused Care from Pediatric-Focused Care.

Principal Investigator:

Angie Lim, RN, PhD (c), XXX-XXX-XXXX

Co-Investigator(s):

Lenora Marcellus, PhD, RN (PhD Supervisor), Lenora.marcellus@uvic.ca

Research Contact:

Angie Lim, RN, PhD (c), XXX-XXX-XXXX

Lenora Marcellus, RN, PhD, Department of Nursing, University of Victoria,

Lenora.marcellus@uvic.ca

Introduction

We would like to invite you to take part in our research study. This consent form describes the research study and what it means to participate. This consent form may have words that you do not understand. Please ask the study staff to explain anything that you do not understand. Please take as much time as you need to think about your decision to participate or not, and ask any questions you have. If it is helpful to you, you are encouraged to discuss the study with family, friends, your personal physician, other health professionals, or any members of your community that you trust. All participation is voluntary and you are not under any obligation to participate.

Why am I being asked to participate?

You are being invited to participate in this study because you had an organ transplant and we are interested in how you are managing the process of transition to adult care.

Why is this study being done?

This study is being done because to understand how adolescent kidney and/or liver transplant recipients prepare to move from pediatric to adult care. The results of this study will help the healthcare team better understand how we can support the transition process for other transplant recipients.

How many participants will be in this study?

Up to 30 children are expected to participate in this study.

What will happen if I join this study?

Your participation in this study will involve participating in an online virtual interview about your transition preparation following your transplant. It will take about 1 hour of your time to participate. Sometimes a second follow-up interview may be required – that would take 15-20 minutes virtually.

You will be asked to participate in an interview asking about your transition and how you manage your post-transplant care in preparation for moving to adult health care. The interview will be audio recorded and the researcher will make additional notes about your answers. The audio recording will be transcribed using computer software after the interview and will be analyzed by the research team. The transcription will be done by members of the study team. Your name or any other identifying information will not be included during the recording, except your voice. The audio recording will be destroyed at the conclusion of the study.

What are the risks, harms or discomforts of the study?

There are no anticipated risks, harms, or discomforts from participating in the study. During the interview you may experience some anxiety, emotional and/or psychological distress due to the nature of the questions. You can skip questions, take a break or stop answering at any time.

If your responses indicate that there is a serious risk of harm to yourself or others, confidentiality will be broken in order to protect you or another person. If we feel that you need urgent care as result of participating in this research study we will intervene according to routine clinical care practices.

There is an inconvenience of time. The first interview will take about 1 hour and an additional 15-20 minutes if a second interview is needed for a total of 60-80 minutes for the entire research study.

Despite protections being in place, there is a risk of unintentional release of information.

Are there benefits from being in the study?

There are no direct benefits to you for participating in this research study

We hope that the information learned from this study can be used in the future to benefit other adolescent transplant recipients with their transition to adult care.

What are the optional part(s) to this research study?

Participation in a follow-up interview, if needed, by phone is optional.

We may decide to use parts of the transcription without your name and voice in presentations or publications in the format of quotations. You have the option to refuse. Please initial next to your preference:

Options	Initials
I **allow** the use of parts of my de-identified transcription in presentations and publications.	
I **do not** allow the use of parts of my de-identified transcription in presentations and publications.	

Can I choose to leave the study?

It is your choice to take part in this study, participation is voluntary. You can change your mind at any time during the research study. The study team may ask why you are withdrawing for reporting purposes, but you do not need to give a reason to withdraw from the study if you do not want to. Withdrawal from the study will not have any effect on the care you or your family will receive at any hospital. If you decide to leave the study, you can contact the Principal Investigator or a member of the study team to let them know.

If you decide to withdraw before your interview is analyzed, it can be completely deleted from the research. However, once your interview has been analyzed, it may not be possible to withdraw all the data from the study, but there will be no way that what you have said could be traced back to them or be recognizable in any way. If you choose to withdraw, none of your direct interview quotations will be used in any products of the research.

Will I be paid and/or reimbursed if I join this study?

In recognition of your participation, you will be given a certificate of participation and/or 1-2 volunteer hours.

Also, you will receive a $15 gift card as an honorarium for you time.

How will my privacy be protected?

We will respect your privacy. No information about you will be given to anyone or be published without your permission, unless the law requires us to do this.

If you decide to participate in this study, the research team (study investigators, coordinators, nurses, and delegates) will collect personal health information about you. They will collect only the information they need for this study. “Personal health information” is health information about you that could identify you.

The research team will also collect some personal information about you (name, address, phone number, email) for the purposes of contacting you. This personal information will not be shared outside of the research team.

All information collected about you will be “de-identified” by replacing your identifiable information (i.e., name) with a “pseudonym” of your choice. Only the “study code key” can connect the information collected about you to your identity. The study code key will be safeguarded by the research team. Even though the risk of identifying you from the study data is very small, it can never be completely eliminated.

The following people may come to the hospital to look at your personal health information to check that the information collected for the study is correct and to make sure the study followed the required laws and guidelines:

- Representatives of the University of Victoria Research Ethics Board

The research team will keep any personal health information about you in a secure and confidential location for 3 years and then destroy it according to University of Victoria policy.

What if I am injured during/in this study?

If you suffer an injury from participation in this study, medical care will be provided to you in the same manner as you would ordinarily obtain any other medical treatment. In no way does signing this consent form waive your legal rights or release the study doctor(s), sponsors or involved institutions from their legal and professional responsibilities.

If you require treatment for any injuries or illness related to your participation in the study, you should contact the study doctor immediately.

How will I be informed about new information?

We may learn new information during the study that you may need to know. We may also learn about things that might make you want to stop participating in the study. If this happens, you will be notified about any new information in a timely manner. You may also be asked to sign a new consent form that describes these new findings if you decide to continue in the research study.

What are my rights when participating in a research study?

You have the right to receive all information that could help you make a decision about participating in this study. You also have the right to ask questions about this study at any time and to have them answered to your satisfaction. Your rights to privacy are legally protected by federal and provincial laws that require safeguards to ensure that your privacy is respected.

By signing this form you do not give up any of your legal rights against the study doctor, sponsor or involved institutions for compensation, nor does this form relieve the study doctor, sponsor or their agents of their legal and professional responsibilities.

You will be given a copy of this signed and dated consent form prior to participating in this study.

Will I receive study results?

Research results will be shared through a doctoral dissertation, journal publications, and academic conferences. When the results of this study are shared, your identity will not be disclosed. You have the right to be informed of the results of this study once the entire study is complete.

If you would like to be informed of the results of this study, an executive summary of the findings of the research will be prepared and emailed/mailed to you at the conclusion of the research, if you express interest in receiving it.

Who can I call if I have questions about the study?

If you have any questions during your participation in this research study you can contact the Principal Investigator, Angie Lim at XXX-XXX-XXXX or the research team members listed at the beginning of this consent form.

Research Ethics Board Contact Information

The study protocol and consent form have been reviewed by the University of Victoria Research Ethics Board (REB). If you have any questions regarding your rights as a research participant, you may contact the Office of the Research Ethics Board at ethics@uvic.ca or 250-472-4545 during business hours.

Consent to Participate in a Research Study

Study Title: Adolescent Transplant Recipients Transition to Adult-Focused Care from Pediatric-Focused Care.

By signing this research consent form, I understand and confirm that:

1. All of my questions have been answered,
2. I understand the information within this informed consent form,
3. I do not give up any of my legal rights by signing this consent form,
4. I have been told I will be given a signed and dated copy of this consent form.
5. I agree to take part in this study.

I consent to participate in this study.

Printed Name of Participant	Participant signature & date (DD/MMM/YYYY)

Printed Name of person who obtained consent	Role of person obtaining consent	Signature & date (DD/MMM/YYYY)

Investigator Signature

Investigator Signature	Printed name	Date (DD/MMM/YY)

My signature above signifies that the study has been reviewed with the study participant by me and/or by my delegated staff. My signature may have been added at a later date, as I may not have been present at the time the participant's signature was obtained.

Consent to Participate in a Research Study

(Parent/Guardian Participants Consent – Participant Under 13 years)

Study Title: Adolescent Transplant Recipients Transition to Adult-Focused Care from Pediatric-Focused Care.

Principal Investigator:
Angie Lim, RN, PhD (c), XXX-XXX-XXXX

Co-Investigator(s):

Lenora Marcellus, PhD, RN (PhD Supervisor), Lenora.marcellus@uvic.ca

Research Contact:
Angie Lim, RN, PhD (c), XXX-XXX-XXXX
Lenora Marcellus, RN, PhD, Department of Nursing, University of Victoria,
Lenora.marcellus@uvic.ca

Introduction

As your child's Substitute Decision Maker, you are being asked to provide informed consent on behalf of your child. If your child gains the capacity to consent for themself, consent will be sought from them and your consent for them will end. Throughout this form, first and second-person pronouns (e.g., "I", "me", "my", "you") means the person you are representing, "we" represents the SickKids researchers.

We would like to invite you to take part in our research study. This consent form describes the research study and what it means to participate. This consent form may have words that you do not understand. Please ask the study staff to explain anything that you do not understand. Please take as much time as you need to think about your decision to participate or not, and ask any questions you have. If it is helpful to you, you are encouraged to discuss the study with family, friends, your personal physician, other health professionals, or any members of your community that you trust. All participation is voluntary and you are not under any obligation to participate.

Why am I being asked to participate?

You are being invited to participate in this study because you had an organ transplant and we are interested in how you are managing the process of transition to adult care.

Why is this study being done?

This study is being done because to understand how adolescent kidney and/or liver transplant recipients prepare to move from pediatric to adult care. The results of this study will help the healthcare team better understand how we can support the transition process for other transplant recipients.

How many participants will be in this study?

Up to 30 children are expected to participate in this study.

What will happen if I join this study?

Your participation in this study will involve participating in an online virtual interview about your transition preparation following your transplant. It will take about 1 hour of your time to participate. Sometimes a second follow-up interview may be required – that would take 15-20 minutes virtually.

You will be asked to participate in an interview asking about your transition and how you manage your post-transplant care in preparation for moving to adult health care. The interview will be audio recorded and the researcher will make additional notes about your answers. The audio recording will be transcribed using computer software after the interview and will be analyzed by the research team. The transcription will be done by members of the study team. Your name or any other identifying information will not be included during the recording, except your voice. The audio recording will be destroyed at the conclusion of the study.

What are the risks, harms or discomforts of the study?

There are no anticipated risks, harms, or discomforts from participating in the study. During the interview you may experience some anxiety, emotional and/or psychological distress due to the nature of the questions. You can skip questions, take a break or stop answering at any time.

If your responses indicate that there is a serious risk of harm to yourself or others, confidentiality will be broken in order to protect you or another person. If we feel that you need urgent care as result of participating in this research study we will intervene according to routine clinical care practices.

There is an inconvenience of time. The first interview will take about 1 hour and an additional 15-20 minutes if a second interview is needed for a total of 60-80 minutes for the entire research study.

Despite protections being in place, there is a risk of unintentional release of information.

Are there benefits from being in the study?

There are no direct benefits to you for participating in this research study

We hope that the information learned from this study can be used in the future to benefit other adolescent transplant recipients with their transition to adult care.

What are the optional part(s) to this research study?

Participation in a virtual follow-up interview, if needed, is optional.

We may decide to use parts of the transcription without your name and voice in presentations or publications in the format of quotations. You have the option to refuse. Please initial next to your preference:

Options	Initials
I **allow** the use of parts of my de-identified transcription in presentations and publications.	
I **do not** allow the use of parts of my de-identified transcription in presentations and publications.	

Can I choose to leave the study?

It is your choice to take part in this study, participation is voluntary. You can change your mind at any time during the research study. The study team may ask why you are withdrawing for reporting purposes, but you do not need to give a reason to withdraw from the study if you do not want to. Withdrawal from the study will not have any effect on the care you or your family will receive at any hospital. If you decide to leave the study, you can contact the Principal Investigator or a member of the study team to let them know.

If you decide to withdraw before your interview is analyzed, it can be completely deleted from the research. However, once your interview has been analyzed, it may not be possible to withdraw all the data from the study, but there will be no way that what you have said could be traced back to them or be recognizable in any way. If you choose to withdraw, none of your direct interview quotations will be used in any products of the research.

Will I be paid and/or reimbursed if I join this study?

In recognition of your participation, you will be given a certificate of participation and/or 1-2 volunteer hours.

Also, you will receive a $15 gift card as an honorarium for you time.

How will my privacy be protected?

We will respect your privacy. No information about you will be given to anyone or be published without your permission, unless the law requires us to do this.

If you decide to participate in this study, the research team (study investigators, coordinators, nurses, and delegates) will collect personal health information about you, including things learned from the study procedures. They will collect only the information they need for this study. “Personal health information” is health information about you that could identify you.

The research team will also collect some personal information about you (name, address, phone number, email) for the purposes of contacting you. This personal information will not be shared outside of the research team.

All information collected about you will be “de-identified” by replacing your identifiable information (i.e., name) with a “pseudonym” of your choice. Only the “study code key” can connect the information collected about you to your identity. The study code key will be safeguarded by the research team. Even though the risk of identifying you from the study data is very small, it can never be completely eliminated.

The following people may come to the hospital to look at your personal health information to check that the information collected for the study is correct and to make sure the study followed the required laws and guidelines:

- Representatives of the University of Victoria Research Ethics Board

The research team will keep any personal health information about you in a secure and confidential location for 3 years and then destroy it according to University of Victoria policy.

What if I am injured during/in this study?

If you suffer an injury from participation in this study, medical care will be provided to you in the same manner as you would ordinarily obtain any other medical treatment. In no way does signing this consent form waive your legal rights or release the study doctor(s), sponsors or involved institutions from their legal and professional responsibilities.

If you require treatment for any injuries or illness related to your participation in the study, you should contact the study doctor immediately.

How will I be informed about new information?

We may learn new information during the study that you may need to know. We may also learn about things that might make you want to stop participating in the study. If this happens, you will be notified about any new information in a timely manner. You may also be asked to sign a new consent form that describes these new findings if you decide to continue in the research study.

What are my rights when participating in a research study?

You have the right to receive all information that could help you make a decision about participating in this study. You also have the right to ask questions about this study at any time and to have them answered to your satisfaction. Your rights to privacy are legally protected by federal and provincial laws that require safeguards to ensure that your privacy is respected.

By signing this form you do not give up any of your legal rights against the study doctor, sponsor or involved institutions for compensation, nor does this form relieve the study doctor, sponsor or their agents of their legal and professional responsibilities.

You will be given a copy of this signed and dated consent form prior to participating in this study.

Will I receive study results?

Research results will be shared through a doctoral dissertation, journal publications, and academic conferences. When the results of this study are shared, your identity will not be disclosed. You have the right to be informed of the results of this study once the entire study is complete.

If you would like to be informed of the results of this study, an executive summary of the findings of the research will be prepared and emailed/mailed to you at the conclusion of the research, if you express interest in receiving it.

Who can I call if I have questions about the study?

If you have any questions during your participation in this research study you can contact the Principal Investigator, Angie Lim at XXX-XXX-XXXX or the research team members listed at the beginning of this consent form.

Research Ethics Board Contact Information

The study protocol and consent form have been reviewed by the University of Victoria Research Ethics Board (REB). If you have any questions regarding your rights as a research participant, you may contact the Office of the Research Ethics Board at ethics@uvic.ca or 250-472-4545 during business hours.

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Consent to Participate in a Research Study

Study Title: Adolescent Transplant Recipients Transition to Adult-Focused Care from Pediatric-Focused Care.

By signing this research consent form, I understand and confirm that:

1. All of my questions have been answered,
2. I understand the information within this informed consent form,
3. I do not give up any of my or my child's legal rights by signing this consent form,
4. I have been told I will be given a signed and dated copy of this consent form.
5. I agree to take part in this study.

I consent on behalf of ________________________ (name of child) to participate in this study.

Printed Name of Parent/Guardian	Parent/guardian signature & date (DD/MMM/YYYY)

Printed Name of person who obtained consent	Role of person obtaining consent	Signature & date (DD/MMM/YYYY)

Investigator Signature

Investigator Signature	Printed name	Date (DD/MMM/YY)

My signature above signifies that the study has been reviewed with the study participant by me and/or by my delegated staff. My signature may have been added at a later date, as I may not have been present at the time the participant's signature was obtained.

Name (print)	Signature	Date (DD/MMM/YY)

____

Role of person assisting in the consent process

Consent to Participate in a Research Study

(Parent/Guardian Participant Consent)

Study Title: Adolescent Transplant Recipients Transition to Adult-Focused Care from Pediatric-Focused Care.

Principal Investigator:

Angie Lim, RN, PhD (c), XXX-XXX-XXXX

Co-Investigator(s):

Lenora Marcellus, PhD, RN (PhD Supervisor), Lenora.marcellus@uvic.ca

Research Contact:

Angie Lim, RN, PhD (c), XXX-XXX-XXXX

Lenora Marcellus, RN, PhD, Department of Nursing, University of Victoria, Lenora.marcellus@uvic.ca

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Introduction

We would like to invite you to take part in our research study. This consent form describes the research study and what it means to participate. This consent form may have words that you do not understand. Please ask the study staff to explain anything that you do not understand. Please take as much time as you need to think about your decision to participate or not, and ask any questions you have. If it is helpful to you, you are encouraged to discuss the study with family, friends, your personal physician, other health professionals, or any members of your community that you trust. All participation is voluntary and you are not under any obligation to participate.

Why am I being asked to participate?

You are being invited to participate in this study because your child had an organ transplant and we are interested in how they manage the process of transition to adult care.

Why is this study being done?

This study is being done because to understand how adolescent kidney and/or liver transplant recipients prepare to move from pediatric to adult care. The results of this study will help the healthcare team better understand how we can support the transition process for other transplant recipients.

How many participants will be in this study?

Up to 30 children and 3 parents/guardians are expected to participate in this study.

What will happen if I join this study?

Your participation in this study will involve participating in an online virtual interview about your child's transition preparation following transplant. It will take about 1 hour of your time to participate. Sometimes a second follow-up virtual interview may be required – that would take 15-20 minutes.

You will be asked to participate in an interview asking about your child's transition and how they manage the post-transplant care in preparation for moving to adult health care. The interview will be audio recorded and the researcher will make additional notes about your answers. The audio recording will be transcribed using computer software after the interview and will be analyzed by the research team. The transcription will be done by members of the study team. Your name or any other identifying information will not be included during the recording, except your voice. The audio recording will be destroyed at the conclusion of the study.

What are the risks, harms or discomforts of the study?

There are no anticipated risks, harms, or discomforts from participating in the study. During the interview you may experience some anxiety, emotional and/or psychological distress due to the nature of the questions. You can skip questions, take a break or stop answering at any time.

If your responses indicate that there is a serious risk of harm to yourself or others, confidentiality will be broken in order to protect you or another person. If we feel that you need urgent care as result of participating in this research study we will intervene according to routine clinical care practices.

There is an inconvenience of time. The first online virtual interview will take about 1 hour and an additional 15-20 minutes if a second virtual interview is needed for a total of 60-80 minutes for the entire research study.

Despite protections being in place, there is a risk of unintentional release of information.

Are there benefits from being in the study?

There are no direct benefits to you for participating in this research study

We hope that the information learned from this study can be used in the future to benefit adolescent transplant recipients with their transition to adult care.

What are the optional part(s) to this research study?

Participation in a virtual follow-up interview, if needed, is optional.

We may decide to use parts of the transcription without your name and voice in presentations or publications in the format of quotations. You have the option to refuse. Please initial next to your preference:

Options	Initials
I **allow** the use of parts of my de-identified transcription in presentations and publications.	
I **do not** allow the use of parts of my de-identified transcription in presentations and publications.	

Can I choose to leave the study?

It is your choice to take part in this study, participation is voluntary. You can change your mind at any time during the research study. The study team may ask why you are withdrawing for reporting purposes, but you do not need to give a reason to withdraw from the study if you do not want to. Withdrawal from the study will not have any effect on the care you or your family will receive at any hospital. If you decide to leave the study, you can contact the Principal Investigator or a member of the study team to let them know.

If you decide to withdraw before your interview is analyzed, it can be completely deleted from the research. However, once your interview has been analyzed, it may not be possible to withdraw all the data from the study, but there will be no way that what you have said could be traced back to them or be recognizable in any way. If you choose to withdraw, none of your direct interview quotations will be used in any products of the research.

Will I be paid and/or reimbursed if I join this study?

In recognition of your participation, you will be given a certificate of participation.

Also, you will receive a $15 gift card as an honorarium for you time.

How will my privacy be protected?

We will respect your privacy. No information about you will be given to anyone or be published without your permission, unless the law requires us to do this.

If you decide to participate in this study, the research team (study investigators, coordinators, nurses, and delegates) will collect personal health information about you. They will collect only the information they need for this study. “Personal health information” is health information about you that could identify you.

The research team will also collect some personal information about you (name, address, phone number, email) for the purposes of contacting you. This personal information will not be shared outside of the research team.

All information collected about you will be “de-identified” by replacing your identifiable information (i.e., name) with a “pseudonym” of your choice. Only the “study code key” can connect the information collected about you to your identity. The study code key will be safeguarded by the research team. Even though the risk of identifying you from the study data is very small, it can never be completely eliminated.

The following people may come to the hospital to look at your personal health information to check that the information collected for the study is correct and to make sure the study followed the required laws and guidelines:

- Representatives of the University of Victoria Research Ethics Board

The research team will keep any personal health information about you in a secure and confidential location for 3 years and then destroy it according to University of Victoria policy.

What if I am injured during/in this study?

If you suffer an injury from participation in this study, medical care will be provided to you in the same manner as you would ordinarily obtain any other medical treatment. In no way does signing this consent form waive your legal rights or release the study doctor(s), sponsors or involved institutions from their legal and professional responsibilities.

If you require treatment for any injuries or illness related to your participation in the study, you should contact the study doctor immediately.

How will I be informed about new information?

We may learn new information during the study that you may need to know. We may also learn about things that might make you want to stop participating in the study. If this happens, you will be notified about any new information in a timely manner. You may also be asked to sign a new consent form that describes these new findings if you decide to continue in the research study.

What are my rights when participating in a research study?

You have the right to receive all information that could help you make a decision about participating in this study. You also have the right to ask questions about this study at any time and to have them answered to your satisfaction. Your rights to privacy are legally protected by federal and provincial laws that require safeguards to ensure that your privacy is respected.

By signing this form you do not give up any of your legal rights against the study doctor, sponsor or involved institutions for compensation, nor does this form relieve the study doctor, sponsor or their agents of their legal and professional responsibilities.

You will be given a copy of this signed and dated consent form prior to participating in this study.

Will I receive study results?

Research results will be shared through a doctoral dissertation, journal publications, and academic conferences. When the results of this study are shared, your identity will not be disclosed. You have the right to be informed of the results of this study once the entire study is complete.

If you would like to be informed of the results of this study, an executive summary of the findings of the research will be prepared and emailed/mailed to you at the conclusion of the research, if you express interest in receiving it.

Who can I call if I have questions about the study?

If you have any questions during your participation in this research study you can contact the Principal Investigator, Angie Lim at XXX-XXX-XXXX or the research team members listed at the beginning of this consent form.

Research Ethics Board Contact Information

The study protocol and consent form have been reviewed by the University of Victoria Research Ethics Board (REB). If you have any questions regarding your rights as a research participant, you may contact the Office of the Research Ethics Board at ethics@uvic.ca or 250-472-4545 during business hours.

Consent to Participate in a Research Study

Study Title: Adolescent Transplant Recipients Transition to Adult-Focused Care from Pediatric-Focused Care.

By signing this research consent form, I understand and confirm that:

1. All of my questions have been answered,
2. I understand the information within this informed consent form,
3. I do not give up any of my legal rights by signing this consent form,
4. I have been told I will be given a signed and dated copy of this consent form.
5. I agree to take part in this study.

I consent to participate in this study.

Printed Name of Participant	Participant signature & date (DD/MMM/YYYY)

Printed Name of person who obtained consent	Role of person obtaining consent	Signature & date (DD/MMM/YYYY)

Investigator Signature

Investigator Signature	Printed name	Date (DD/MMM/YY)

My signature above signifies that the study has been reviewed with the study participant by me and/or by my delegated staff. My signature may have been added at a later date, as I may not have been present at the time the participant's signature was obtained.

Consent to Participate in a Research Study

(Healthcare Provider Participant Consent)

Study Title: Adolescent Transplant Recipients Transition to Adult-Focused Care from Pediatric-Focused Care.

Principal Investigator:
Angie Lim, RN, PhD (c), XXX-XXX-XXXX

Co-Investigator(s):

Lenora Marcellus, PhD, RN (PhD Supervisor), Lenora.marcellus@uvic.ca

Research Contact:
Angie Lim, RN, PhD (c), XXX-XXX-XXXX
Lenora Marcellus, RN, PhD, Department of Nursing, University of Victoria,
Lenora.marcellus@uvic.ca

Introduction

We would like to invite you to take part in our research study. This consent form describes the research study and what it means to participate. Please ask the study staff to explain anything that you do not understand. Please take as much time as you need to think about your decision to participate or not and ask any questions you have. All participation is voluntary, and you are not under any obligation to participate.

Why am I being asked to participate?

You are being invited to participate in this study because your care for organ transplant recipients as part of your professional practice and we are interested in how they manage the process of transition to adult care.

Why is this study being done?

This study is being done because to understand how adolescent kidney and/or liver transplant recipients prepare to move from pediatric to adult care. The results of this study will help the healthcare team better understand how we can support the transition process for other transplant recipients.

How many participants will be in this study?

Up to 30 children and parents/caregivers and up to 5 health care providers are expected to participate in this study.

What will happen if I join this study?

Your participation in this study will involve participating in an online virtual interview about your care of children preparing to transition to adult care following transplant. It will take about 1 hour of your time to participate. Sometimes a second follow-up virtual interview may be required – that would take 15-20 minutes.

You will be asked to participate in an interview asking about your role in caring for adolescent transplant recipients and how they manage the post-transplant care in preparation for transition to adult health care. The interview will be audio recorded and the researcher will make additional notes about your answers. The audio recording will be transcribed using computer software after the interview and will be analyzed by the research team. The transcription will be done by members of the study team. Your name or any other identifying information will not be included during the recording, except your voice. The audio recording will be destroyed at the conclusion of the study.

What are the risks, harms or discomforts of the study?

There are no anticipated risks, harms, or discomforts from participating in the study. During the interview you may experience some anxiety, emotional and/or psychological distress due to the nature of the questions. You can skip questions, take a break or stop answering at any time.

If your responses indicate that there is a serious risk of harm to yourself or others, confidentiality will be broken in order to protect you or another person. If we feel that you need urgent care as result of participating in this research study we will intervene according to routine clinical care practices.

There is an inconvenience of time. The first online virtual interview will take about 1 hour and an additional 15-20 minutes if a second virtual interview is needed for a total of 60-80 minutes for the entire research study.

Despite protections being in place, there is a risk of unintentional release of information.

Are there benefits from being in the study?

There are no direct benefits to you for participating in this research study

We hope that the information learned from this study can be used in the future to benefit adolescent transplant recipients with their transition to adult care.

What are the optional part(s) to this research study?

Participation in a follow-up virtual interview, if needed, is optional.

We may decide to use parts of the transcription without your name and voice in presentations or publications in the format of quotations. You have the option to refuse. Please initial next to your preference:

Options	Initials
I **allow** the use of parts of my de-identified transcription in presentations and publications.	
I **do not** allow the use of parts of my de-identified transcription in presentations and publications.	

Can I choose to leave the study?

It is your choice to take part in this study, participation is voluntary. You can change your mind at any time during the research study. The study team may ask why you are withdrawing for reporting purposes, but you do not need to give a reason to withdraw from the study if you do not want to. Withdrawal from the study will not have any effect on the care you or your family will receive at any hospital. If you decide to leave the study, you can contact the Principal Investigator or a member of the study team to let them know.

If you decide to withdraw before your interview is analyzed, it can be completely deleted from the research. However, once your interview has been analyzed, it may not be possible to withdraw all the data from the study, but there will be no way that what you have said could be traced back to them or be recognizable in any way. If you choose to withdraw, none of your direct interview quotations will be used in any products of the research.

Will I be paid and/or reimbursed if I join this study?

In recognition of your participation, you will be given a certificate of participation.

Also, you will receive a $15 gift card as an honorarium for you time.

How will my privacy be protected?

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The research team will collect some personal information about you (name, address, phone number, email) for the purposes of contacting you. This personal information will not be shared outside of the research team.

All information collected about you will be “de-identified” by replacing your identifiable information (i.e., name) with a “pseudonym” of your choice. Only the “study code key” can connect the information collected about you to your identity. The study code key will be safeguarded by the research team. Even though the risk of identifying you from the study data is very small, it can never be completely eliminated.

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Research Ethics Board Contact Information

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Consent to Participate in a Research Study

Study Title: Adolescent Transplant Recipients Transition to Adult-Focused Care from Pediatric-Focused Care.

By signing this research consent form, I understand and confirm that:

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3. I do not give up any of my legal rights by signing this consent form,
4. I have been told I will be given a signed and dated copy of this consent form,
5. I agree to take part in this study.

I consent to participate in this study.

Printed Name of Participant	Participant signature & date (DD/MMM/YYYY)

Printed Name of person who obtained consent	Role of person obtaining consent	Signature & date (DD/MMM/YYYY)

Investigator Signature

Investigator Signature	Printed name	Date (DD/MMM/YY)

My signature above signifies that the study has been reviewed with the study participant by me and/or by my delegated staff. My signature may have been added at a later date, as I may not have been present at the time the participant's signature was obtained.

Appendix F: Interview Question Guide for Each Participant Group

This is the initial research guide to help guide interviews. As per Grounded Theory methodology, these questions will evolve as themes emerge from the data.

Research Question*: How do adolescent kidney and/or liver transplant recipients manage the transition from pediatric to adult care?*

Group A: Adolescent Participants:

- Age at time of interview: _____________
- Gender: ____________

Initial Open-ended questions:

- Can you tell me about your transplant and how you came to need one?
- Can you talk to me about your life since transplant?
  - Possible probes as required in each interview to collect a narrative story of their experience of transplantation and transition:
    - What happened next?
    - Has it changed? If so, in what way? If not, tell me more.
    - Have you ever talked or thought about the transition process into adult health care?
    - Can you tell me about how you are preparing for your transition to adult care?
    - What would you do to make the transition process easier? What changes would you like to see? What would have made the world a better place for you son/daughter?

Ending Questions:

- Is there anything else you want to tell me about that we haven't gotten to discuss yet?
- Are there any questions you have for me?

- If you think of anything else afterward that you forgot to mention, feel free to contact me using the email address we used to schedule this interview.

- I may reach out to you for a quick 15-20min follow-up if I think of anything else to ask you or have questions that I need to clarify

Group B: Parents/Caregivers:

Initial Background Data Questions:

- Tell me a little bit about [child's name]
    - Diagnoses
    - Age at time of interview
    - Gender

Initial Open-ended questions:

- How has your family adapted to [child's] diagnosis?
    - Possible probes as required in each interview to collect a narrative story of their experience of transplantation and transition:
        - Parental role? Responsibility distribution?
        - When did you first start talking about transition?
        - Do you think your child is happy with how the transition process is going/has gone?
        - (As a parent) how do you feel about this transition process?
        - What would you do to make the transition process easy? What changes would you like to see? What would have made the world a better place for you son/daughter?
- Is there anything else you want to tell me about that we haven't gotten to discuss yet?

Ending Questions:

- Is there anything else you want to tell me about that we haven't gotten to discuss yet?
- Are there any questions you have for me?

- If you think of anything else afterward that you forgot to mention, feel free to contact me using the email address we used to schedule this interview.

- I may reach out to you for a quick 15-20min follow-up if I think of anything else to ask you or have questions that I need to clarify

Group C: Healthcare Provider Participants:

- Role: ________________
- Years of Practice: ______________________________
- Percentage of time devoted to patient care: _____________________

Initial Open-ended questions:

- Describe your work with adolescent liver/renal transplant recipients?
    - Possible probes as required in each interview to collect a narrative story of their experience caring for adolescent transplant recipients and transition:
        - Do you have any concerns?
        - How would you describe the self-care of adolescent liver/renal transplant recipients that you work with?
        - What factors do you see as influencing the self-care and transition readiness of the adolescent liver/renal transplant recipients that you work with?
        - Describe how the idea transition influences your work with adolescent liver/renal transplant recipients

- Could you tell me about a time when a patient with an organ transplant had a very successful transition and transferred smoothly to adult care with you? Please refrain from using patient names when describing (Goal is quality of anecdotes over quantity)
    - Possible probes:
        - What outcomes made it clear that the process was successful?
        - What did you observe in particular about the patient that may have contributed to their success?
        - What did you observe about the patient's family that may have contributed to their success?
        - Were there any specific milestones the patient or family met? If so, what were they?
        - What facilitated them meeting those milestones or having a successful transfer to adult care?
        - What threatened their ability to meet those milestones or have a successful transfer to adult care?
        - As their provider, how did you play a role in their successful transition and transfer to adult care?

- Could you tell me about a time when a patient with an organ transplant who you were caring for had a transition that did not go smoothly, and perhaps resulted in an adverse medical outcome either prior to, or after transfer to adult care? (Quality over quantity)
  - Possible probes:
    - What did you observe about the patient that may have contributed to an unsuccessful transition and transfer?
    - What did you observe about the patient's family that may have contributed to an unsuccessful transition and transfer?
    - Were there any milestones that were missed that contributed to the failure to successfully transition and subsequent transfer? These milestones could be specific to the patient, family, or providers.
    - When and how did you suspect that the transition was on a trajectory toward being unsuccessful? For example, were there indicators made it clear that the transition was unsuccessful? What were they?

Ending Questions:

- Since you became a XX, what has changed over time in your work adolescent liver/renal transplant recipients?
  - What has contributed to these changes?
- Is there anything else that I should understand about what contributes to your work with adolescent liver/renal transplant recipients that we haven't already talked about?
- Are there any questions you have for me?
- What other experts should we interview about this topic? It's OK if they are from other institutions. (Ask for names and email addresses if they have them and whether it is ok to reference the interviewee who made the recommendation in the email invitation.)
- If you think of anything else afterward that you forgot to mention, feel free to contact me using the email address we used to schedule this interview.
- I may reach out to you for a quick 15-20min follow-up if I think of anything else to ask you or have questions that I need to clarify

Probes

- Can you elaborate on this?

- That's interesting, tell me more about…
- Can you think of an example?

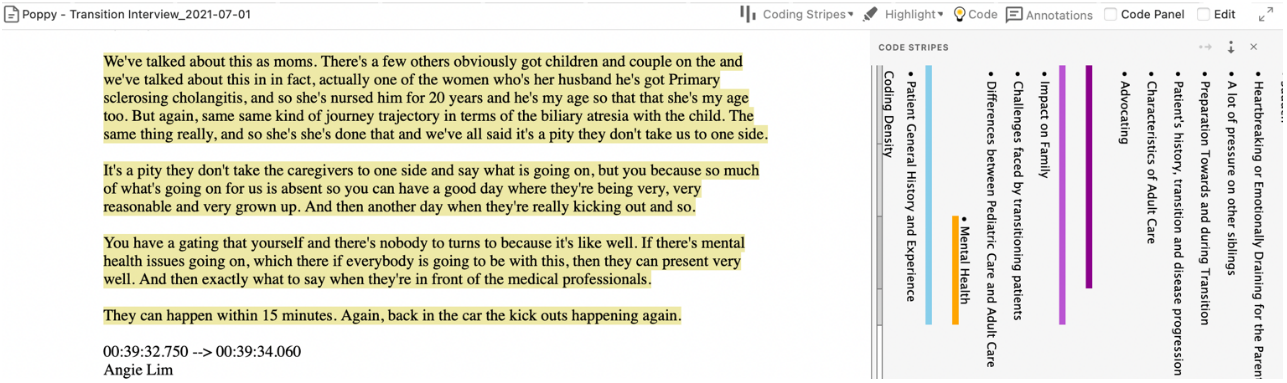
References:

Charmaz, K., (2014). *Constructing grounded theory* (2nd ed.). London; Thousand Oaks, Calif: Sage.

Schreiber, R.S. (2001). The "how to" of grounded theory: Avoiding the pitfalls. In R. S. Schreiber & P.N. Stern (Eds.), *Using grounded theory in nursing* (pp. 55-83). New York: Springer Pub. Co.

Franklin, M. S., Beyer, L. N., Broktin, S. M., Maslow, G. R., Pollock, M. D., & Docherty, S. L. (2019). Health care transition for adolescent and young adults with intellectual disability: Views from the parents. *Journal of Pediatric Nursing, 47,* p. 148-158.

Appendix G: Example of Line-By-Line Coding



We've talked about this as moms. There's a few others obviously got children and couple on the and we've talked about this in in fact, actually one of the women who's her husband he's got Primary sclerosing cholangitis, and so she's nursed him for 20 years and he's my age so that that she's my age too. But again, same same kind of journey trajectory in terms of the biliary atresia with the child. The same thing really, and so she's she's done that and we've all said it's a pity they don't take us to one side.

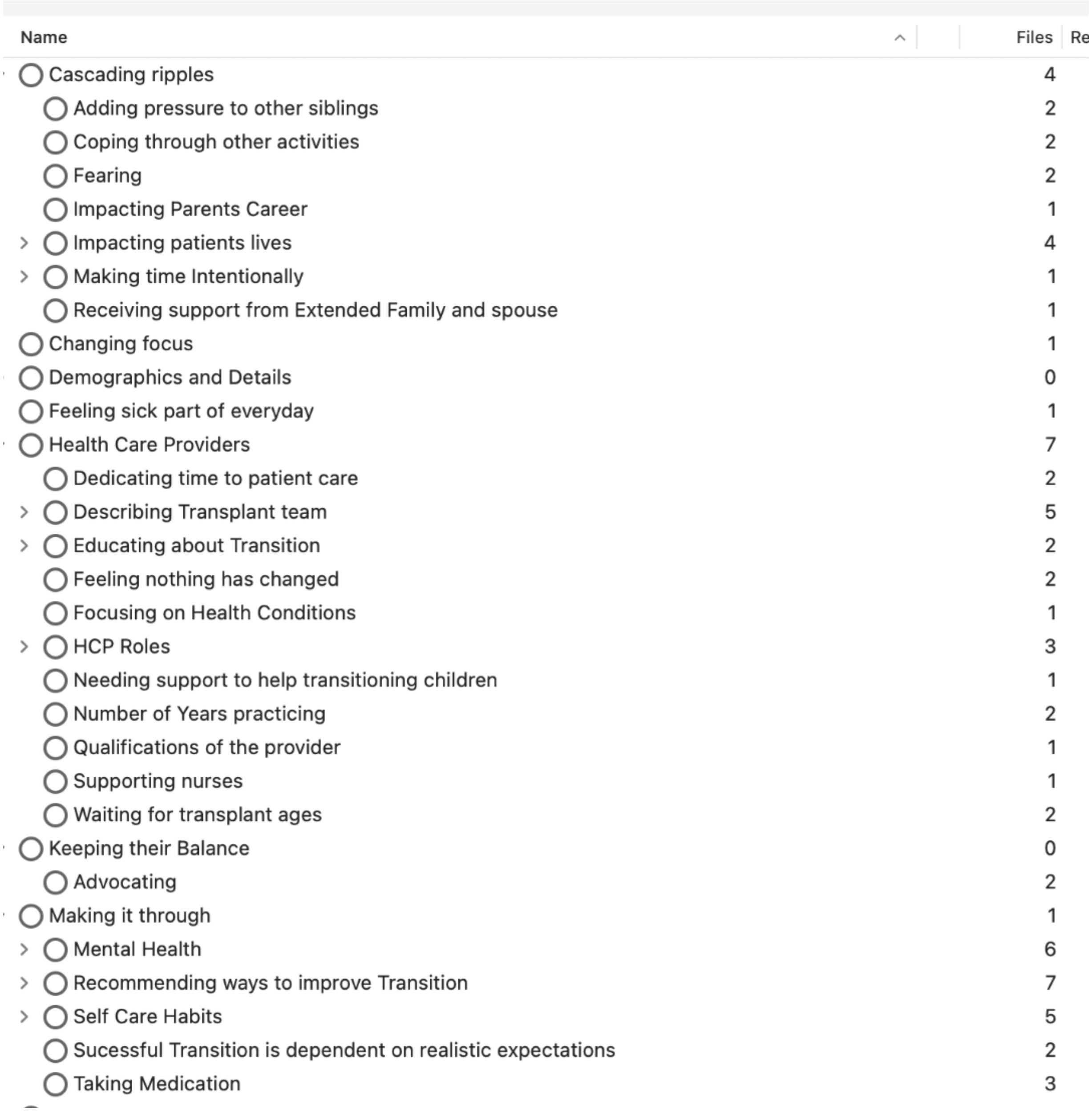
It's a pity they don't take the caregivers to one side and say what is going on, but you because so much of what's going on for us is absent so you can have a good day where they're being very, very reasonable and very grown up. And then another day when they're really kicking out and so.

You have a gating that yourself and there's nobody to turns to because it's like well. If there's mental health issues going on, which there if everybody is going to be with this, then they can present very well. And then exactly what to say when they're in front of the medical professionals.

They can happen within 15 minutes. Again, back in the car the kick outs happening again.

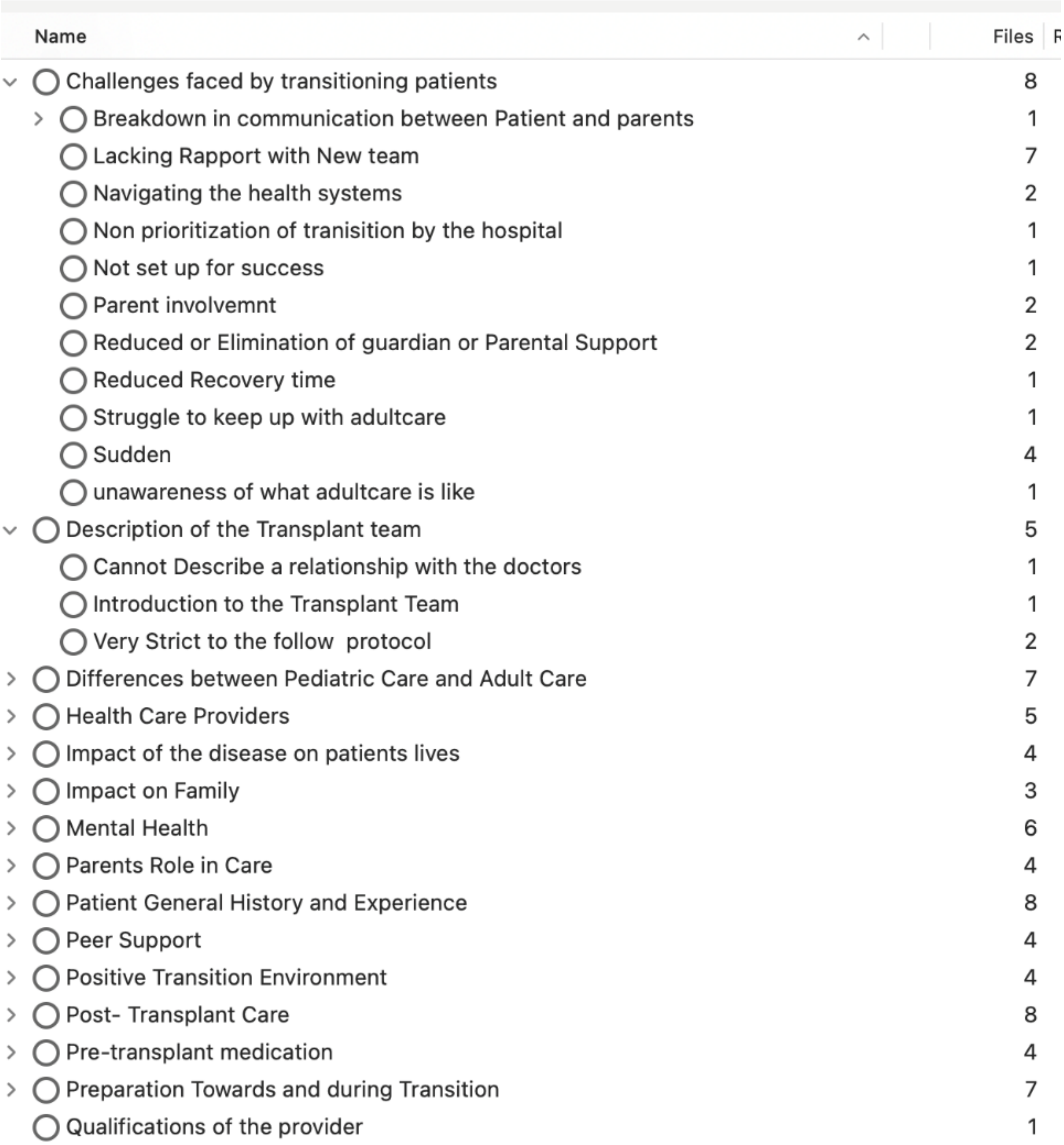
00:39:32.750 --> 00:39:34.060
Angie Lim

Appendix H: Example of Second-Level Coding



Name	Files	Re
○ Cascading ripples	4	
○ Adding pressure to other siblings	2	
○ Coping through other activities	2	
○ Fearing	2	
○ Impacting Parents Career	1	
> ○ Impacting patients lives	4	
> ○ Making time Intentionally	1	
○ Receiving support from Extended Family and spouse	1	
○ Changing focus	1	
○ Demographics and Details	0	
○ Feeling sick part of everyday	1	
○ Health Care Providers	7	
○ Dedicating time to patient care	2	
> ○ Describing Transplant team	5	
> ○ Educating about Transition	2	
○ Feeling nothing has changed	2	
○ Focusing on Health Conditions	1	
> ○ HCP Roles	3	
○ Needing support to help transitioning children	1	
○ Number of Years practicing	2	
○ Qualifications of the provider	1	
○ Supporting nurses	1	
○ Waiting for transplant ages	2	
○ Keeping their Balance	0	
○ Advocating	2	
○ Making it through	1	
> ○ Mental Health	6	
> ○ Recommending ways to improve Transition	7	
> ○ Self Care Habits	5	
○ Sucessful Transition is dependent on realistic expectations	2	
○ Taking Medication	3	

Appendix I: Example of Third-Level Coding



Name	Files
Challenges faced by transitioning patients	8
Breakdown in communication between Patient and parents	1
Lacking Rapport with New team	7
Navigating the health systems	2
Non prioritization of tranisition by the hospital	1
Not set up for success	1
Parent involvemnt	2
Reduced or Elimination of guardian or Parental Support	2
Reduced Recovery time	1
Struggle to keep up with adultcare	1
Sudden	4
unawareness of what adultcare is like	1
Description of the Transplant team	5
Cannot Describe a relationship with the doctors	1
Introduction to the Transplant Team	1
Very Strict to the follow protocol	2
Differences between Pediatric Care and Adult Care	7
Health Care Providers	5
Impact of the disease on patients lives	4
Impact on Family	3
Mental Health	6
Parents Role in Care	4
Patient General History and Experience	8
Peer Support	4
Positive Transition Environment	4
Post- Transplant Care	8
Pre-transplant medication	4
Preparation Towards and during Transition	7
Qualifications of the provider	1

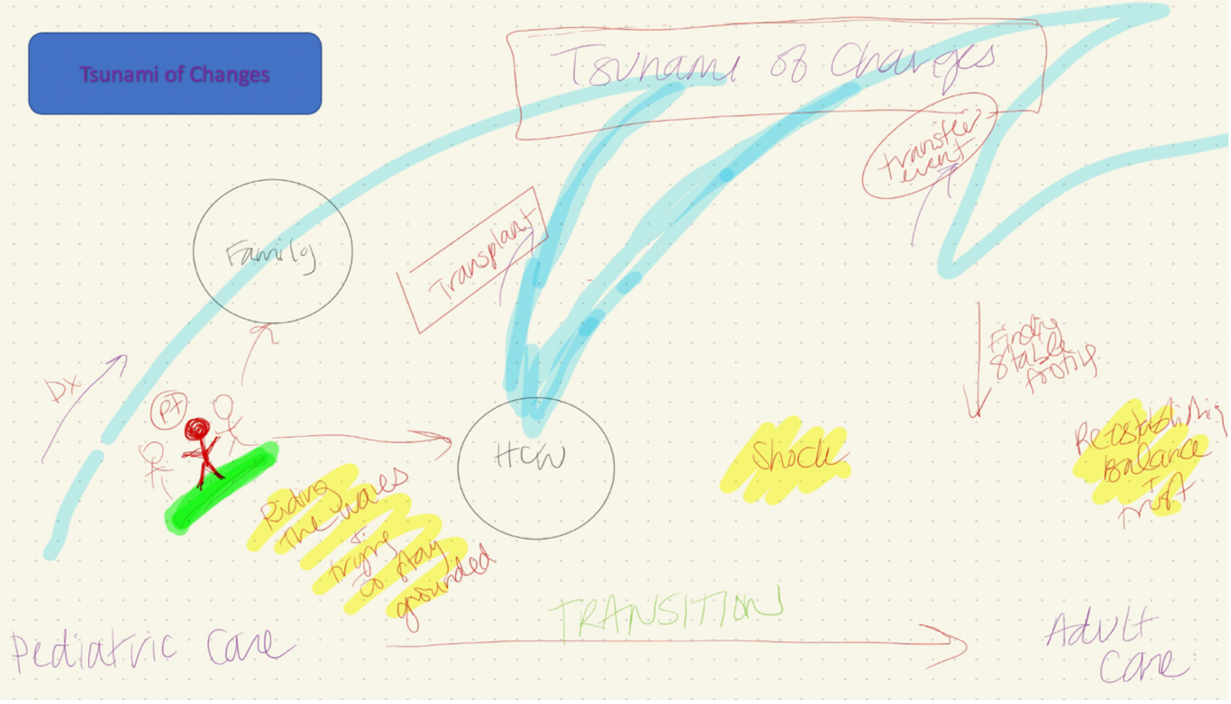
Appendix J: Example of Initial Theoretical Memo

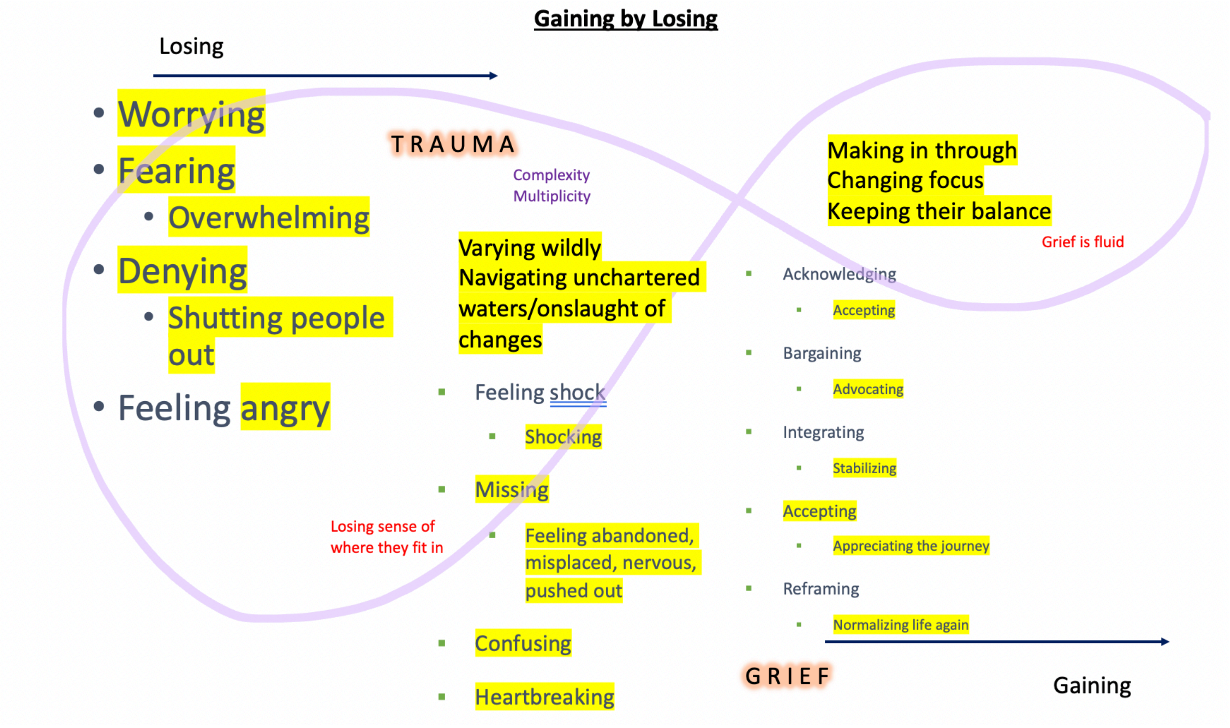
Oct 18 @2145
John – Pediatric Transplant Nurse

This interview of a transplant nurse was informative and reaffirming of my personal experiences. It was helpful to hear a nurse immersed in transplant care reflect on their experiences and challenges in supporting transition care at the inpatient level. I recognize my positionality as an insider and how my beliefs have framed my research question and approach to interview questions. Perhaps beneficial to this interview and remaining open to their experiences is that I have not been practicing on the transplant unit through the duration of the pandemic. This has helped provide some separation between myself, patients/families and my colleagues and I think helped the nurse feel comfortable sharing their current reality and experiences with me.

In preparing for my second HCW interview tomorrow I am giving thought to any areas that have not yet been addressed or discussed in previous interviews. It will be important to ensure that I ask for additional details if not provided, despite thinking I know the answers to have a participant articulate their experiences and thoughts.

Appendix K: Example of Diagram Memos





Gaining by Losing

Losing

- Worrying
- Fearing
  - Overwhelming
- Denying
  - Shutting people out
- Feeling angry

TRAUMA

Complexity
Multiplicity

Varying wildly
Navigating unchartered waters/onslaught of changes

- Feeling shock
  - Shocking
- Missing
  - Feeling abandoned, misplaced, nervous, pushed out
- Confusing
- Heartbreaking

Losing sense of where they fit in

Making in through
Changing focus
Keeping their balance

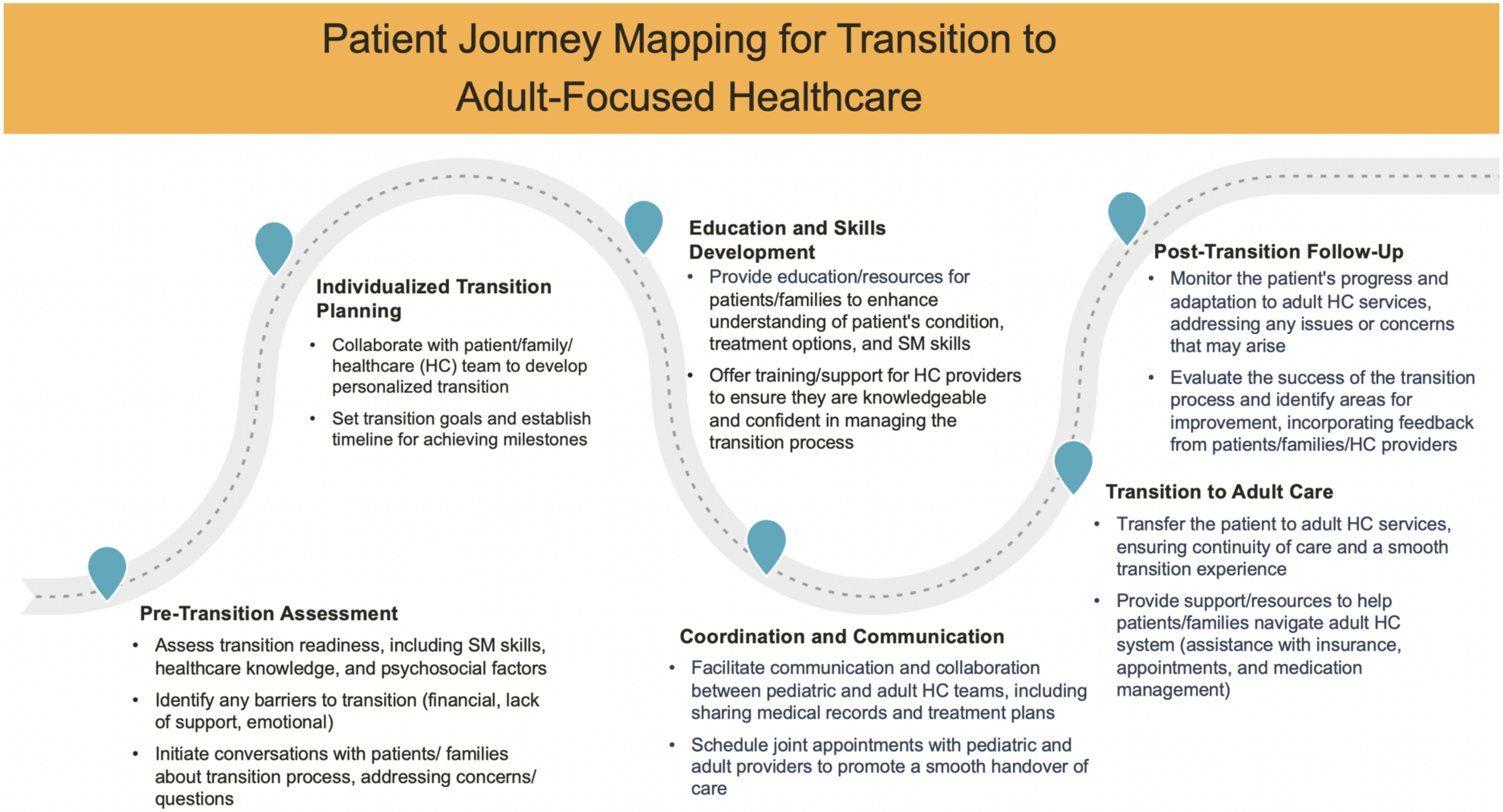
Grief is fluid

- Acknowledging
  - Accepting
- Bargaining
  - Advocating
- Integrating
  - Stabilizing
- Accepting
  - Appreciating the journey
- Reframing
  - Normalizing life again

GRIEF

Gaining

Appendix L: Patient Journey Map for Transition to Adult-Focused Healthcare



Patient Journey Mapping for Transition to Adult-Focused Healthcare

Pre-Transition Assessment

- Assess transition readiness, including SM skills, healthcare knowledge, and psychosocial factors
- Identify any barriers to transition (financial, lack of support, emotional)
- Initiate conversations with patients/ families about transition process, addressing concerns/ questions

Individualized Transition Planning

- Collaborate with patient/family/ healthcare (HC) team to develop personalized transition
- Set transition goals and establish timeline for achieving milestones

Education and Skills Development

- Provide education/resources for patients/families to enhance understanding of patient's condition, treatment options, and SM skills
- Offer training/support for HC providers to ensure they are knowledgeable and confident in managing the transition process

Coordination and Communication

- Facilitate communication and collaboration between pediatric and adult HC teams, including sharing medical records and treatment plans
- Schedule joint appointments with pediatric and adult providers to promote a smooth handover of care

Transition to Adult Care

- Transfer the patient to adult HC services, ensuring continuity of care and a smooth transition experience
- Provide support/resources to help patients/families navigate adult HC system (assistance with insurance, appointments, and medication management)

Post-Transition Follow-Up

- Monitor the patient's progress and adaptation to adult HC services, addressing any issues or concerns that may arise
- Evaluate the success of the transition process and identify areas for improvement, incorporating feedback from patients/families/HC providers