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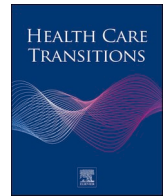
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# Riding the wave: A grounded theory of transplant transition in adolescents and youth adults

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## ABSTRACT

**Objectives:** The health care transition from pediatric to adult-focused health care for adolescent and young adult (AYA) organ transplant recipients is a critical yet understudied period. Unique challenges include supporting adherence to immunosuppressive regimens and addressing psychosocial factors that impact long-term graft survival and recipient well-being. The objective of this study was to understand how AYAs prepared for and engaged in the transition process.

**Methods:** Constructivist grounded theory, underpinned by symbolic interactionism, was employed to systematically gather, synthesize, analyze, and conceptualize qualitative data from in-depth interviews with 14 transplant recipients, their families, and pediatric nurses, and related online social media stories.

**Results:** The overall process participants experienced was that of *riding the wave of change: transforming through transition*, which they did through navigating four phases: (1) anticipating the impending transition, (2) losing security when transitioning to uncertainty, (3) seeking supportive anchors in the swell of transition, and (4) gaining a new sense of self.

**Conclusions:** AYA transplant recipients undergo numerous changes as they enter adulthood and adult-focused health care. There are many opportunities for pediatric and adult health care providers to collaborate to strengthen support for AYA recipients and their families during this critical period. Developmental and trauma-informed approaches are recommended to support successful transition.

## 1. Introduction

Solid-organ transplantation is an established therapeutic approach for end-stage, organ-specific diseases and prevails as a leading treatment for children and youth with organ failure.<sup>1,2</sup> However, because transplantation is a chronic condition requiring ongoing monitoring, solid organ transplantation is considered a treatment modality, not a cure. Since the introduction of transplantation, the number of solid organ transplants performed worldwide has continued to increase.<sup>1,2</sup> In Canada, 1482 pediatric solid organ transplants were performed between 2018 and 2021.<sup>3-6</sup>

With continued advances in both the surgical and medical management of transplantation, health outcomes for pediatric transplant recipients have improved significantly.<sup>7</sup> For example, the five-year survival rates for liver and renal transplant recipients are estimated at around 90–96%.<sup>7,8</sup> In Canada, pediatric-focused health care systems provide transplantation care to recipients up to 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 continue to experience adverse outcomes during the transition period from pediatric to adult health care, with the most common and impactful effects being frequent emergency room visits, increased hospital admissions, graft failure, and death.<sup>9-11</sup>

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, critiqued as paternalistic due to the assumed requirement of following medical treatment orders,<sup>12</sup> presents a paradoxical challenge for transplant recipients in which capacities for autonomy, independence, and self-management are critical for health maintenance. However, adherence remains critical for transplant recipients' survival. Non-adherent behaviours in transplant recipients may

*Abbreviations:* AYA, adolescent and young adult; HCP, health care provider; HCT, health care transition.

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include not taking medications as prescribed or missing follow-up medical appointments, thereby placing them at risk of rejection or graft loss.<sup>8-10</sup> Non-adherent behaviours are common among AYA transplant recipients, with rates almost four times higher in the pediatric transplant population when compared to adults.<sup>13</sup>

Consequently, graft loss and mortality rates are highest in adolescent transplant recipients compared to all other pediatric transplant recipients and are considerably worse around the time of transition to adult care.<sup>8-10</sup> Given the propensity for non-adherent adolescent transplant recipients to require frequent hospital admissions for rejection treatment, many researchers have historically focused on the physiological responses to transplant and non-adherence to post-transplant regimens rather than on this group's psychosocial and developmental needs. There has been limited emphasis on the associated psychosocial impact of transplantation. Research has 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.<sup>2,8,14</sup>

This transition period signifies a critical period for AYA's developmental trajectories that may have significant and enduring implications, especially for those AYAs with chronic medical conditions.<sup>8,15</sup> Although there have been significant advancements in pediatric transplantation, the health care transition (HCT) research to support this population has progressed more slowly. There is also limited research focusing 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.<sup>16</sup> These gaps are 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.

Given the limited understanding of how a health care team can best support AYAs with the psychosocial impact of transplantation and transition, we explored how AYA transplant recipients managed the transition process from pediatric to adult-focused care. Our overarching research question was: *How do adolescent and young adult kidney and liver transplant recipients manage the transition from pediatric to adult health care?* The primary objective of this study was to determine how AYAs prepared for and engaged in the transition process. A secondary aim was to identify how nurses and health care providers (HCPs) supported the psychosocial adaptation of AYA transplant recipients through their transition.

## 2. Methods

### 2.1. Design

We employed constructivist grounded theory (CGT) to examine how AYA transplant recipients' managed their transition and how the multifaceted relationship between AYA transplant recipients, the health care environment, and the HCPs role shaped the transition experience.<sup>17</sup> This qualitative approach allowed for development of a theory explaining the process of how AYA transplant recipients viewed their world, created meaning from their diverse life experiences, and managed transition.

#### 2.1.1. Theoretical underpinnings

The principles underpinning our theoretical positioning included views that there is no single objective reality, but that human perspectives, shared interactions, and attributed meanings construct our reality. We locate ourselves within a constructivist epistemology, wherein researchers aim to understand the complex world of lived experiences from the perspective of those who live it. Constructivism resonates with our clinical backgrounds in pediatric nursing and family-centred care, with our practice centred on striving to understand the experiences of patients and their families. Thus, we were active participants in the

research process rather than objective witnesses not involved in the data or emerging theory.

The philosophical lens of symbolic interactionism informed this CGT study, emphasizing the subjectivity inherent in the co-created relationship between researcher and participant, with meaning-making and knowledge rooted in cultural, historical, and social contexts.<sup>17-21</sup> Moreover, symbolic interactionism provided a mechanism to address how individuals crafted personal realities to interpret their experiences and attach meaning to events through intricate and ongoing social interactions.<sup>17-20</sup> This approach also provided the means to recognize how our personal values and experiences influenced the research process and the emergent theory. For example, the first author (AL) brought significant experience from her practice as a Registered Nurse in an acute care hospital setting focused on the care of AYAs with solid organ transplants. The process of reflexivity was central to the research and instrumental in examining and acknowledging the influence of researcher positioning, power dynamics, and structural elements. Beyond our nursing perspective, our personal identities, beliefs, and lived experiences also played a role in the research process. Having a lived experience of a younger sibling who underwent a devastating transition has not only prompted further study in this domain, but also providing unique personal perspectives that informed the research and theory development. Consistent shared reflection, along with CGT approaches including constant comparison and memoing, ensured that the interpretations and findings remained grounded in the participants' narratives. This commitment to reflexivity was essential in maintaining the integrity and authenticity of the findings.

#### 2.1.2. Ethics

Ethical approval was granted by the University of Victoria Human Research Ethics Board (19-0474-01). We recruited participants via social media platforms and online distribution of study posters. To ensure informed consent, interested potential participants were provided with an introductory study letter and study overview, and an opportunity was provided to ask questions before consent was obtained.

#### 2.1.3. Setting

In response to the COVID-19 pandemic, the Canadian government declared a state of emergency in March 2020. As a result, jurisdictions across Canada experienced multiple lockdowns restricting individual movement and in-person activities, meaning that most research activities were paused, discontinued, or redesigned to limit face-to-face activities.<sup>22</sup> This study, originally designed to be conducted face-to-face within one community, was redesigned to be conducted virtually, expanding the research setting to include health systems across Canada, with participants from two Canadian provinces, Ontario and British Columbia. Additionally, online blogs and stories were integrated as data sources, allowing the experiences of recipients from centres within the United States to be integrated.

#### 2.1.4. Sampling

Three groups of participants were recruited for this study: kidney and/or liver transplant recipients between the ages of 12 and 28 who had been transplanted in a pediatric care centre a minimum of six months from the time of study participation to capture a wide array of experiences along the transition continuum (Group A), family caregivers (FCs) of pediatric transplant recipients aged 12-28 (Group B), and all HCPs from the interprofessional team who identified as having experience caring for transplant recipients aged 12-28 for at least six months (Group C). Participant demographics are summarized in [Table 1](#).

Sampling began with an initial purposive approach, followed by theoretical sampling which continued throughout the process of theory development.<sup>17,23</sup> Theoretical sampling was used to expand on emerging categories to develop a rich theory that accounted for variation across participants' experiences.<sup>17,23</sup> We aimed to recruit AYAs (Group A) as young as 12; however, the youngest participant was 18

**Table 1**  
Socio-Demographic Characteristics of Participants.

Participant's Characteristic Pseudonyms	Sex	Age at Interview/ Story	Age at Time of Transplant in Years	Type of Transplant
<b>Group A: Adolescent and Young Adult Transplant Recipients</b>				
Jane	Female	28	11, 17	Liver
Leila	Female	24	4 months, 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	28	16	Kidney
Online Story	Female	20	8	Kidney
Online Story (USA)	Female	20	12	Liver
Online Story (USA)	Female	20	12	Kidney
Online Story (USA)	Female	23	17	Kidney
Online Story (USA)	Male	28	7	Kidney
Online Story (USA)	Male	19	10	Liver
Online News Article	Male	18	3	Kidney
<b>Group B: Family Caregiver</b>				
Poppy	Female (mother)		13	Child's Transplant Liver
Donna	Female (mother)		12	Liver
Bryon	Male (father)		17	Liver
Online Blog (USA)	Female (mother)	17	7	Kidney
<b>Group C: Pediatric Health Care Professionals</b>				
			<b>Years of Experience</b>	<b>Education</b>
Kelly	Female	34	8	BScN
Ariya	Female	43	16	BScN, MN
John	Male	38	18	BScN, MN (in progress)

years old at the time of the interview (Table 1). Eight interview participants in Group A, 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 kidney or liver transplant recipients as participants. Three participants in Group B (family caregivers of transplant recipients), including one cis-male and two cis-females, and one digital online blog for a total of four participants. Group C, transplant healthcare professionals, included three participants comprised of one cis-male and two cis-females with a range of experience as baccalaureate-prepared pediatric nurses, two were master's prepared and a third was in a master's program. Although intending to recruit HCPs across disciplines at pediatric and adult care centres, the participants were registered nurses practicing at one pediatric centre.

## 2.2. Data collection

Data were collected in multiple ways, including interviews, online chats, and documents. Within the GT methodology, anything that surrounds what is being told and potentially helps researchers generate concepts is considered data, with the emerging conceptualization and theory guiding further data collection.<sup>23</sup>

### 2.2.1. Interviews

Participants were invited to participate in individual semi-structured interviews via video-conferencing platforms. The initial interview guide (Appendix A) was modified over time based on codes and categories emerging during the analysis, with questions constructed as open-ended

and supported with additional probing questions that reflected the data collected and emerging themes.<sup>17</sup> Virtual interviews were audio and video recorded and transcribed verbatim by one researcher (AL). Reflexive field notes were made following each interview to capture the interview setting, tone, and any other reflections that arose. NVivo® Version 12 qualitative data analysis software was used to manage the transcripts.

### 2.2.2. Online chats

Three participants expressed interest in the study but had challenges attending a virtual interview time. These participants continued to engage, ask questions, and provide information through the online chat function of social media platforms Facebook and Instagram.<sup>24–26</sup> Rather than verbal exchange, the interaction occurred through typed text, where we communicated asynchronously with participants by sharing questions, prompts, responses, and comments. The comfort of these participants with the chat mode of interviewing may reflect the generational preferences of Group A participants who have frequent opportunities to express their thoughts and feelings through text communication means and social media presence.<sup>24</sup> Reflexive field notes were also made throughout ongoing chats.

### 2.2.3. Documents

Specific documents included data such as clinical guidelines, organizational policies, program descriptions, and clinical team bulletins from one leading Canadian pediatric health centre with a specialty focus on organ transplantation, and from relevant professional associations. Additional sources of data included publicly posted online stories, blogs, and media articles detailing experiences of transition, as detailed in Table 1.<sup>27–34</sup>

## 2.3. Data analysis

All forms of data, including interview and chat transcripts and documents, were initially read and re-read for an overview of the data. Data collection and analysis occurred concurrently using the process of constant comparison. This process allowed for the development of emerging codes and preliminary categories early in the research process. Coding began with line-by-line or first-level coding using the participant's own words.<sup>17,35</sup> To ensure the codes represented participant experiences, gerunds or action words were used where possible.<sup>17,35</sup> Analysis was 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.<sup>17,35</sup> In third-level coding, the relationships between categories were elucidated through the evolution of theoretical codes, hypothesizing how the substantive codes related to each other and then integrating them into a theory.<sup>35</sup> A core category was identified and a grounded theory was developed to explain the relationships and differences between categories and concepts.

The use of memoing and diagramming throughout the analytic process helped create an audit trail, supported development of theoretical sensitivity, and addressed rigour.<sup>17,35,36</sup> Memoing also supported our process of reflexivity throughout the data analysis process, through the documentation of ideas, thoughts, assumptions, and beliefs about the substantive area and comparing these to the findings to see if they were supported.<sup>37</sup>

## 3. Results

Participants shared different experiences of transitions, but overall, the process of transition was identified as significant for the AYA recipients, their families and FCs, highlighting the basic social problem of transitioning to adult-focused care. This problem was resolved or managed by the basic social process of *transforming through transition*, represented by the analogy of riding a wave that evolved from the

participant’s reflections of the experience (Fig. 1). AYAs depended on family, peers, and HCPs to help them learn how to *anticipate the impending transition* from pediatric to adult care following a solid organ transplant. As AYAs moved through the same process of transition to adulthood as their peer counterparts without medical complexities, they developed a sense of *losing security when transitioning to uncertainty* as they left behind safe systems of support they had known through a substantial portion of their lives. Pediatric nurses often felt unsure of how to best support these simultaneous developmental and health transitions, creating a divide between pediatric and adult care centres. Likewise, FCs and HCPs struggled with finding the right balance of support for each AYA in letting go while promoting independence. AYAs *sought supportive anchors in this swell of transition*, finding 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, *gaining a new sense of self* through this process.

Although this process is described and depicted linearly, in reality, participants moved through waves of change in many directions. 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 health care team. At the same time, FCs often helped recipients make sense of the transition and move toward transformation during the shift to adult care. Each theme is explored in more depth, accompanied by chosen quotes from participants for clarification. More quotes related to each theme are available in [Appendix B](#).

### 3.1. Anticipating the impending transition

Participants shared many feelings about the impending transition to

adult care and the impact these feelings had on the movement toward transformation. Beneath the surface, many emotions underpinned the anticipating phase, including *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, there were ranging views and emotions while anticipating transition. Despite the expressed turmoil, it was a necessary preliminary step toward transformation.

#### 3.1.1. Feeling distressed about the transition

Participants characterized their transition from pediatric care predominantly by negative and distressing emotions, such as worry, fear, and uncertainty. Although Leila was glad to have some of the same doctors, she expressed substantial emotional concerns about the transition:

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)

Many AYAs struggled to articulate the precise nature of their emotions, suggesting a potential gap in their emotional vocabulary or introspective capacities. For some recipients, the prospect of assuming substantial self-care responsibilities once their FCs’ involvement diminished proved to be a daunting challenge. Josh described how overwhelmed he felt at the thought of taking on this health care work:

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

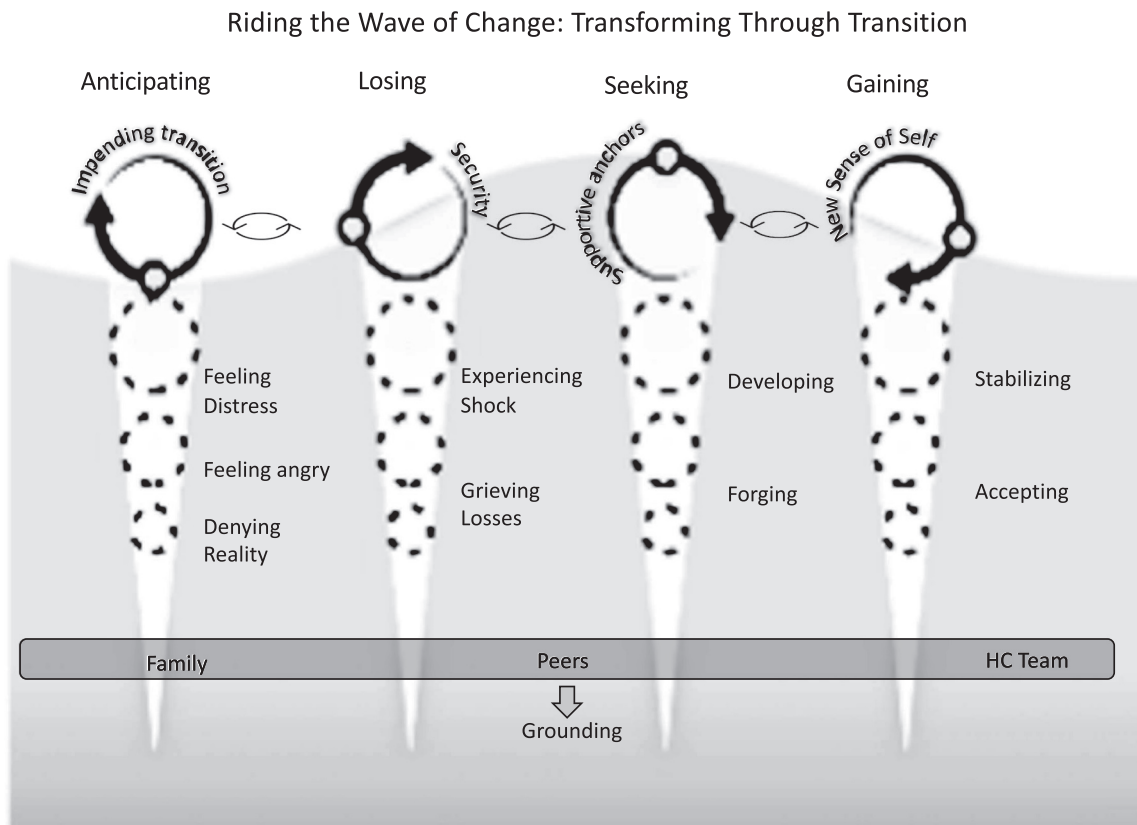


Fig. 1. Emergent Grounded Theory.

screwing it up, you know like about my kidney and what happens if I screw up. (Josh, recipient)

Josh described the weight of responsibility he was starting to personally feel for not exacerbating his health challenges. This experience was of particular significance when examined through the lens of developmental psychology and developmental stages. As AYAs strived to achieve autonomy and independence, they encountered myriad emotional, cognitive, and social challenges inherent to adolescence and young adulthood. This disruption heightened feelings of distress, uncertainty, and vulnerability, as AYAs experienced a lack of continuity in care and thus diminished trust in their adult care providers.

### 3.1.2. *Feeling angry about being made to feel insignificant*

Recipients frequently reported experiencing feelings of anger, which stemmed from a perceived sense of insignificance and isolation within the adult care system. This felt lack of attention and genuine care contributed to increased resistance to engaging with the adult care system, with some recipients ultimately disengaging from the health care process altogether, as shared by Nancy:

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)

Feeling insignificant provided a reason for them to resist treatment and potentially drop out of the system:

I used to have to go by bus two to three hours each way to be there for five minutes, 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 health care system was a sentiment echoed by many recipients who felt that the adult care team disregarded their concerns and needs. This lack of attention was especially significant for AYAs, who typically place considerable importance on building relationships with HCPs. Consequently, when these connections were absent or weakened, they experienced heightened distress.

### 3.1.3. *Denying reality*

Many recipients were reluctant to embrace the transition process and the associated responsibilities. 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:

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 in environment and care approaches between pediatric and adult health care were broadly shared between participants in all groups. For instance, Nancy, Leila, and Jane depicted adult care as brief and devoid of the numerous supplementary supports they had grown accustomed to, 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). In these instances, the support provided to participants that did not encourage independence or self-management inadvertently left them feeling ill-equipped for the transition, thus impeding their autonomy.

## 3.2. *Losing security when transitioning to uncertainty*

The second category of *losing security when transitioning to uncertainty* explored recipients' figurative and literal sense of losing feelings of safety when transitioning to an uncertain place during their HCT. This category represents 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: *experiencing shock* and *grieving the loss of relationships*.

### 3.2.1. *Experiencing shock*

The transition from pediatric care to adult health care frequently proved to be a challenging experience, regardless of the extent of their prior preparation. This perception of an abrupt shift and the subsequent 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 was cognizant of the impending transition due to her age:

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)

Even though aware of the pending HCT, many recipients felt unprepared for the change, resulting in shock at the time of transition. Similarly, Jane, a recipient, 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." As a result, they believed they were either minimally prepared or wholly unprepared to enter adult health care, where independence was crucial. Without clear communication or guidance, participants felt overwhelmed and uncertain about the changes that awaited them in the adult health care system. FCs also recognized that the transition to adult care meant reduced access to their child's medical records and involvement in 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 capacity.

### 3.2.2. *Grieving the loss of relationships*

Recipients and FCs expressing feelings of grief and sadness over the termination of relationships with their pediatric HCPs. The sudden absence of familiar and trusted health care teams was a considerable challenge for individuals moving from pediatric to adult care. 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 health care team as an extension of his family:

Ah. I don't know how I prepared exactly. 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. 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 and many other participants shared, the relationships between pediatric patients, FCs, and their care team were unique due to their development over time and the genuine care and connection they

embodied. Brendan (recipient) stated “My experience at [ADULT HOSPITAL] 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”.<sup>29,38</sup>

Such relationships were grounded in trust and familiarity, with recipients and their families depending on their HCPs for support and guidance throughout their medical journey, often starting in infancy. On the other hand, transitioning to adult care often appeared to be less personal, presenting fewer opportunities for patients to build a similar degree of trust and rapport with their new HCPs. This sentiment was echoed by participants who noted that frequent changes of physicians in adult care made it difficult to form the kind of enduring relationships they were accustomed to in pediatric care. As a result, AYAs faced a twofold emotional challenge: they not only had to cope with the loss of long-standing relationships from their pediatric years, but they also needed to navigate through the impersonal and transitory nature of relationships in adult health care.

### 3.3. Seeking supportive anchors in the swell of transition

Recipients navigated many challenges and changes throughout the transition process. They were required to *develop self-management* strategies to help them take control of their health care and adapt to new environments and routines and *forge new relationships* to help them feel more secure and anchored during the transition process.

#### 3.3.1. Developing self-management skills

During the HCT process, AYAs were faced with the task of taking on greater responsibility for their own health care needs, as described by Leila:

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)

This required developing self-management skills, such as advocating for themselves, making informed decisions about their care, and relinquishing FC guidance. By doing so, AYAs gained a sense of control and agency over their health care journey, which was important as they navigated a time of change and uncertainty in their lives. Nonetheless, readiness to assume this responsibility varied among the AYAs, with some being more adept than others at self-advocacy during the transition period. Specifically, recipients who had early exposure and assistance in cultivating self-care and advocacy skills during their pre-teen years demonstrated greater ability to manage their health care needs.

Family caregivers were a critical factor in empowering recipients to feel more in control of their health. When FCs 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 as they enabled recipients to navigate their care more independently and effectively. However, there were instances where the opposite was seen, and self-advocacy was hindered by FCs who would not allow the recipient to assume responsibility for their care. Kelly, a Registered Nurse, shared how she identified the need to coach FCs through this process:

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)

Nurse participants emphasized the importance of identifying potential barriers to patients’ autonomy and empowerment in managing their health. In instances where recipients had overreliance on their families, nurses advocated for FC education and fostering patient autonomy as key strategies to bolster the patient’s confidence and sense of empowerment in navigating their health care journey.

#### 3.3.2. Forging new relationships

The development of new relationships became critical to establishing a connection with the adult care team. When AYAs did not feel heard or understood by their HCPs, they were less likely to express their needs and preferences. This led to a cycle of frustration and disengagement that could ultimately result in suboptimal health outcomes such as organ rejection. Conversely, recipients who had FC support and were encouraged to engage in self-care before the transition appreciated the autonomy they had gained and eagerly began forging new relationships. Jane shared the feeling of appreciation for the gains and development she experienced:

I guess like just uncertainty thinking about how I would build trust with the new team if they know if they, like, 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. So yeah, I think that was basically what I was thinking. (Jane, recipient)

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). Family caregivers were instrumental in the process of establishing trust and relationships by contributing to the development of strong relationships between pediatric and adult health care teams to ensure that their child’s care was coordinated, and they received the support they needed to transition successfully. For HCPs, their role in supporting the bridge between pediatric and adult health care 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 health care 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 FCs and HCPs.

### 3.4. Gaining a new sense of self

AYAs underwent profound personal growth and development during their HCT, primarily through two processes: *stabilizing through normalizing* and *accepting a new reality*. Most recipients led fulfilling lives despite the potential debilitation from chronic conditions necessitating organ transplantation. The accomplishment of this feat was attributable to their efforts to normalize their health care journey, ultimately leading to the emergence of a transformed self. 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 health care. 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.

### 3.4.1. Stabilizing through normalizing

Recipients experienced a stabilizing effect in their HCT as they began normalizing their routines within the new environment. This entailed acclimating to the new health care team and adjusting to a different care system. Generally, participants required some time to become familiar with these changes, which ultimately led to a feeling of stability and reassurance. According to Donna, who juxtaposed the two periods in care (pediatric and adult), her child 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)

Both FCs and the health care team played vital roles in supporting transition and patient transplant success. AYAs received FC guidance to become autonomous and stabilizing in their care, with their FCs simultaneously letting go of control and coaching them toward self-management. As they adapted to their new routines in adult care, participants shared strategies to help manage their health care, 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.

A crucial stabilization component was the capacity to accomplish health care milestones, such as proficiently managing medications, attending appointments, and adhering to care plans. Riley described how she took on these responsibilities:

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)

For many AYAs, these milestones held particular significance, as they were occasionally the first of their age to survive into adulthood with their condition. Although this presented challenges in finding relatable peers, it also rendered the 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 health care management. This encompassed seeking access to care without reliance on their FCs 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.

### 3.4.2. Accepting a new reality

The transition from pediatric to adult health 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 AYA's identity and sense of self as they moved

from a dependent role in pediatric care to assuming greater responsibility for their health in adult care. At the heart of accepting a new reality was recognizing the transition itself and the responsibilities with which it came. Participants 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, thereby developing a greater sense of autonomy and control over their lives. This contributed to improved self-efficacy, greater engagement in self-care behaviours, and acceptance of their new reality. This involved assuming responsibility for medication management, self-care practices, and decision-making related to their health.

Thus, recipients emphasized the importance of realizing that after a transplant, it was ultimately the individual's responsibility to manage their health.

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 health care 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 health care...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 health condition highlighted how her illness identity<sup>39,40</sup> and chronic health condition became integrated into her sense of self, including not only viewing the disease and treatment but also how much the disease affected the way she thought about herself. Leila's experience demonstrates 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. In the context of this study and the transformation through transition, AYA's identities encompassed how the transplant was a core aspect of self-identity, thereby shaping behaviours, emotions, and relationships as they moved towards accepting their new reality.

## 4. Discussion

The 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. Intentional HCT planning and support for AYAs with chronic health conditions was crucial to ensure that patients received adequate care as they navigated the shift from pediatric to adult health care systems. The recipients managed many undercurrents whereby they were aware of the imminent HCT and experienced anticipatory emotions based on how they believed the transition would occur or how they would be treated in adult-focused care. Throughout this process, relationships with family, peers, and HCPs helped AYAs become grounded through the waves of change, providing stability and propelling them toward a steadier footing as they gained a new sense of self and acceptance of their new reality. This emphasized 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.

Meleis et al.'s (2000) transition framework provides a useful lens for understanding and addressing the shared experiences of AYA organ transplant recipients in moving from pediatric to adult-focused care.<sup>41</sup> Three dimensions of this framework structure the following discussion to explore the psychological, social, and cultural factors influencing an

individual's adaptability to change, and inform the development of interventions to support individuals during these transitions.

#### 4.1. *The nature of transition and transition readiness*

In the context of this study, it was uncertain if the delay in moving into adult roles was a result of sensation-seeking and gaining multiple experiences before assuming adult roles and responsibilities as described in Arnett's developmental theory of emerging adulthood,<sup>42</sup> or due to a focus on managing their transplant and transition to adult care and educational pursuits for these participants. Also, the risky behaviours typically associated with AYA sensation-seeking, such as engaging in unprotected sex, substance use, or driving at high speeds or while intoxicated,<sup>42</sup> were not consistent with the experiences shared by study participants. Rather, 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. Transplant recipients faced distinct challenges as they transitioned to adulthood. Managing their transplant, adhering to complex medical regimens, and traversing the health care system as they moved from pediatric to adult care presented unique hurdles that significantly impacted their priorities, behaviours, and overall experiences during this critical developmental period.<sup>8,43,44</sup>

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.<sup>44,45</sup> The responsibility for managing these regimens often shifts from FCs to young transplant recipients during the transition to adulthood, which can be daunting and stressful.<sup>46</sup> Moreover, the transition from pediatric to adult health care systems can be fraught with difficulties, as AYAs must establish relationships with new HCPs, adapt to different care philosophies, and navigate complex health care systems.<sup>46,47</sup> These challenges may be exacerbated by disparities in the availability and quality of transitional care services, which can vary widely between health care institutions and geographical regions.<sup>48</sup> 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 health care system rather than engaging in the traditional emerging adulthood experiences described by Arnett.<sup>42</sup> 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.

Developmental readiness, reflected by self-determination, self-efficacy, psychological maturity, motivation, and developmental skills and traits, contributes to AYA's preparation for the roles and behaviours required of adult life.<sup>49,50</sup> Recognizing these developmental attributes, HCT should include alignment of planning and support across systems. The evidenced-based recommendations to tailor transition for AYAs centred around individual readiness rather than age alone should be integrated to accomplish this goal.<sup>38,51,52</sup>

#### 4.2. *Transition conditions*

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. For many pediatric patients, this diagnosis and subsequent treatment occur in infancy or early childhood, meaning that they have never known 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 health condition 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 health care system, adhering to a strict

medication regimen, and adjusting to the physical and emotional changes that came with transplantation.

AYAs 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.<sup>53</sup> Physical changes following transplantation, including weight gain, skin changes, and other side effects of immunosuppressive medications, can significantly affect recipients' self-image, body satisfaction, and social functioning.<sup>54,55</sup> 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 excess hair growth, potentially exacerbating the already challenging process of identity formation during adolescence.<sup>56</sup>

Comparable to other chronic health conditions, the post-transplant journey shares certain characteristics with conditions such as diabetes, cystic fibrosis, or congenital heart diseases, wherein AYAs must adapt to new care routines, treatment plans, and self-management expectations.<sup>47,51,57</sup> 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.<sup>58</sup> The emotional impact of transplantation, encompassing mood swings, anxiety, and depression, may parallel the psychological experiences of individuals with chronic health conditions, who often grapple with feelings of uncertainty, loss of control, and social isolation.<sup>58,59</sup>

#### 4.3. *Patterns of response*

For participants in this study, self-care, autonomy, and trauma were the dominant patterns of response identified. Self-care emerged as a significant response pattern for participants, reflecting the importance of prioritizing one's health and well-being during the HCT process in seeking supportive anchors in the swell of transition. This finding is consistent with the growing body of research emphasizing the importance of self-care in promoting positive health outcomes.<sup>49</sup> Autonomy was also identified as a key pattern of response, with participants describing the importance of taking an active role in their health care decision-making. The emphasis on autonomy underscores the importance of respecting individuals as rational and moral agents. By giving recipients a voice in their health care decision-making, HCPs acknowledge their autonomy and treat them with dignity and respect.

Trauma emerged as a significant pattern of response for many participants. Trauma is defined by the Substance Abuse and Mental Health Services Administration as resulting "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"<sup>60(p2)</sup>. Trauma is a deeply unsettling experience that shatters one's sense of safety, security, and stability.<sup>61</sup> 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. The literature tells us that trauma is less about what happened and more about the impact on a person.<sup>60</sup> This perspective is relevant for the participants in this study, given the significant stress and uncertainty associated with the HCT process.

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. During data collection, participants shared 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. 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 appointments 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.

Through considering the experiences of transition recipients from a trauma perspective, there may be subsequent impacts on their development and future experiences. Integration of this perspective with transition practices would guide health care providers to support AYAs emotional as well as acute physical medical care. Trauma-informed care is an emerging approach in health care that emphasizes the importance of recognizing and responding to the impact of trauma on people's health and well-being.<sup>61</sup> In a white paper by Menschner and Maul for the Center for Health Care Strategies<sup>62</sup>, 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<sup>62</sup>, which includes patient empowerment, choice, collaboration, physical and psychological safety, acknowledgment of trauma, and trustworthiness, all concepts that arose in this study.

#### 4.4. Implications for practice, research, and policy

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 managed this process. The main concern for recipients was learning how to navigate the unsteady waters alone. Based on our study results, implications for health care transition practice, healthcare organizations, research, and policy development, are presented.

Considering the potential negative impact of transition on health, the state of limited funding for HCT planning and services in Canada for AYAs with chronic health conditions is concerning, necessitating an examination of the complex interplay among various systemic, economic, and socio-cultural factors. Financial constraints and competing priorities within the health care system<sup>63</sup> can also lead to inadequate funding allocation for HCT planning and services. The incongruency between providing years of highly intensive and costly transplant services yet not supporting ongoing health and well-being must be noted. The relative invisibility of these challenges in public discourse and policy debates hinders the development of targeted policies and the mobilization of resources to address the specific needs of this population.<sup>16</sup> Furthermore, disparities in access to health care services for specific populations, such as those considered disadvantaged and those living in rural and remote areas, further compound the challenges in securing adequate funding for HCT services.

##### 4.4.1. Practice implications

The process of transition represents a formidable challenge 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 health care system, strict medication adherence, and the physical and emotional changes concomitant with transplantation, occurring concurrently with a developmentally monumental time<sup>51,58</sup> HCPs play an important role in supporting AYAs and other recipients during the transition process by providing education, emotional support, and connection to resources to help them build self-management skills and supportive relationships.<sup>16</sup> Early adoption of

HCT planning can help introduce and pace change gradually, alleviating the feeling of losing security when transitioning to uncertainty. 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. AYAs will be better equipped to advocate and appreciate, leading to new therapeutic relationships to support their care.

Health team members provide stabilizing care to help transplant recipients achieve consistency and predictability in managing their health, including medication management, symptom control, and self-care practices.<sup>16</sup> Advocacy is required 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 AYA's health care experiences. HCPs can help mitigate the shock of transition by taking proactive and personalized approaches 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. Specifically, they must recognize the emotional and potentially traumatic 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.

HCPs 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. One way HCPs can provide this support is by positively promoting the adult hospitals to help AYAs and their FCs develop confidence and trust in their new HCPs and lay the foundation for establishing new relationships.<sup>16</sup>

Mental health is a crucial aspect of overall health and well-being, especially for AYAs with chronic health conditions.<sup>64,65</sup> 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 health conditions, 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 from this study, it would be beneficial to employ interventions such as peer support programs alongside routine mental health assessment to address the unmet needs of recipients in preparation for and throughout the transition.

To enhance HCP competence and confidence in managing adolescent transplant recipients, interdisciplinary collaboration and continuous professional development opportunities should be prioritized.<sup>16</sup> This may include educational workshops, mentorship programs, transfer clinics and the incorporation of transition planning education into medical and nursing school curricula and professional development programs.<sup>16,49,50,66,67</sup> Transfer clinics, where adult providers connect with AYAs alongside pediatric providers, provide a "warm handover" (where connections are facilitated) and increase the likelihood of AYAs connecting to their adult team. Establishing a culture of lifelong learning and fostering communication among HCPs across specialties and pediatric and adult-focused care will facilitate the exchange of knowledge and expertise, ultimately leading to improved HCT planning and improved patient outcomes.

##### 4.4.2. Research implications

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 health-care condition, this study helps others understand transitional strategies for AYAs living with other chronic health conditions. Furthermore, this study can provide useful insights for future research into the transitional needs of this unique population. Collaboration is needed among

researchers, HCPs, and policymakers to develop and study the implementation of flexible and adaptable transition protocols tailored to specific health care systems and contexts.<sup>66</sup> This approach will enable the integration of local expertise, resources, and cultural factors, ensuring that HCT protocols are effective and relevant for the populations they address. Researchers should explore the integration of patient and family engagement strategies to ensure that AYAs and their families are active partners in this research.<sup>16,66</sup> Adopting standardized protocols that incorporate flexibility and customization can help ensure that transition planning aligns with patient- and family-centred care principles.<sup>67</sup> Quality improvement methodologies hold potential for systematic implementation of 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. Additionally, research focused on approaching HCT 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 is warranted.

#### 4.4.3. Policy implications

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 best evidence suggesting that HCT should be gradual and reflective of individual development,<sup>16,47,67</sup> 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, as seen from the experiences shared by our study participants, are simply not yet ready, while others may be ready earlier. Instead, there should be a shift to align with pediatric health care values and philosophy, initiating a family-centred and personally individualized approach to transition. This shift will ensure that AYAs receive the ongoing family support desired to reduce trauma and promote successful and healthy HCTs with positive long-term outcomes.

## 5. Limitations and delimitations

One of the primary delimitations in this study was the specific focus on AYAs with liver and/or kidney transplants transitioning to adult-focused health care. This concentration may circumscribe the applicability of the results to other solid organ transplant groups or populations experiencing HCTs, such as those with chronic health conditions or alternative health conditions. Consequently, exploring transition experiences with diverse populations, including AYAs who are neurodiverse, would enhance understanding of HCT 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, meant that younger individuals' perspectives during the HCT process remained unexplored. Therefore, incorporating a wider age range or including younger participants in future studies could yield a more comprehensive understanding of the HCT 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 health care systems and cultural contexts. By including a more diverse geographical representation in future studies, researchers could elucidate how HCTs are experienced in different settings, thereby expanding the generalizability of the findings. Although we explored specific contexts of the transition experience for AYAs with a kidney and/or liver transplant, our findings could potentially be relevant in analogous situations such as AYAs living with other chronic health conditions, affording some degree of theoretical generalizability. The relevance of study findings extends beyond merely geographic generalizability. Carminati<sup>68</sup> notes that qualitative

researchers frequently navigate the balance between depth of understanding and breadth of applicability. Given CGTs' focus on a specific context and population, extrapolating the results to broader contexts or other populations may be inappropriate. Rather, the participatory nature of CGT, grounded in the principles of constructivism, values the voices and perspectives of the research participants, leading to the co-creation of a theory that is directly influenced by the experiences of the AYA transplant recipients, ensuring that the theory is 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.

Conducting this research during the pandemic meant that recruitment and data collection were restricted to online approaches due to COVID-19 precautions. Recruitment for this study lasted longer than anticipated and virtual data collection via video conferencing was the primary source of participant engagement. Although initially anticipated as a limitation, this proved to increase the responsiveness of AYA participants and the request for chat-based interview modalities as this was a form of communication with which they were familiar and comfortable. However, while these methods proved effective in engaging AYA participants, they may not have captured non-verbal cues and interpersonal dynamics as comprehensively as in-person interviews. Adopting video conferencing and chat-based interviews as the primary data collection methods may have also affected the richness of the collected data.

## 6. Conclusion

AYA transplant recipients undergo many changes as they enter adult-focused health care systems. Maintaining the health of a transplanted solid organ is a lifelong effort 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 FCs and HCPs. To foster the evolution of health care transition services, it is imperative to move beyond theoretical discussions surrounding support towards active implementation of change rooted in developmental and trauma-informed care frameworks.

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### Ethical statement for solid state ionics

Hereby, I Angie Lim consciously assure that for the manuscript, Transition experiences of young adult transplant recipients: A grounded theory, the following is fulfilled:

- 1) This material is the authors' own original work, which has not been previously published elsewhere.
- 2) The paper is not currently being considered for publication elsewhere.
- 3) The paper reflects the authors' own research and analysis in a truthful and complete manner.
- 4) The paper properly credits the meaningful contributions of co-authors and co-researchers.
- 5) The results are appropriately placed in the context of prior and existing research.
- 6) All sources used are properly disclosed (correct citation). Literally copying of text must be indicated as such by using quotation marks and giving proper reference.

7) All authors have been personally and actively involved in substantial work leading to the paper, and will take public responsibility for its content.

The violation of the Ethical Statement rules may result in severe consequences.

To verify originality, your article may be checked by the originality detection software iThenticate. See also <http://www.elsevier.com/editors/plagdetect>.

I agree with the above statements and declare that this submission follows the policies of Solid State Ionics as outlined in the Guide for Authors and in the Ethical Statement.

#### **CRedit authorship contribution statement**

**Angie Lim:** Conceptualization, Data collection, Data analysis,

Manuscript preparation. **Lenora Marcellus:** Conceptualization, Oversight, Data analysis, Manuscript preparation.

#### **Declaration of Competing Interest**

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

#### **Data availability**

The data that has been used is confidential.

#### **Appendix A. : 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?

o 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 15–20 min 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]
- o Diagnoses
- o Age at time of interview
- o Gender

#### **Initial open-ended questions:**

- How has your family adapted to [child's] diagnosis?

o 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 15–20 min 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?
- o 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)
    - o 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)
    - o 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?
- o 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 15–20 min 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?

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## Appendix B. Additional participant quotes

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### Category One: Anticipating the Impending Transition: Feeling Distress About the Transition

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#### Group A

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)

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)

"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).

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)

"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).

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)

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)

#### Group B

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)

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)

#### Group C

"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).

### Category One: Anticipating the Impending Transition: Feeling angry about being made to feel insignificant

#### Group A

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)

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**Category One: Anticipating the Impending Transition: Feeling Distress About the Transition**

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)

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)

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)

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)

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)

"I hate that the transition even exists. Like, I get it, but I hate it" (Leila, recipient).

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)

**Category One: Anticipating the Impending Transition: Denying Reality****Group C**

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)

**Category Two: Losing Security When Transitioning to Uncertainty: Experiencing Shock****Group A**

"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).

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)

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)

**Group B**

"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)

**Group C**

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)

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)

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)

...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)

**Category Two: Losing Security When Transitioning to Uncertainty: Grieving the Loss of Relationships.****Group A**

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**Category One: Anticipating the Impending Transition: Feeling Distress About the Transition**

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)

"When you spend 18 years at one hospital with the type of care I got from [PEDIATRIC HOSPITAL], there is nothing that can compare."

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)

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)

"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).

**Group C**

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)

**Category Three: Seeking Supportive Anchors in the Swell of Transition: Developing Self-Management Skills****Group A**

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)

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)

**Group C**

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)

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)

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)

**Category Three: Seeking Supportive Anchors in the Swell of Transition: Forging New Relationships****Group A**

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)

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)

"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).

**Category Four: Gaining a New Sense of Self: Stabilizing Through Normalizing****Group A**

"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). 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 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).

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)

**Group B**

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**Category One: Anticipating the Impending Transition: Feeling Distress About the Transition**

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)

**Group C**

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)

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)

**Category Four: Gaining a New Sense of Self: Accepting a New Reality****Group A**

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)

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