TRANSITION TO ADULT HEALTHCARE AMONG SOLID ORGAN TRANSPLANT RECIPIENTS: MEDICAL OUTCOMES & RELATIONS TO SUCCESS

by

KELLY E. REA

(Under the Direction of Ronald L. Blount)

ABSTRACT

Adolescent and young adult (AYA) solid organ transplant recipients experience worsening medical outcomes during transition and transfer to adult healthcare. The current study assessed pre- and post-transfer healthcare utilization and medical outcomes, as well as psychosocial functioning and independence in self-management using two different criteria for transition success among 49 AYA solid organ transplant (i.e., heart, kidney, liver) recipients recently transferred to adult healthcare. Successful retention in adult healthcare three years post-transfer was significantly related to more clinical outcomes, as compared to simply attending the first adult appointment within one year, with the current sample demonstrating significant declines in appointment attendance over time. Retention in adult healthcare was associated with greater time since transplant, lower pre-transfer anxiety, receiving a liver or heart transplant, and having private insurance. Findings underscore the importance of providing support for AYAs after transfer, attention to interventions aimed at maintaining or increasing attendance over time, and identification of risk factors and intervention for unsuccessful transition.

INDEX WORDS: Transition, Transfer, Solid Organ Transplantation, Adolescence, Young Adulthood, Healthcare

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CHAPTER 1

INTRODUCTION

With recent medical advances, solid organ transplantation is increasingly the treatment of choice for pediatric patients experiencing organ failure (LaRosa, Jorge Baluarte, & Meyers, 2011). Almost 2,000 children received an organ transplant in the United States in 2019, while approximately 2,100 children remain on the national organ waiting list (UNOS data as of April 10, 2020). While organ transplantation is both a life-saving and life-prolonging procedure, patients are trading one chronic medical condition for another (Burra & De Bona, 2006). Managing a transplanted organ requires learning a new medical regimen, one that patients and their families have likely not experienced prior to transplantation. Transplant management involves adherence to a strict medication schedule, attendance at frequent medical and laboratory appointments, and possible restrictions in activity and diet (Griffin & Elkin, 2011).

Throughout the last few decades, advances in surgical techniques and new immunosuppressant medications have dramatically increased the survival rate among organ transplant recipients. As such, over 80% of pediatric organ transplant recipients are now surviving into young adulthood (LaRosa et al., 2011). With these increases in survivorship, more adolescent and young adult (AYA) organ transplant recipients are making the transfer from pediatric to adult healthcare. However, this period of transition, with its accompanying increases in autonomy and responsibility for their healthcare, is also associated with higher rates of medication non-adherence and organ rejection (Annunziato et al., 2007; Hommel, Ramsey, Rich,

& Ryan, 2017; Smith, Ho, McDonald, 2002). Thus, this time remains a significant area for continued research (Fredericks, 2009).

Transition and Transfer

Pediatric and adult healthcare represent distinct systems. Pediatric healthcare focuses on family involvement and heavily utilizes caregivers in healthcare management. This is important in the pediatric system, as pediatric patients are not assumed to be autonomous or fully knowledgeable about their health and associated responsibilities (Kennedy & Sawyer, 2008). In contrast, adult healthcare focuses on the patient, typically without involvement of the caregiver, as adult patients are assumed to have the capacity to navigate their healthcare decision making and management independently (Kennedy & Sawyer, 2008). As such, there has been increased attention to preparing AYAs to gradually increase autonomy and responsibility. *Transition* is the purposeful, planned movement from pediatric to adult healthcare, including increasing AYA responsibility for healthcare tasks and removing parental involvement, while *transfer* refers to the discrete event of change in both the location and the provider of care from a pediatric to an adult healthcare system (Blum et al., 1993; Sawyer, Blair, & Bowes, 1997; White et al., 2018). *Transition readiness* assesses how prepared AYAs feel in assuming responsibility for their healthcare and changing from pediatric to adult settings (Blum et al., 1993; Sawyer et al., 1997; White et al., 2018).

Transition and Transfer in Organ Transplantation

Among organ transplant recipients, the process of transition to adult healthcare is often associated with poorer medication adherence and worse medical outcomes (Annunziato et al., 2007; Foster et al., 2011; Samuel et al., 2011). Immunosuppressant medication adherence is critical to maintaining organ graft health and preventing organ rejection, such that nonadherence

to the regimen, as determined by greater variability in immunosuppressant medication dosing, is related to increased rates of organ rejection and even death (Morrissey, Flynn, & Lin, 2007). Within the period of transition encompassing the transfer event, AYA organ transplant recipients are observed to have poorer medication adherence (Annunziato et al., 2007), as well as higher risk of graft failure as compared to other age groups (Samuel et al., 2011).

In response to evidence that AYA solid organ transplant recipients may experience deteriorating health under the demands of adult healthcare and their assumption of greater self-management, there has been an increase in intervention and other research efforts related to this crucial transition period. A recent consensus conference report regarding the specific transition needs of AYAs with solid organ transplants determined skill and responsibility acquisition is needed prior to transfer, while patients still benefit from oversight by pediatric providers and caregivers (Bell et al., 2008). These competencies include communication about their transplant, awareness of the implications of their medical condition on their well-being, and demonstrated responsibility for medications and healthcare management (Bell et al., 2008). While the focus of transition readiness and preparation occurs largely on the pediatric side of healthcare, where these competencies can be evaluated and improved, it is increasingly recognized that the transition process does not conclude with the transfer to adult healthcare (Bell et al., 2008, Kennedy & Sawyer, 2008). It is recommended that adult providers receiving patients from pediatric settings continue to provide developmentally appropriate care throughout the ongoing process of transition as these patients adjust to their new healthcare setting. However, among adult transplant centers, this is often not the case. Adult transplant centers have between five and ten times the patient load as pediatric settings. The settings are faster-paced and assume adequate preparation of patients to respond to questions and express concerns quickly during visits (Bell et

al., 2008). While organ transplant patients are expected to attend appointments every three months in pediatric care, appointment frequency is reduced to every six or twelve months in adult healthcare. For newly transferred patients, this change in healthcare culture and frequency of follow-up is difficult and may result in patient dissatisfaction with the adult healthcare system.

Qualitatively, AYA solid organ transplant recipients report difficulty in managing the transition and reluctance to leave the familiarity of pediatric care (McCurdy et al., 2006), as well as expectations that adult care will be significantly different (Anthony et al., 2009). However, little research has examined post-transfer outcomes and healthcare utilization among AYAs who have undergone a solid organ transplant. Importantly, across multiple studies of AYAs with a kidney transplant, participation in transition preparation programming has been inconsistent in improving post-transfer outcomes, with one study demonstrating no improvements in post-transfer outcomes (Remorino et al., 2006) and another finding decreased rates of organ loss after participation (Harden et al., 2012). Unfortunately, not every patient participates in such programming, and even with increases in transition preparation, AYAs with an organ transplant continue to face challenges post-transfer. Continued difficulties in healthcare transition despite increases in attention to this process and participation in transition readiness programming suggests that other aspects of these patients' lives are implicated in the transition process and thus relevant for examination and intervention. However, in order to effectively examine factors related to transition outcomes, the field must first come to agreement about what constitutes transition success.

Initial Engagement with Adult Healthcare

Clinic attendance is the most common post-transfer outcome measure among young adults with chronic medical conditions (Coyne, Hallowell, & Thompson, 2017). For many

studies examining transition, the indicator of transition "success" is patients' attendance at an adult healthcare appointment for the first visit within a specific time frame, such as prior to a specific age or within one year of their last pediatric appointment (Andemariam et al., 2014; Darbari et al., 2019; Reid et al., 2004). A recent poll of adolescent health experts reached near unanimous agreement that attending any appointment in adult healthcare and thus not being lost to follow-up is the most critical juncture of successful transition, underscoring the importance of considering initial appointment keeping with an adult healthcare provider as crucial in the transition process (Suris & Akre, 2015). A recent systematic review determined that the proportion of AYAs with a variety of medical conditions who actually attended their first adult healthcare visit after transferring care ranged from 47% to 100%, with high variability in the duration of time between last pediatric visit and first adult visit (Rachas et al., 2016). This suggests that, despite being a critical feature of attendance, initial engagement is not occurring consistently.

Furthermore, while engagement with adult healthcare is an important initial indicator of the success of the transfer event, this single event is limited in nature, as oftentimes the first appointment at an adult clinic is guided by the pediatric provider or occurs with high caregiver involvement. A single event representation of healthcare engagement and transition success also does not take into account the likelihood of future gaps in healthcare attendance as pediatric provider and caregiver involvement decreases. Gaps in healthcare service remain a significant problem throughout the period of transition for AYAs with chronic medical conditions, as there is a possibility of cessation or inconsistent care, even after initially engaging with the adult healthcare system.

Retention and Continuity in Adult Healthcare

While initial engagement with adult healthcare is an important step along the transition process signaling the transfer from a pediatric to adult setting, the establishment of and retention in continual and uninterrupted adult care is the ultimate goal of transition (White et al., 2018). Transfer of care is not the end of the transition process. With continued emphasis on the importance of transition and support occurring on both pediatric and adult sides of healthcare, more tailored developmentally appropriate care may be afforded to AYAs in both settings (Kennedy & Sawyer, 2008). Unfortunately, a drop off in appointment attendance after transfer has been demonstrated in various medical populations. A systematic review of continuity of care during transition demonstrated that the frequency and percentage of appointments attended was lower in adult care as compared to pediatric care among AYAs with a variety of medical conditions (Rachas et al., 2016). Among young adults with diabetes who transferred from pediatric to adult providers, rates of non-attendance and dropouts were found to increase after transfer across several studies (Johnston, Bell, Tennet, Carson, 2006; Kipps et al., 2002). In assessing attendance across the first three years post-transfer, young adults with congenital adrenal hyperplasia were found to attend significantly fewer appointments in their third year, as compared to when they first transferred care (Gleeson, Davis, Jones, O'Shea, & Clayton, 2013). While it remains important to ensure that pediatric patients are making the initial step in engaging with adult healthcare, establishing continual care and greater retention among AYAs with chronic medical conditions remains of vital concern. As such, it is necessary to understand the complex factors in patients' lives that impact their continuity of care during transition.

Complexity of Transition Process

A recent theoretical model developed by the Health Care Transition Research Consortium sought to address this issue by outlining the complex, interrelationships between

individual, familial, and healthcare system variables which influence transition among AYAs with chronic medical conditions (Betz et al., 2014). This model describes four domains that are considered inter-related and integral to healthcare transition, including individual factors (e.g., demographic and disease characteristics, development and functioning, healthcare self-management), family and social support factors (e.g., family functioning, social support), healthcare system factors (e.g., access to providers, clinic characteristics), and environmental factors (e.g., educational system, community services; Betz et al., 2014). This model highlights the many aspects of AYAs' lives that can impact their transition to adult healthcare and serves as a framework upon which this burgeoning field of research and intervention can be built.

On a systemic level, the period of transition can lead to lapses in healthcare or medication access. During this time, AYAs may experience changes in their health insurance as a result of no longer being covered under their caregivers' insurance plan, or after acquiring their own insurance plans (Bell et al., 2008). National trends in AYA healthcare access and utilization demonstrate that, over the past decade, the percentage of AYAs with insurance has increased; however, there remains a marked drop-off in insurance coverage between adolescence and young adulthood, the period which also aligns with transition and transfer to adult healthcare (Park et al., 2014). Lapses in insurance coverage for a full year were associated with fewer doctor visits and increased unmet health care needs (Park et al., 2014). Overall, the transition from adolescence to young adulthood is fraught with psychosocial influences and healthcare access variability that affect young adults' abilities to manage their healthcare. It is vital that healthcare providers from both pediatric and adult systems recognize the many influences on their patients' healthcare utilization and seek to ameliorate barriers or provide support where possible in order to promote a successful transition process.

Factors Associated with Transition Success among AYAs with Chronic Medical Conditions

Several studies among AYAs with chronic medical conditions have examined aspects of AYA's lives associated with single event engagement indicators of transition success (i.e., first appointment attendance in adult healthcare). Among AYAs with congenital heart defects, successful transition was defined as attending at least one follow-up adult appointment before reaching age 22 (Reid et al., 2004). Using this criterion of successful transition, several factors from the individual domain were related to greater transition success, including older age at last pediatric visit, the presence of other comorbid medical conditions, and prior attendance at medical appointments without caregivers (Reid et al., 2004). In a study of AYAs with diabetes, individual factors specifically concerning their disease course and management were associated with increased likelihood of patients being lost to follow-up in adult healthcare, including younger age at diagnosis, increased burden of diabetes management, and fewer appointments attended in the year prior to transfer (Mistry, Van Blyderveen, Punthakee, & Grant, 2015). This study suggests the importance of considering individual factors not only related to self-management, which are potentially amenable to intervention, but also non-modifiable disease characteristics, such as age at diagnosis and disease severity or burden.

Among AYA patients with sickle cell disease, successful transition (i.e., any appointment attendance in adult center or appointment attendance prior to age 22 or regardless of whether they occurred prior to age 22 but without an emergency department visit) was related to fewer hospitalizations prior to transfer, younger age at start of transition, private (vs. public) insurance, and closer distance to the healthcare facility (Andemariam et al., 2014; Darbari et al., 2019). Findings from these studies highlight the importance of considering factors from both the individual domain and the healthcare system domain as potential barriers to transition success.

Studies to date examining transition success in adult healthcare do not appear to focus on or demonstrate significant findings related to the family domain put forth by Betz and colleagues (2014; Goossens et al., 2016). It is possible that the family domain is more impactful on the pediatric side of the transition process, as caregivers are reducing their level of involvement in their child's healthcare in preparation for transfer, and adult healthcare facilities also likely have privacy policies that would restrict parental involvement in their children's healthcare once the child is past age 18 and receiving services at an adult facility.

A recent systematic review determined that several predictors of gaps in healthcare utilization during transition exist among AYAs with chronic medical conditions across several domains, including demographic (e.g., lower income, male gender, and distance from facility) and healthcare utilization factors (e.g., lower rate of outpatient visit attendance in pediatrics, not attending initial adult outpatient visits; Goossens et al., 2016). It is important that these patients initially engage with adult healthcare, but there remains the possibility of gaps in care later on, thus emphasis on retention is crucial. Only one study to date has examined factors in relation to retention in adult healthcare. Decreased frequency of adult outpatient clinic visits per year among AYAs with diabetes was associated with older patient age and greater time since diagnosis, based on AYA self-report (Stanczyk, Chobot, Polanska, & Jarosz-Chobot, 2014).

Among organ transplant recipients, those who transferred to adult healthcare prior to age 21 were found to have higher rates of organ loss as compared to patients who transferred when they were older than 21 years (Foster et al., 2011). One study among AYA organ transplant recipients found that psychological distress prior to and after transfer was related to poorer medication adherence (Annunziato, Arrato, Rubes, & Arnon, 2015). In an additional study of AYAs with a kidney transplant, transfer of care was related to continuation or worsening of

adherence patterns and medical stability, with stability and adherence prior to transfer not predicting adherence post-transfer (Remorino et al., 2006). This suggests that it may be difficult to predict post-transfer outcomes from pre-transfer behaviors given changes in the culture of healthcare between the two settings. No studies have examined retention in adult healthcare in the years post-transfer among AYA solid organ transplant recipients, nor have studies examined individual or systemic factors related to healthcare utilization during this critical time, despite recognition that attendance at appointments is essential during transition and as an indicator of success. Thus, there is great need for studies to examine healthcare utilization and retention in adult healthcare within this population.

The Present Study and Hypotheses

There has been a recent call for studies that identify factors affecting transition outcomes among AYAs with solid organ transplants (Bell et al., 2008). This has primarily been examined in relation to medical outcomes (e.g., organ rejections, medication adherence), thus there remains a gap in the literature with regard to post-transfer healthcare utilization among AYA solid organ transplant recipients. Many of the recent examinations of transition success among other chronic illness populations have focused on the single event of attending the first adult healthcare appointment as an indicator of successful transition. However, given that the transition process is thought to continue throughout the first several years in adult healthcare, first appointment attendance is not a comprehensive indicator of success on its own. As such, the current study examined the use of a longitudinal indicator of transition success (i.e., *retention in adult healthcare* via appointment attendance across the first three years after transfer; Coyne, Hallowell, & Thompson, 2017) in addition to the traditional single event indicator of transition success (i.e., *timing of first adult healthcare engagement* within 12 months of the last pediatric

outpatient visit). It was hypothesized that 1) first adult outpatient appointment attendance within 12 months of the last pediatric appointment, as opposed to first attendance after 12 months, will be related to better medical outcomes, including greater medication adherence, fewer emergency department visits, lower number and duration of hospitalizations, and lower number of organ rejection episodes and subsequent transplant re-evaluations. Relatedly, it was hypothesized that 2) an average appointment attendance rate of at least one appointment per year over the first three years post-transfer, as compared to an average of less than one appointment per year, would also be related to better medical outcomes (i.e., greater medication adherence, fewer emergency department visits and hospitalizations, lower rate of organ rejection and re-evaluations). Given that the initial transfer event is often guided by pediatric providers or caregivers, it was hypothesized that 3) the rate of appointment attendance would significantly decline across the three years post-transfer, as patients are further removed from their pediatric care providers and caregiver involvement continues to decrease. If substantiated, this hypothesis would lend credence to the importance of emphasizing retention in adult healthcare as a marker of transition success, not just initial engagement.

Additionally, the current study examined patient and healthcare system characteristics both amenable to intervention (e.g., emotional functioning, transition readiness) and not as amenable to intervention (e.g., insurance status, age, distance from facility) as possible risk or protective factors for retention in adult healthcare among AYAs who have had an organ transplant. Based on previous studies of transfer and engagement with adult healthcare among AYAs with a variety of chronic health conditions, it was hypothesized that 4) transition success will be associated with the following pre- and post-transfer variables across individual and systemic domains: a) various medical and condition management factors, including increased

time elapsed since transplant and increased perceived self-management and readiness for transition prior to transfer, b) several individual level demographic and functional factors, including female gender, older age at transfer, and lower anxiety and depressive symptoms prior to transfer, and c) variables from the systemic domain, including greater attendance at pediatric outpatient visits prior to transfer, organ transplant type corresponding to the specific clinic attended, closer distance to the adult facility, and having private insurance (as compared to public or no insurance).

CHAPTER 2

METHODS

Participants

The sample for this study included 49 AYA solid organ (i.e., heart, kidney, liver) transplant recipients who have transferred to adult healthcare. The current study was part of a larger investigation into transplant outcomes in an AYA sample. Inclusion criteria at the time of recruitment included patients between 12 and 21 years of age, with English language fluency, and who were at least 12 months post-transplantation to allow for stabilization of medical care and adjustment to adherence behaviors. Patients who had an identified significant developmental delay as indicated by medical chart review or caregiver report were excluded.

Procedures

Participants were initially recruited prior to their transfer to adult healthcare while they were at a major pediatric transplant center during an outpatient visit. At recruitment, informed consent was provided by caregivers and assent obtained from participants under the age of 18. Participants over the age of 18 provided informed consent directly. All participants completed paper and pencil questionnaires while in the waiting room or clinic rooms. Retrospective medical chart review was conducted using the pediatric institution's electronic medical record system to identify participants who had transferred to adult healthcare and were thus eligible for the current study. Medical chart review data from eligible patients was collected as part of this investigation into the post-transfer medical outcomes in this sample, utilizing primarily the adult institution

electronic medical record system. Institutional Review Board approval was obtained prior to recruitment.

Data Collection/Measures

Retrospective Medical Chart Review. A retrospective medical chart review of all patients recruited in the larger investigation was conducted to determine eligibility for the current study. Participants who transferred to the Emory University Hospital system for their adult healthcare were eligible. Charts were reviewed for relevant participant demographic factors pre- and post-transfer (i.e., gender, age, race and ethnicity, insurance type, and location of residence/distance from Emory system). Relevant clinical information (i.e., biopsy-proven rejections, organ loss, dialysis, re-evaluation for transplant, re-transplantation, death) and healthcare utilization (i.e., appointment attendance leading up to transfer and post-transfer, emergency department visits, inpatient hospitalizations) information were extracted from the pediatric and adult healthcare medical record systems. Post-transfer medical outcomes and healthcare utilization were extracted for the three years post-transfer, per recommendations by Coyne and colleagues (2017).

Medication adherence as assessed via Medication Level Variability Index (MLVI) was also extracted in the three years post-transfer for patients taking tacrolimus. MLVI is an objective biomarker of tacrolimus immunosuppressant medication adherence validated in several pediatric and adult samples (Shemesh et al., 2017). It is essential that immunosuppressant medications be taken on a strict timed schedule to maintain a steady level in individuals, preventing organ rejection. MLVI is calculated as the standard deviation of at least three blood levels of tacrolimus, such that a higher MLVI indicates more variability in the levels. In the literature, the clinical cut off of 2.5 standard deviations has been established, such that MLVI

values greater than the cut-off are associated with non-adherence and increased risk for adverse medical outcomes, including organ rejection and loss (Shemesh et al., 2017; Christina et al., 2014). In the current study, MLVI was analyzed both as a continuous (i.e., higher MLVI = less adherence) and a categorical measure, using a predefined threshold of MLVI > 2.5 in determining non-adherence. Using an MLVI cut-off of 2.5 standard deviations as a threshold of non-adherence has demonstrated clinical relevance in recent studies of non-adherence in pediatric and adult organ transplant populations (Shemesh et al., 2017; Christina et al., 2014).

Readiness for Transition. Prior to transfer, AYAs completed the Readiness for Transition Questionnaire (RTQ), a 22-item measure assessing transition readiness, degree of adolescent responsibility, and degree of parent involvement in a variety of healthcare behaviors in AYA transplant recipients (Gilleland, Amaral, Mee, & Blount, 2011). The RTQ is composed of three subscales: RTQ-Overall, RTQ-Adolescent Responsibility, and RTQ-Parent Involvement. The RTQ-Overall subscale is the summed score from two items: 1) "Overall, how ready do you think you are to assume complete responsibility for your healthcare?" and 2) "Overall, how ready do you think you are to transition from care at (pediatric hospital specified) to adult care?" These items were rated on a four-point scale (i.e., 1=*Not at all ready*, 2=*Somewhat ready*, 3=*Mostly ready*, 4=*Completely ready*). Higher scores indicate greater perceived readiness for transition. The RTQ-Adolescent Responsibility subscale is comprised of 10 items assessing the frequency of AYA responsibility for 10 different healthcare behaviors (e.g. scheduling appointments, refilling prescriptions, communicating with medical staff) rated on a four-point scale (i.e., 1=*Not responsible at all*, 2=*Sometimes responsible*, 3=*Often responsible*, or 4=*Almost always responsible*). Higher scores on this subscale indicate greater perceived degree of attained responsibility. The RTQ-Parental Involvement subscale is comprised of 10 items parallel to the

RTQ-Adolescent Responsibility subscale assessing the degree of caregiver involvement in the healthcare tasks, rated on a similar four-point scale (1=*Not involved at all*, 2=*Sometimes involved*, 3=*Often involved*, or 4=*Almost always involved*). Higher scores on this subscale indicate greater perceived caregiver involvement. In the current study, the RTQ-Overall achieved an excellent level of internal reliability (α = 0.91), while the RTQ-Adolescent Responsibility (α = 0.84) and the RTQ-Parental Involvement (α =0.80) achieved good levels of internal reliability.

Emotional Functioning. Prior to transfer, AYAs completed a measure assessing emotional functioning; the Anxiety and Depression subscales of the Behavior Assessment System for Children- 2nd Edition Self Report of Personality, Adolescent Version (BASC-2-SRP-A; Reynolds & Kamphaus, 2004). Items on the Anxiety subscale assess cognitive and physiological components of anxiety, including "I worry about little things" and "I can never seem to relax." The Depression subscale contains items such as "Nothing goes my way" and "I don't seem to do anything right." Items are rated on a four-point scale (i.e., 0=*Never*, 1=*Sometimes*, 2=*Often*, 3=*Almost always*). Raw scores are summed and transformed into T-scores based on age and gender norms and the final T-scores will be used in the subsequent proposed analyses. In the current study, the BASC Anxiety subscale achieved an excellent level of internal reliability (α = 0.94) and the BASC Depression subscale achieved a good level of internal reliability (α = 0.85).

Analytic Strategy

Data storage and analyses were conducted in SPSS v26 (IBM Corp., 2019) and MPlus Version 8.3 (Muthén & Muthén, 2017). Initial descriptive analyses were run on all study variables to assess assumptions of normality.

Hypothesis 1 & 2: Indicators of Successful Transition. Hypotheses 1) and 2) examined differences in medical outcomes between patients grouped based on two sets of dichotomous criteria for transition success: *timing of first adult healthcare engagement* (i.e., first adult appointment attended within 12 months of the last pediatric visit, deemed successful, versus after 12 months, deemed unsuccessful; Hypothesis 1) and *retention in adult healthcare* (i.e., an average of at least one appointment attended per year in the first three years post-transfer, deemed successful, versus less than one appointment attended on average per year, deemed unsuccessful; Hypothesis 2). Statistical methods to address these hypotheses included chi-square tests to assess associations among categorical variables, including successful transition (yes or no) and dichotomous clinical outcomes (i.e., presence of organ rejections, re-evaluations, re-transplantations). When the assumptions of chi-square analyses were not met, Fisher's Exact Test was utilized. To compare group means between successful and unsuccessful transition groups, independent samples t-tests were used when assumptions of normality were met, while Mann-Whitney U-Tests were used when variables were non-normally distributed. Group means were compared for relevant continuous variables, including continuous MLVI, number of emergency department visits and inpatient hospitalizations, and duration of inpatient hospitalizations.

Hypothesis 3: Change in Appointment Attendance. Hypothesis 3) examined the trajectory of appointment attendance over the first three years post-transfer to adult healthcare. Linear growth curve modeling was used to examine the trajectory of annual appointment attendance among recently transferred AYA organ transplant recipients. Full information maximum likelihood was used to accommodate missing data. For the slope (i.e., rate of annual appointment attendance), factor loadings of average appointment attendance at year 1, year 2,

and year 3 were fixed at 0, 1, and 2, respectively. Growth curve equations to estimate attendance rate per year at adult healthcare appointments are presented in equations (1) and (2).

$$\text{Level 1: Attendance}_{it} = \pi_{0i} + \pi_{1i}(\text{Time}) + e_{it} \quad (1)$$

$$\text{Level 2: } \pi_{0i} = \gamma_{00} + U_{0i},\ \text{Var}(U_{0i}) = \tau_{00} \quad (2)$$

$$\pi_{1i} = \gamma_{10} + U_{1i},\ \text{Var}(U_{1i}) = \tau_{11}$$

$$\text{Cov}(U_{0i}, U_{1i}) = \tau_{01}$$

The level 1 equation specifies that attendance at clinic appointments for a participant (*i*) at time (*t*) is a function of the initial level of appointment attendance, or intercept (π_{0i}), while adjusting for the passage of time via the slope (π_{1i}). Level 2 equations specify that the intercept is a function of the fixed predicted value of Attendance at Time = 0 (γ_{00}), plus random individual effects (U_{0i}), and the slope is a function of the fixed predicted value change in Attendance for every one unit increase in Time (γ_{10}), plus random individual effects (U_{1i}). The resulting combined equation is presented in (3).

$$\text{Attendance}_{it} = \gamma_{00} + \gamma_{10}(\text{Time}). \quad (3)$$

Hypothesis 4: Factors Related to Transition Success. Hypothesis 4) examined pre- and post-transfer variables across individual and systemic domains related to retention in adult healthcare as an indicator of transition success, as examined in Hypothesis 2. Statistical methods for this data analysis included chi-square tests in assessing association among categorical variables, including successful retention in adult healthcare, gender, minority status, and insurance status (private or public). When assumptions of chi-square analyses were not met, Fisher's Exact Test was utilized. For comparing group means between successful and unsuccessful transition groups, independent samples t-tests were used when assumptions of normality are met, while Mann-Whitney U-Tests were used when variables were skewed and

non-normally distributed. Group means were compared for relevant continuous variables, including age at transfer, time since transplant at transfer, appointment attendance prior to transfer, RTQ subscale and total scores, BASC-SRP-A subscales, and distance of residence from the Emory facility.

A Priori Power Analyses

A priori power analyses were run to determine the ideal sample size for powering the proposed analyses using G*Power software (Faul, Erdfelder, Lang, & Buchner, 2009). These power analyses indicated that a sample size of 128 participants was needed to have 80% power for detecting a medium effect size in independent samples t-tests using the traditional $p = 0.05$ for statistical significance (Hypotheses 1, 2, and 4). To determine a sufficient sample size for conducting a Mann-Whitney U-Test analyses, a priori power analyses were run using an alpha of 0.05, a power of 0.80, a medium effect size for a two-tailed test, and it was determined that a sample size of 134 participants was desirable (Hypotheses 1, 2, and 4). For chi-square analyses, a sample size of 88 was desirable for 80% power in detecting a medium effect size (Hypotheses 1, 2, and 4). To estimate the approximate sample size for a repeated measures model, a similar power analysis estimating the sufficient sample size for the roughly equivalent repeated measures ANOVA test was conducted. Using an alpha of 0.05 and a power of 0.80 in detecting a medium effect size for a two-tailed test, a sample of 28 participants repeated at three timepoints was required (Hypothesis 3). Given the inherent rarity of the current sample, the current study was underpowered and thus effect sizes are provided for all analyses, as well as significance.

CHAPTER 3

RESULTS

Descriptive Statistics

Table 1 presents full descriptive statistics, including means, standard deviations, ranges, and frequencies of sample characteristics and study variables. In the current sample of 49 AYAs, the average participant age at transfer was 20.62 years (*SD* = 0.52). Approximately half of the patients were female, and the majority were Caucasian and had received a kidney transplant. Approximately half of the sample received post-transfer care via private insurance. In the first three years after transfer, eight participants (16%) initiated dialysis, six participants (12%) were re-listed for transplant, one participant (2%) was re-transplanted, and one participant died (2%).

Hypotheses 1 & 2: Indicators of Transition Success

To assess differences in medical outcomes between patients grouped based on two sets of dichotomous criteria for transition success, *timing of first adult healthcare engagement* and *retention in adult healthcare*, independent samples t-tests, Mann-Whitney *U* tests, and Fisher's Exact tests were utilized. Full results are presented in Table 2.

Timing of First Adult Healthcare Engagement. Thirty-seven participants (76%) attended the first adult appointment within one year of transfer. There was not a significant difference in the number of ED visits between those who attended within one year and those who did not ($t(47)=-1.45$, $p=.17$, Cohen's $d = 0.55$). The number and duration of hospitalizations were both approximately twice as high among those who did not attend first appointment within one year as compared to those who did attend within one year. However, Mann-Whitney *U* tests did

not reveal a significant difference (number of hospitalizations: U=168.50, Z=1.50, p=.13, non-parametric r = 0.21; duration of hospitalizations: U=168.50, Z=1.49, p=.14, non-parametric r = 0.21). Among the subsample of those who were taking Tacrolimus (n=29), there was not a significant difference in MLVI between those who were taking Tacrolimus who attended within one year (n=24) and those who did not attend within one year (n=5; t(27)=-1.75, p=.09, Cohen's d = 0.75). There was a higher percentage of those deemed adherent by MLVI cutoff among those who attended within one year (16/24 = 67%) as compared to those who did not (1/5 = 20%); however, Fisher's Exact test yielded a non-significant result (p=.13, Odds ratio = 8.00). Within the full sample, there was a significantly higher percentage of those who experienced rejection episodes (33%) and transplant re-evaluations for an additional transplant (42%) among those who did not attend within one year as compared to those who did (rejection episodes: 5%, Fisher's Exact test p<.01, Odds ratio = 8.75; re-evaluations: 8%, Fisher's Exact test p<.01, Odds ratio = 8.10).

Retention in Adult Healthcare. Thirty-seven participants (76%) attended an average of at least one appointment per year in the first three years post-transfer. There was not a significant difference in the number of ED visits between those who were retained in adult healthcare by attending on average one clinic appointment per year across first three years and those who were not (t(47)=1.91, p=.08, Cohen's d = 0.74). The number and duration of hospitalizations was higher among those who were not retained in adult healthcare (number of hospitalizations: M=1.25, SD=1.55; duration of hospitalizations: M=6.33 days, SD=9.25) as compared to those who were retained (number of hospitalizations: M=.35, SD=.68; duration of hospitalizations: M=1.30 days, SD=3.59), though the results of Mann-Whitney U tests indicated that only the number of hospitalizations was significant (number of hospitalizations: U=151.50, Z=1.98,

p=.048, non-parametric *r* = 0.28; duration of hospitalizations: *U*=152.50, Z=1.94, *p*=.052, non-parametric *r* = 0.28). Among the subsample of participants taking Tacrolimus (n=29), there was a significant difference in the MLVI between those who were retained in adult healthcare (n=26) and were taking Tacrolimus and those who were not retained (n=3; *t*(27)=2.40, *p*=.02, Cohen's *d* = 1.14). Almost twice the percentage of patients were deemed adherent by MLVI cutoff among those who were retained in adult healthcare (16/26 = 62%) as compared to those who were not retained (1/3 = 33%); however, Fisher's Exact test yielded a non-significant result (*p*=.55, Odds ratio = 3.20). Within the full sample, there was a significantly lower percentage of those who experienced rejection episodes (8%) and transplant re-evaluations (5%) among those who were retained in adult healthcare as compared to those who were not (rejection episodes: 25%, Fisher's Exact test *p*=.03, Odds ratio = 2.83; re-evaluations: 50%, Fisher's Exact test *p*<.001, Odds ratio = 17.50).

Hypothesis 3: Change in Appointment Attendance

On average, the number of appointments attended per year decreased over time from year one (*M* = 1.61) to year three (*M* = 1.06; See Figure 1). To statistically quantify the rate of change in annual appointment attendance over time (i.e., from transfer to three years post-transfer) a linear growth curve model was estimated using MPlus. Full results are presented in Table 3 and the structural equation model is presented in Figure 2. This model demonstrated good model fit and was thus appropriate to interpret (χ^2=0.00, *p*=.98; AIC=367.67). Mean first year appointment attendance (γ_{00}) per year was 1.61 with significant variation (τ_{00} = 1.13, $p < .01$), indicating significant differences among AYA transplant recipients in their initial level of appointment attendance post-transfer. Additionally, the slope was significant (γ_{10} = -0.28, $p = .014$) demonstrating that on average there is a significant decline in appointment attendance across the

first three years post-transfer. Significant variation in the slope ($\tau_{11} = 0.48$, $p < .01$) also demonstrates that the rate of change for some patients was significantly steeper or flatter than the average slope across all patients. The resulting growth curve equation is presented in (4).

$$\text{Attendance}_{it} = 1.61 - 0.28\,(\text{Time}) \quad (4)$$

Hypothesis 4: Factors Related to Transition Success

To examine pre- and post-transfer variables across individual and systemic domains related to retention in adult healthcare as an indicator of transition success, as defined by attending an average of at least one appointment per year in the first three years post-transfer, independent samples t-tests, Mann-Whitney *U* tests, and Fisher's Exact tests were utilized. Full results are presented in Table 4. There were no significant differences in age at transfer between those considered a successful transition and those who were not ($t(47)=1.21$, $p=.23$, Cohen's $d = 0.36$). However, those who successfully transitioned had significantly greater time since transplant compared to those who did not successfully transition ($t(47)=2.69$, $p=.01$, Cohen's $d = 0.76$). There were no significant differences in self-reported readiness for transition prior to transfer between those who successfully or unsuccessfully transitioned, across any of the RTQ subscales ($t(45)=.25$-1.29, ps=.20-.81, Cohen's ds = 0.09-0.45). Those who successfully transitioned reported significantly lower anxiety as compared to those who were unsuccessful ($t(44)=2.18$, $p=.04$, Cohen's $d = 0.67$). Levels of depression were higher among those who did not successfully transition, though not significantly so ($U=130.50$, $Z=1.92$, $p=.054$, non-parametric $r = 0.28$). No significant differences in distance from adult facility emerged ($U=237.00$, $Z=.35$, $p=.73$, non-parametric $r = 0.05$). There was a higher percentage of kidney transplant recipients (45%) among those who unsuccessfully transitioned as compared to heart transplant recipients (0%) and liver transplant recipients (12%; heart: Fisher's Exact test $p=.01$,

Odds ratio > 8.33; liver: $\chi_2(1, n=39)=5.11$, $p=.02$, Odds ratio = 6.25). There were no significant differences in rate of successful transition between heart and liver transplant recipients (Fisher's Exact test $p=.52$, Odds ratio = 0). Additionally, there was a significantly higher percentage of those without private health insurance among those who unsuccessfully transition (33%) as compared to those who were successful (6%; Fisher's Exact test: $p=.04$, Odds ratio = 8.00). Chi square analyses revealed no differences in gender or minority status between those who successfully or unsuccessfully transitioned (gender: $\chi_2(1, N=49)=0.47$, $p=.35$, Odds ratio = 1.89; minority status: $\chi_2(1, N=49)=2.48$, $p=.12$, Odds ratio = 2.93).

CHAPTER 4

DISCUSSION

The current study sought to examine the period of transition among AYA organ transplant recipients. Specifically, this study examined two indicators of transition success: the *timing of first adult healthcare engagement* (i.e., attending one post-transfer clinic visit within one year of transfer), as well as a longitudinal indicator of transition success, *retention in adult healthcare* (i.e., attending on average at least one appointment per year across three years post-transfer). Further, the trajectory of appointment attendance across three years was examined. Additionally, this study assessed relations to transition success across individual and systemic domains, including prior psychological functioning, reported transition readiness, and distance from adult facility. This investigation is in response to multiple calls to examine healthcare outcomes and utilization during the critical period of transition among youth with chronic medical conditions (Rachas et al., 2016; Coyne et al., 2017). Results revealed that both indicators assessing transition success were related to clinical outcomes, though there were more significant findings for the longitudinal indicator of successful retention in adult healthcare as compared to simply attending an appointment with an adult provider within one year of transfer. Successful retention in adult healthcare was related to significantly lower number of hospitalizations, less variability in immunosuppressant levels, and lower rates of rejection episodes and transplant waitlist re-evaluations. Additionally, there was a significant decline in rates of clinic appointment attendance across the first three years post-transfer. Lastly, successful retention in adult healthcare was related to greater time since transplant, lower pre-transfer anxiety, and having

private insurance. Interestingly, the rate of successful transition was also significantly lower among kidney transplant recipients.

This study examined health outcomes and healthcare utilization among AYA transplant recipients in relation to the traditionally accepted indicator of transfer success: timing of first adult healthcare engagement within 12 months of the last pediatric outpatient visit. The current study revealed a significant relationship between timing of first engagement and incidence of rejection episodes and re-evaluations for another organ transplant in the three years post-transfer. No other significant differences were found between those who did or did not attend their first appointment within a year of transfer. As an indicator of transfer success, this criterion yields information regarding the timing of AYAs' first engagement in the adult healthcare system and whether adult healthcare was established at all, though ideally at least within a year after their last clinic visit at a pediatric transplant center. This is consistent with a recent international consensus that it is critical that AYAs establish healthcare in the adult setting rather than being lost to follow up (Suris & Akre, 2015). This indicator also reflects the practice that, for many pediatric settings, the transfer event indicates a "letting go" of the pediatric provider in concession to the adult healthcare provider assuming patient care, thus, just knowing whether patients made it through the door of adult healthcare would be sufficient (Bell et al., 2008). However, this one-year criterion for transfer success is limited in scope, in that it does not indicate the level of patient involvement after transfer (e.g., confirming adult appointment attendance, regular communication with adult providers). Given the incomplete information provided by this indicator, it is impossible to know if patients are retained in adult healthcare, or perhaps not attending adult healthcare clinic appointments regularly or at all after their first appointment.

This study also supports the use of a longitudinal indicator of transition success related to retention in adult healthcare over time. Results suggest retention in adult healthcare is a meaningful measure of transition success based on its relations to medical outcomes in the critical first few years of transition among AYA transplant recipients. As was found when evaluating the criteria of attending an adult healthcare appointment within one-year of transfer, those who were not retained in healthcare over three years also had higher rates of rejection episodes and transplant re-evaluations (indicating previously transplanted organ failure). In addition, and beyond the findings for the timing of initial engagement within one-year criteria, those who were not retained in adult healthcare had a significantly greater number of hospitalizations and variability in immunosuppressant levels. Thus, the three-year retention criteria was more sensitive to a greater number of meaningful clinical outcomes. The findings regarding rejection episodes and graft loss are consistent with a national study of kidney transplant outcomes post-transfer, in which Coyne and colleagues (2017) reported that rates of organ graft loss increased from 4% to 10.8% during the three years post-transfer, and the number of individuals who lost their graft increased every year following transfer. The finding of poorer medication adherence as determined by the MLVI for less frequent clinic attenders is consistent with research indicating that, across several years post-transfer, AYA organ transplant recipients demonstrate increasing nonadherence (Annunziato et al., 2007; Coyne et al., 2017). The current study adds to this literature by suggesting that increased nonadherence may also relate to poorer retention in adult healthcare. Those patients who are not attending regular adult appointments may experience limited accountability in adhering to their medication-taking. In the current study, successful retention in adult healthcare was also associated with fewer hospitalizations. This is consistent with multiple previous studies among AYA transplant recipients and those

with kidney failure, in which attendance at adult clinic appointments decreases in the year post-transfer (Chaturvedi, Jones, Walker, & Sawyer, 2009; Remorino & Taylor 2006) while the duration of hospitalizations increases post-transfer (Chaturvedi et al., 2009), as well as the rate of *avoidable* hospitalizations, including those related to infection, rejection, or dehydration (Samuel et al 2014).

In comparing these two indicators of success, timing of first engagement with adult healthcare has the benefit of being more readily accessible, easier to determine, and convenient, as it requires only one time point of assessment. However, it is also limited by this cross-sectional nature. Retention in adult healthcare, while more time intensive to determine, yields more descriptive information over time, is able to identify different trajectories in appointment attendance, and, in the current study, is also in the current study related to more long-term clinical outcomes, including medication adherence and hospitalizations over the first three years post-transfer. As an indicator of transition success, maintained engagement in adult healthcare also has the benefit of encompassing the previous indicator (i.e., timing of engagement with adult healthcare) and recognizing the importance of continuing to monitor outcomes and attendance throughout this vulnerable period among AYA organ transplant recipients. While it is critical to attend the first appointment in the adult healthcare setting, this alone is not sufficient, particularly given evidence of significantly declining rates of attendance after transfer.

In the current study, growth curve analyses revealed a significant decline in appointment attendance across the first three years post-transfer, as well as significant variation in the rate of initial appointment attendance in the first-year post-transfer. This further supports that notion that a multi-faceted approach to understanding transition success (i.e., timing of first engagement *and* retention) is necessary to fully capture what is occurring in this vulnerable period. In the

United States Scientific Registry of Transplant Recipients in which clinics within the Organ Procurement and Transplantation Network submit data regarding all waitlisted and transplanted organ recipients, there are increases in missing data each year following transfer, possibly indicative of decreased attendance at appointments or increased loss to follow up (Coyne et al., 2017). This drop off in attendance has also been clearly shown in other medical populations following transfer to adult healthcare, including multiple studies among AYAs with diabetes (Sheehan, While, & Coyne, 2014). The current study's findings and the findings of previous research underscore the first three years post-transfer as being a critical time for possible decline in attendance and medical status, and emphasizes an opportunity for targeted support for those at risk for these poorer outcomes.

In order to provide this support and intervention, it is essential to understand who is at risk for poorer attendance, including the individual and systemic factors related to retention in adult healthcare. In the current study, transition success was related to greater time since transplantation. It is possible that patients who receive an organ transplant earlier in childhood have greater time to adjust and achieve a sense of normalcy and routine prior to transferring to adult healthcare, while those who receive a transplant later in development experience a more difficult adjustment, closer to the transfer event. Transplantation during adolescence, as compared to earlier in childhood, has been related to lower medication adherence, one aspect of the medical regimen that AYAs must adhere to, in addition to attendance at lab and clinic appointments (Berquist et al., 2006). While adjusting to the complex medical regimen required of organ transplant recipients is already difficult, transplantation during adolescence, a developmental period fraught with its own physical changes and psychological stressors, is thus posited to be exponentially more challenging. As such, AYAs who are more recently

transplanted, thus simultaneously adjusting to their new organ with associated medical regimen requirements *and* adolescence and young adulthood, may be at increased risk for unsuccessful transition and management of their care, particularly in the transition to adult healthcare.

Those who were not successfully retained in adult healthcare in the first three years post-transfer reported significantly higher levels of anxiety prior to transfer. Although not statistically significant, depression symptoms prior to transfer were also higher among those who were not retained as compared to those who were successfully retained in adult healthcare. Severity of mental health symptoms has been similarly linked to medication adherence, such that greater symptom severity was significantly related to poorer medication adherence among recently transferred transplant recipients (Annunziato et al., 2015). Additionally, previous research has demonstrated a significant interaction between adherence and changes in mental health following transfer, further underscoring the need to monitor mental health and adherence to the medical regimen after transfer to adult healthcare (Annunziato et al., 2015). The current study's results and prior literature support the notion that pre-transfer efforts to help patients lower anxiety and depression are needed, and that these efforts should continue post-transfer, as mental health symptoms, including anxiety and depression, are found to be stable over time among AYAs (Prenoveau et al 2011; Fergusson, Horwood, Ridder, & Beautrais, 2005), and mental health is critically important to general health outcomes among youth (Halfon, Larson, & Slusser, 2013; Lavigne & Faier-Routman, 1992). While the current study determined several factors helpful in identifying those at risk but not modifiable via intervention (e.g., time since transplant), anxiety and depression are potentially modifiable risk factors for unsuccessful transition that warrant continued intervention and future research.

Interestingly, reported transition readiness prior to transfer was not related to actual transition success. While future research is needed to determine why this may be the case, it is possible that AYAs are not able to accurately predict their own transition readiness without fully understanding and experiencing the demands of adult healthcare. A recent survey of pediatric liver transplant providers revealed that discussions with AYAs regarding transition were most frequently centered on medication adherence, condition knowledge, and medical history, while topics related to finances and medication coverage were rarely discussed (Gold, Martin, Breckbill, Avitzur, & Kaufman, 2015). Further education about what is required of patients in adult healthcare settings may be warranted, with transition preparation occurring earlier and in a more standardized manner, and involving AYAs more actively regarding topics they are likely to encounter in adult healthcare, such as insurance coverage (Chaturvedi et al., 2009; Gold et al., 2015).

Several systemic factors were related to transition success, including organ type and insurance status. Among kidney transplant recipients, there was a significantly lower percentage of those with successful transitions as compared to heart and liver transplant recipients. Future research will need to investigate this further; however, it is possible that in the event that a kidney transplant fails, there is the option to receive regular dialysis treatments as a means of prolonging life and available time until another organ becomes available. This may serve as a "safety net" of sorts for this organ group, and thus, the necessity of establishing regular care may not appear as essential. Additionally, in the current study, having private insurance was related to greater rates of transition success as compared to public or no insurance. This is consistent with a prior study among AYAs with sickle cell disease, in that Darbari and colleagues (2019) found significantly higher rates of transition success among those with private insurance as compared

to public or no insurance. Private insurance status may be related to lower barriers to attending appointments as compared to individuals with Medicaid or no insurance (e.g., not having to self-pay), and may account for the significant results in the present study. It is important to note that post-transfer insurance status was likely confounded with AYAs socioeconomic status post-transfer, and, though post-transfer SES was not assessed, higher SES among individuals with private insurance may also account for differences in the current study. Relatedly, in the state of Georgia, Medicaid transportation is available to patients, which is one manner of reducing barriers to attending appointments and may partially explain the current study's finding that distance from facility was not related to transition success, which was inconsistent with Andemariam and colleagues' (2014) findings regarding further distance from facility relating to poorer transition among AYAs with sickle cell disease.

The current study presents a multitude of areas for possible intervention to further understand and improve transition among AYA transplant recipients. It is not enough to focus on preparing AYAs prior to the transfer event. It is also essential to assist those who *have* transferred. As such, on the adult side of healthcare, providers should monitor and be ready to intervene with those AYAs who have drifted in their attendance. Prior to intervention, it is important for adult providers to be aware of several identified risk factors for decreased retention in adult healthcare, including individuals who have Medicaid or no health insurance, those with elevated anxiety pre-transfer, those closer to the transplant event, and those who received a kidney transplant. Given the limited research thus far, it is important to monitor these individuals more closely post-transfer, as it remains to be seen what factors are functionally tied to these poorer outcomes. Future research is needed to understand these and other potential risk factors for poorer retention in adult healthcare, as well as assess possible interventions. To promote

attendance at appointments in adult healthcare, clinics may consider offering evening or weekend hours to allow for AYAs who are now working or going to school and thus do not have the time or financial flexibility to take time off to receive care. Additionally, there is the opportunity to move towards telehealth appointments, particularly for medical populations which are rarer and have less clinics available in their region or with limited availability. Transplant recipients may be able to get their labs drawn at a facility closer to their home and have regular telehealth appointments with their provider, supplemented with more infrequent in person clinic visits. Lastly, the current study showed that individuals who received a kidney transplant and those who were more recently transplanted were more likely to be unsuccessful in the transition to adult healthcare. As such more targeted transition planning and preparation may be necessary for these AYAs, with greater follow-up on continued attendance after transfer. One way to broaden the information available during this time is for pediatric and adult providers to communicate about patients who are transferring care and be alerted when individuals are not attending appointments. In a recent study across several institutions, many pediatric and adult transplant coordinators reported a desire for continued collaboration post-transfer, but only 60% of centers actually routinely do so (Lerret et al., 2012). This more prolonged "soft hand-off" of transition allows the pediatric provider to bring both the established relationship with the patient and potential knowledge of previous strategies aimed at improving attendance, while simultaneously facilitating patient and adult provider relationship building.

Despite the significant strengths the current study adds to the paucity of transition literature in organ transplant, there are several limitations which must be considered, as well as future directions. Transfer to adult healthcare during periods of crisis (e.g., pregnancy, legal involvement) when pediatric providers are unable or unwilling to continue providing care is one

possible complication of this process (Sawyer. Blair, & Bowes, 1997). As such, one limitation of the current study is the unknown context of different life stressors which may have been occurring when transfer was initiated. Additionally, some patients may have participated in transition readiness programming within or outside of the pediatric institution that is not documented, which may have influenced transition success. There remains the possibility that patients initially transferred care to the current adult healthcare institution and then changed to a different adult facility without documentation in the medical chart, and thus may have received and maintained care during the study period. The present study is also limited by the small sample size and recruitment in one geographical location. As such, the current sample may not be generalizable to the broader transplant population undergoing transition of care, particularly given that the children's facility and adult facility are geographically close with a professional partnership. However, despite this small sample size, results still emerged that were statistically significant and present areas for future research. Additionally, some of the findings were not significant at $p = .052$ and .054, with some nonsignificant findings demonstrating medium to large effect sizes. Larger and multisite samples are needed in order to increase sample size and to enhance the generalizability of the findings. Given difficulties among AYA transplant recipients during the transition period, assessment regarding the efficacy of current transition readiness programming may also be warranted, as well as attention towards developing future intervention strategies. Lastly, research is needed to assess psychological functioning, responsibility for healthcare tasks, and quality of life following transfer. As is found in the pediatric literature, it is likely that these variables are also associated with health outcomes in the post-transfer period. Finding relations between post-transfer functioning and healthcare outcomes would also suggest opportunities for targeted intervention.

Conclusion

In response to the great need to examine transition success among organ transplant recipients, the current study demonstrated a significant decline in appointment attendance over the three years post-transfer to adult healthcare, with successful retention in adult healthcare over these three years related to improved medical outcomes, including medication adherence and fewer hospitalizations. Retention in adult healthcare was also related to several individual and systemic factors, including greater time since transplant, lower pre-transfer anxiety, and having private insurance. Findings from the current study underscore the importance of continuing to provide support for AYAs after transfer. It is not enough to merely focus on preparation prior to the transfer event. Areas for potential intervention and future research include continuing to identify risk factors for declining attendance and improving accessibility of care during the tumultuous period of adolescence and young adulthood, as well as systematically assessing post-transfer psychological functioning and healthcare responsibility.

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Table 1. *Sample Demographics and Study Variables*

		Descriptives/Frequencies (N=49)	
Sample demographics		*M*(*SD*)/n(%)	Range
Age at transfer (yrs)		20.62(0.52)	18.67-21.42
Time since Transplant (yrs)		10.42(5.92)	2.75-20.50
Gender (male)		27(55%)	
Transplant Type	Kidney	22(45%)	
	Liver	17(35%)	
	Heart	10(20%)	
Race	White	26(53%)	
	Black	17(35%)	
	Asian	3(6%)	
	Biracial	3(6%)	
Ethnicity	Hispanic	4(8%)	
	Non-Hispanic	45(92%)	
Insurance	Private	23(47%)	
	Public or uninsured	26(53%)	
Study variables		*M*(*SD*)/n(%)	Range
Number of ED visits		.96(1.46)	0-6
Number of hospitalizations		.57(1.02)[a]	0-4
Duration of hospitalizations (days)		2.53(5.84)[a]	0-26
Number of appointments attended year 1		1.61(1.11)	0-4
Number of appointments attended year 2		1.32(1.14)	0-4
Number of appointments attended year 3		1.06(1.06)	0-3
MLVI[b]		2.61(1.90)	.37-7.78
Adherent by MLVI[b] cutoff		17(59%)	
Experienced rejection episodes		6(12%)	
Revaluated for transplant		8(16%)	
Relisted for transplant		1(2%)	
Death		1(2%)	
RTQ teen responsibility		32.36(5.79)	15-40
RTQ parent involvement		30.19(8.62)	10-40
RTQ overall subscale		5.51(1.60)	2-8
BASC anxiety T-score		42.17(11.69)	32-85
BASC depression T-score		46.28(10.56)[a]	40-89
Miles from adult facility		94.54(256.45)[a]	6.64-1796.76

Note.

[a]Indicates skewed variable

[b]Only *n*=29 participants were taking Tacrolimus

Table 2. *Medical Outcomes Associated with Two Indicators of Transition Success: Timing of First Adult Healthcare Engagement and Retention in Adult Healthcare*

	Timing of first adult healthcare engagement (Attended first appointment within 1 year)				Retention in adult healthcare (average # of appointments attended in first three years ≥ 1)			
	Yes	No			Yes	No		
	M(*SD*)/n(%) *n*=37	*M*(*SD*)/n(%) *n*=12	*t*/*U*/χ^2	*Effect Size*	*M*(*SD*)/n(%) *n*=37	*M*(*SD*)/n(%) *n*=12	*t*/*U*/χ^2	*Effect Size*
Number of ED visits	.73(1.10)	1.67(2.15)	1.45[a]	0.55[a]	.65(.95)	1.92(2.23)	1.91[a]	0.74[a]
Number of hospitalizations	.46(.93)	.92(1.24)	168.50[b]	0.21[b]	**.35(.68)**	**1.25(1.55)**	**151.50[b]***	**0.28**[b]
Duration of hospitalizations	2.08(5.24)	3.92(7.49)	168.50[b]	0.21[b]	1.30(3.59)	6.33(9.25)	152.50[b]	0.28[b]
Rejection episodes	**2(5%)**	**4(33%)**	**10.29[c]****	**8.75[c]**	**3(8%)**	**3(25%)**	**7.29[c]***	**2.83[c]**
Transplant re-evaluations	**3(8%)**	**5(42%)**	**9.13[c]****	**8.10[c]**	**2(5%)**	**6(50%)**	**18.40[c]*****	**17.50[c]**
	n=24	*n*=5			*n*=26	*n*=3		
MLVI[d]	2.34(1.69)	3.92(2.46)	1.75[a]	0.75[a]	**2.35(1.65)**	**4.92(2.74)**	**2.40[a]***	**1.14**[a]
Adherent by MLVI[d] cutoff	16/24 (67%)	1/5 (20%)	3.72[c]	8.00[c]	16/26 (62%)	1/3 (33.%)	.88[c]	3.20[c]

Note. * $p < .05$, ** $p < .01$, *** $p < .001$. Bolded rows are significant. ED = Emergency department; MLVI = Medication Level Variability Index. Cohen's *d* interpretation: small effect = 0.20 - 0.49, medium effect = 0.50 - 0.79, large effect ≥ 0.80. Non-parametric *r* interpretation: small effect = 0.10 – 0.29, medium effect = 0.30 – 0.49, large effect ≥ 0.50. Odds ratio interpretation: >1 = increased incidence

[a]Independent samples t-test, Cohen's *d* effect size

[b]Mann-Whitney *U* test, non-parametric *r* effect size

[c]Fisher's Exact Test, Odds ratio effect size

[d]*n*=29 out of the full sample of 49 participants were taking Tacrolimus, from which MLVI data may be derived

Table 3. *Estimates of Basic Linear Growth Curve Model for Average Appointment Attendance Per Year in First Three Years Post-Transfer*

	Estimate	*p*-value
Intercept		
Mean (γ_{00})	1.612	.000***
Variance (τ_{00})	1.128	.002**
Slope		
Mean (γ_{10})	-0.281	.014*
Variance (τ_{11})	0.479	.006**
Model Fit		
AIC	367.667	
X_2 (df)	0.00(1)	.989
RMSEA	0.000	.989
CFI	1.000	
SRMR	0.001	

Note. *$p < .05$. ** $p < .01$. *** $p < .001$.

Table 4. *Individual and Systemic Factors Related to Transition Success*

	Retention in adult healthcare (average # of appointments attended in first three years ≥ 1)			
	Yes *M*(*SD*)/n(%) *n*=37	No *M*(*SD*)/n(%) *n*=12	*t*/χ^2/*U*	*Effect size*
Age at transfer	20.67(.48)	20.47(.62)	1.21[a]	0.36[a]
Time since transplant	**11.36(6.27)**	**7.51(3.45)**	**2.69[a]***	**0.76**[a]
RTQ Overall	5.69(1.64)	5.00(1.41)	1.29[a]	0.45[a]
RTQ Teen Responsibility	32.49(6.36)	32.00(3.86)	.25[a]	0.09[a]
RTQ Parent Involvement	30.51(9.16)	29.25(7.07)	.44[a]	0.15[a]
BASC Anxiety	**40.03(9.96)**	**48.25(14.38)**	**2.18[a]***	**0.67**[a]
BASC Depression	44.09(6.96)	52.50(15.92)	130.50[b]	0.28[b]
Driving distance to adult facility (miles)	47.73(42.49)	109.72(293.55)	237.00[b]	0.05[b]
Transplant Type				
Kidney	12(55%)	10(45%)	**5.11[d,e]****	**6.25**[d,e]
Liver	15(88%)	2(12%)	1.27[c,f]	0.30[c,f]
Heart	10(100%)	0(0%)	**6.61[c,g]****	**17.64**[c,g]
Gender				
Male	19(70%)	8(30%)	.86[d]	1.89[d]
Female	18(82%)	4(18%)		
Insurance Status				
Not private insurance	20(67%)	10(33%)	**4.56[c]***	**8.00**[c]
Private insurance	16(94%)	1(6%)		
Race				
Minority (i.e., non-White)	15(65%)	8(35%)	2.48[d]	2.93[d]
Non-minority (i.e., White)	22(85%)	4(15%)		

Note. * $p < .05$, ** $p < .01$, *** $p < .001$. Bolded rows are significant. Cohen's *d* interpretation: small effect = 0.20 - 0.49, medium effect = 0.50 - 0.79, large effect ≥ 0.80. Non-parametric *r* interpretation: small effect = 0.10 – 0.29, medium effect = 0.30 – 0.49, large effect ≥ 0.50. Odds ratio interpretation: >1 = increased incidence

[a]Independent samples t-test, Cohen's *d* effect size

[b]Mann-Whitney *U* test, non-parametric *r* effect size

[c]Fisher's Exact Test, Odds ratio effect size

[d]Chi Square Test for Independence, Odds ratio effect size

[e]Kidney vs. liver

[f]Liver vs. heart

[g]Heart vs. kidney

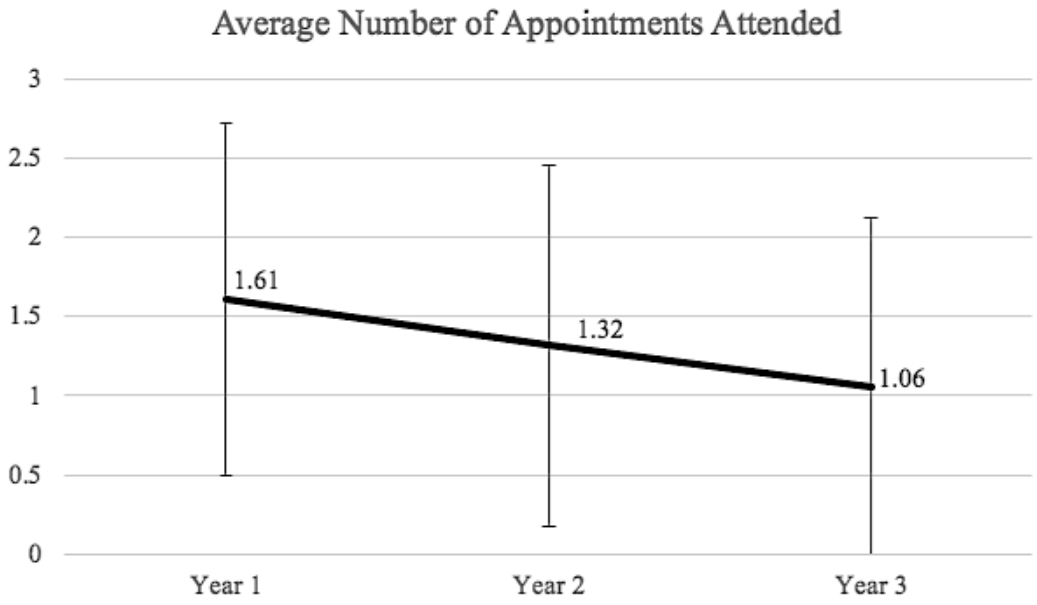

Figure 1. Trajectory of Appointment Attendance Over the First Three Years Post-Transfer.

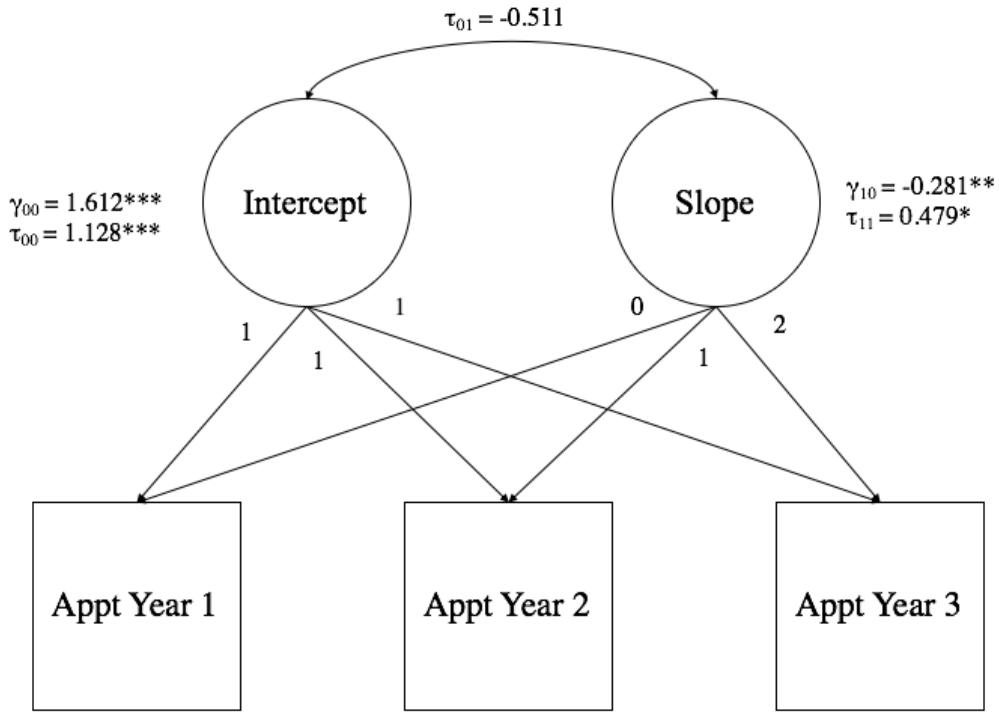

Figure 2. Linear Growth Curve Model and Estimates. Note. *$p < .05$. ** $p < .01$. *** $p < .001$.