OUT OF SIGHT, BUT NOT OUT OF MIND: HEALTH-RELATED QUALITY OF LIFE AND BIOPSYCHOSOCIAL FUNCTIONING FOLLOWING TRANSFER TO ADULT HEALTHCARE AMONG PEDIATRIC SOLID ORGAN TRANSPLANT RECIPIENTS

by

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(Under the Direction of Ronald L. Blount)

ABSTRACT

While transplantation is lifesaving, pediatric solid organ transplant recipients do not experience a return to "normal life." Biopsychosocial effects of organ transplantation, including medical management, modified life goals, and negative impacts on mental health, can result in impaired functioning into adulthood, though less is known about how functioning changes over time throughout transition to adult healthcare. Thirty-four young adult solid organ transplant (i.e., heart, kidney, liver) recipients completed questionnaires assessing pre- and post-transfer sociodemographic information, health-related quality of life (HRQOL), mental health symptoms, and self-efficacy. Results revealed decreases in functioning from pre- to post-transfer (i.e., increases in depressive symptoms) and significantly poorer HRQOL compared to healthy norms. Physical HRQOL was only significantly related to somatization symptoms, while variance in psychosocial HRQOL in the final model was significantly accounted for by age and reported self-efficacy. These results inform several future research and clinical directions.

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

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TABLE OF CONTENTS

Page

CHAPTER

LIST OF TABLES

Page

LIST OF FIGURES

Page

CHAPTER 1

INTRODUCTION

Solid organ transplantation is the treatment of choice for children facing end-stage organ failure as a result of diseases or disorders of the heart, liver, or kidney (LaRosa, Jorge Baluarte, et al., 2011). While transplantation is a life-saving and life-prolonging option for pediatric patients and families, it is increasingly recognized that transplantation is not a cure. Having an organ transplant offers children an opportunity for more typical development than would be available to them had they not had a transplant, including more opportunities for socialization, educational attainment, and improved physical growth and health (Burra & De Bona, 2007). However, despite having greater opportunity for typical development, this is not a return to "normal life." Maintenance of a transplanted organ requires life-long adherence to critical immunosuppressant medication to prevent organ rejection, as well as regular attendance at medical appointments and lifestyle changes to adhere to strict medical regimens, including adjustments to diet and limitations to previously desirable activities, such as contact sports (Dew et al., 2009). Furthermore, the biopsychosocial effects of undergoing an organ transplant, including ongoing medical management and side effects, modified or altered life goals, and negative impacts on mental health, can result in impaired functioning into adulthood (Rainer et al., 2010).

With advances in medical procedures and refinement of immunosuppressive treatment over time, more children receiving a solid organ transplant are surviving to adulthood (LaRosa, Jorge Baluarte, et al., 2011). As such, more young adult transplant recipients now experience transitions related to managing their complex medical condition, including transfer of care from pediatric to adult providers or settings and transition of healthcare responsibility from caregivers to the patients (LaRosa, Glah, et al., 2011). In addition to the changes required to manage their complex medical condition with greater independence and in a different setting, these young adults also simultaneously experience developmentally normative transitions in socialization and educational and employment opportunities. These developmental changes are coupled with desired gains in independence associated with adulthood, as is typical for all young adults, regardless of medical complexity (Eccles et al., 2003). Given the many demands on young adult patients with chronic medical conditions, there is increased focus on promoting successful transition to adult healthcare and overall wellbeing (Kennedy & Sawyer, 2008). Consistent with principles of adolescent medicine, the transition process ideally includes increases in self-management of disease, including adherence, understanding of condition, and appointment attendance, as well as attention to psychosocial factors, such as autonomy and development of peer relationships (Kennedy & Sawyer, 2008). This more holistic, person-centered approach to transition captures and recognizes the many biopsychosocial factors influencing young adult wellbeing, which extends well beyond their medical adherence and outcomes. It is not enough to merely maintain medical health; it is critical to consider and promote overall wellbeing across domains.

Quality of Life as a Critical Measure of Overall Wellbeing

One such measure of wellbeing across domains is quality of life. A recent Delphi study identified 10 critical healthcare transition outcomes as rated by an interdisciplinary group of providers working with adolescent and young adult patients with special healthcare needs (Fair et al., 2016). Of these 10 outcomes, eight were related to medical and healthcare variables aimed at promoting medical outcomes during transition, including condition and medication knowledge, adherence, insurance, appointment attendance, and avoiding hospitalizations (Fair et al., 2016). However, the remaining two outcomes were quality of life and having a social network of friends, highlighting the importance of psychosocial factors in promoting wellbeing among young adults with special healthcare needs (Fair et al., 2016). Further, across all ten identified critical outcomes, quality of life was the highest-rated outcome of importance across providers (Fair et al., 2016). Additionally, a recent review of the current state of quality of life literature among patients with congenital heart disease suggests that quality of life is the "ultimate outcome" of wellbeing, as it is uniquely associated with depression, social support, and perceived health, among other factors (Moons & Luyckx, 2019). This body of literature underscores the importance of assessing and understanding quality of life among young adult organ transplant recipients throughout the transition process.

Health-related quality of life (HRQOL) is multidimensional and individualized, capturing the biopsychosocial factors influencing one's subjective perception of how health impacts daily life through physical, mental, and social wellbeing (Burra & De Bona, 2007; Centers for Disease Control and Prevention, 2018; Post, 2014). As detailed by Ferrans and colleagues' (Ferrans et al., 2005) revision of the conceptual model established by Wilson and Cleary (Wilson & Cleary, 1995), many factors impact HRQOL at the individual and environmental level, including those related to biological functioning, symptoms of altered physical or emotional state, ability to perform day-to-day activities, and general health perceptions (see Figure 1). Measuring HRQOL throughout the transition process presents an opportunity to capture young adult wellbeing influenced by a variety of factors and occurring throughout developmental changes happening during this time, particularly for those young adults with special healthcare needs, such as solid organ transplantation. However, given the many, complex biopsychosocial influences on HRQOL among young adults with solid organ transplants, it is essential to understand what domains have the largest effect on HRQOL to inform targeted intervention and promote wellbeing among this vulnerable population.

Biopsychosocial Influences of Pediatric Organ Transplantation

To adequately understand the complexity of factors impacting young adult transplant recipients and their HRQOL, it is necessary to understand the biopsychosocial impacts of transplantation occurring across the lifespan, beginning in childhood.

Childhood. Children who have undergone kidney, liver, and heart transplantation are noted to have negatively impacted neurocognitive functioning, including difficulties with attention and lower intellectual functioning (Annunziato et al., 2012; Cushman et al., 2020; LaRosa, Jorge Baluarte, et al., 2011). Poorer neurocognitive functioning as a result of end-stage organ failure and eventual organ transplantation can subsequently decrease educational attainment due to challenges learning and functioning in a school setting (Annunziato et al., 2012). Furthermore, increased school absences as a result of illness, medical appointments, or hospitalizations for health crises can negatively influence peer socialization and additionally impact academic achievement (Amatya et al., 2021). Limited social interaction with peers or reduced social skills can subsequently effect young transplant patients' mental health, including increased depressive symptoms or behavioral concerns (Annunziato et al., 2012). For young solid organ transplant recipients, these biopsychosocial influences, which disrupt HRQOL and overall wellbeing during childhood, may further persist into adolescence and adulthood.

Adolescence. In addition to the ongoing impacts of transplantation from childhood, several biopsychosocial factors impacting patient wellbeing emerge specifically during adolescence. Difficulties with planning and organizing associated with the neurocognitive impact of transplantation have demonstrated effects beyond the school setting for adolescent pediatric transplant recipients, including negatively impacting the transition to adult healthcare among kidney recipients (Amatya et al., 2021). Adolescent transplant recipients may experience pubertal delays or disruptions associated with previous experiences of organ failure, further impacting physical growth and negatively affecting ongoing peer socialization and development of romantic relationships (LaRosa, Glah, et al., 2011; LaRosa, Jorge Baluarte, et al., 2011). Pediatric transplant recipients are found to have a lower rate of romantic relationships and friends when compared to healthy peers (LaRosa, Glah, et al., 2011). Increases in social comparison occurring during adolescence and body image or self-esteem issues associated with organ transplantation (e.g., procedural scars) and treatment (e.g., steroid medication-related weight-gain) can also lead to poorer HRQOL among adolescent transplant recipients (Anthony et al., 2010). Combined with biological and physical impacts of transplantation experienced during adolescence, mental health and social impacts can be detrimental to adolescents' wellbeing, with continued impacts into and throughout adulthood.

Adulthood. During transition to adulthood, many transplant recipients experience desired increases in independence and decreased caregiver support, while navigating the compounding biopsychosocial effects of transplantation occurring in childhood and adolescence. These include influences on employment, peer relationships, and lifestyle, as well as medical outcomes. Puma and Doyle (Puma & Doyle, 2021) provide a recent conceptualization of the impact of organ failure and transplantation on adults transplanted in childhood. Early disruptions in childhood education can lead to lower achievement and greater barriers to gaining and keeping employment in adulthood. This has further impact on the management of patients' transplant, as greater disruptions in or barriers to employment can negatively impact access to health insurance and thus necessary healthcare. With regard to peer relationships, reluctance to disclose information regarding their medical condition may impact young adult transplant recipients' ability to build intimate relationships and result in social isolation. Ongoing effects of body image or self-esteem concerns further impact intimate relationship-building. Additionally, the medical impact of organ failure and managing a transplanted organ may influence family-planning (e.g., potential for inheritability of congenital disease, infertility) or reproductive health (e.g., increased risk for sexually transmitted infections due to immunosuppression; (LaRosa, Glah, et al., 2011). Further impacting socialization, young adult transplant recipients may live with their caregivers instead of with peers or independently due to difficulties with employment, financial stability, or medical management. Medical mismanagement presents a significant concern for adolescent and young adult transplant recipients. Rates of non-adherence to critical, life-saving immunosuppressant medications are significantly higher among adolescent and young adult patients when compared to both younger and older patient groups (Annunziato et al., 2007; Foster et al., 2011; Samuel et al., 2011; Smith et al., 2002). Increased adolescent and young adult independence and decreased parental supervision of medication-taking likely accounts for some of the declines in medication adherence during this time. As such, in addition to the psychosocial transitions occurring at this time, young adult transplant recipients are at increased risk for poorer medical outcomes due to nonadherence, including increased rates of organ rejection, loss, and even death, further impacting wellbeing (Annunziato et al., 2007; Foster et al., 2011; Samuel et al., 2011; Smith et al., 2002).

Findings Among Young Adult Transplant Recipients or Adults Transplanted in Childhood

Several studies have examined biopsychosocial outcomes among young adult transplant recipients and adults transplanted in childhood. Studies examining social and lifestyle outcomes reveal several, long-term impacts of pediatric transplantation on adult outcomes for transplant recipients. Fewer educational achievements were reported by young adult liver transplant recipients, with only half of these young adults believing they have the same likelihood for success in their vocational plans when compared to healthy peers (Dommergues et al., 2010). Across several studies, findings suggest lower rates of full or part-time work (Lewis & Marks, 2014) and greater likelihood for unemployment for transplant recipients (Mellerio et al., 2014). Being employed has demonstrated positive associations with higher HRQOL, as well as associations with reduced likelihood of graft failure and increased survival (Petersen et al., 2008; Tjaden et al., 2014). While the majority of transplant recipients in one study reported currently or previously having been in a “love relationship,” difficulties establishing intimate relationships and embarrassment about showing scars or disclosing information about their transplant were noted across several studies of young adult transplant recipients (Bailey et al., 2018; Dommergues et al., 2010). Studies consistently demonstrated higher rates of living with their caregivers and lower rates of living with a partner among transplant recipients, such that being married or living with a partner is associated with greater life satisfaction (Massey et al., 2015; Mellerio et al., 2014). Qualitatively, young adult kidney transplant recipients noted specific difficulties establishing intimate relationships and perceived social isolation (Bailey et al., 2018). It was noted that, while transplantation provides some return to normalcy, patients expected to feel more similar to their peers than they actually did once the end goal of transplantation was reached (Bailey et al., 2018). Achievement of social milestones, such as establishing friend groups and dating, was related to greater overall wellbeing among young adult kidney recipients (Massey et al., 2015).

During transition to adult care, as previously noted, young adult transplant recipients' medical outcomes and adherence to life-saving medications and medical regimens remain a significant concern. Young adult transplant recipients experience high rates of medication non-adherence, organ rejection, and even death when compared to other age groups (Annunziato et al., 2007; Foster et al., 2011; Samuel et al., 2011; Smith et al., 2002). Notably, higher levels of psychological distress have been linked to poorer immunosuppressant medication adherence among young adult transplant recipients during transition of care (Annunziato et al., 2015), suggesting that, not only is it important to consider the emotional wellbeing of young adult transplant recipients as a means of promoting desirable mental health outcomes, but also for promoting desired medical outcomes. However, the link between psychological wellbeing and adherence has not been consistently demonstrated (Massey et al., 2015) and, as such, attention to understanding and improving each of these factors is still needed during transition.

Several studies have also examined mental health and psychological outcomes among young adults and adults transplanted in childhood. The majority of young adult liver transplant recipients note specific feelings of loneliness and anxiety about their health and future (Dommergues et al., 2010). When comparing adults transplanted in childhood to those transplanted as adults, adults transplanted in childhood report greater psychological distress, including greater interpersonal sensitivity and hostility as measured via the SCL-90-R (Cavalli et al., 2019). Among adults transplanted in childhood, higher self-esteem predicted greater positive affect while poorer physical self-concept related to greater negative affect (De Castro et al., 2007). Greater perceived competence and autonomy was also associated with greater overall wellbeing for young adult kidney transplant recipients (Massey et al., 2015). While the majority of young adult transplant recipients in one study reported their HRQOL as “good” or “very good” (Dommergues et al., 2010), another study noted that almost all subscales related to HRQOL, as measured by the Short Form Health Survey (SF-36), were significantly lower among young adult kidney transplant recipients when compared to healthy norms (Aasebø et al., 2009). Interestingly, when comparing SF-36 scores between adults transplanted in childhood and those transplanted as adults, adults transplanted in childhood reported better HRQOL than those transplanted in adulthood (Cavalli et al., 2019).

The importance of supporting transition for young adult organ transplant recipients has been well established, particularly in the transition to new healthcare settings and providers and promoting adherence. However, developmental transitions associated with young adulthood are simultaneously occurring with these transitions in healthcare and medical management, which may further influence young adult transplant recipients’ wellbeing, and receive less attention during transition preparation. Prior studies consistently demonstrate reduced HRQOL among organ transplant recipients across the life span (Burra & De Bona, 2007; Dobbels et al., 2007; Parmar et al., 2017; Tome et al., 2008). However, it is not yet known which of the many biopsychosocial factors most effect HRQOL among young adult transplant recipients.

Gaps in Current Literature

Negative impacts on HRQOL and wellbeing are evident among pediatric solid organ transplant recipients across a variety of developmental periods, including cross-sectional literature examining wellbeing during childhood (Annunziato et al., 2012) and adolescence (LaRosa, Glah, et al., 2011). However, it is not yet clear whether wellbeing is stable or changes over time during the unique transition from pediatric to adult healthcare (Annunziato et al., 2012). Thus, longitudinal research in this area is specifically warranted. Additionally, with quality of life emerging as an “ultimate outcome” among adult patients in other chronic illness populations (Moons & Luyckx, 2019), there is a need to understand which biopsychosocial factors most influence HRQOL for young adult transplant recipients, so as to inform the assessment of patient wellbeing and to provide targeted intervention.

Study Aims and Hypotheses

The overall aim of the present study is to examine HRQOL and biopsychosocial functioning among young adult solid organ transplant recipients during the transition to adult healthcare, particularly in the post-transfer period. Specific aims of the present study are threefold. First, the present study aims to characterize longitudinal changes in pre- and post-transfer functioning among young adult organ transplant recipients during the critical period of transition. It is hypothesized that, given the unique challenges faced by these young adults during transition and early adulthood, post-transfer HRQOL and biopsychosocial functioning, as indexed by medication adherence and mental health symptoms, will be poorer than functioning prior to transfer of care. Second, the present study seeks to compare psychosocial functioning and HRQOL of young adult organ transplant recipients to healthy adult norms to increase understanding of the unique challenges faced by organ transplant recipients, beyond typical developmental challenges faced during transition to adulthood by healthy young adults. It is hypothesized that, compared to norms, young adult organ transplant recipients will experience poorer HRQOL across domains, as well as poorer psychosocial functioning, including greater mental health symptoms and lower rates of employment. Lastly, given the complex biopsychosocial factors pervasive throughout young adulthood, the present study seeks to explore what factors account for the most variance in the critical outcome of HRQOL post-transfer, including demographic variables, post-transfer medical or healthcare factors (e.g., time since transplantation, time since transfer of care, acute health challenges), and post-transfer psychosocial functioning (e.g., mental health symptoms, perceived self-efficacy).

CHAPTER 2

METHODS

Participants

Participants include 34 young adult organ transplant recipients recently transitioned to adult healthcare from their pediatric transplant institution, with recruitment occurring from May 2019 to August 2021. The current study was part of larger longitudinal investigations examining the experiences of children with solid organ transplants. Inclusion criteria include 1) having previously received an organ transplant during childhood prior to transition to adult healthcare, 2) having no documented or reported developmental delay or disorder which would impact independent participation in study, and 3) having English language proficiency to complete measures. This investigation was approved by the Institutional Review Board of participating institutions.

Procedures

In compliance with COVID-related social distancing measures and limitations for on-site data collection, electronic data capture was utilized when available or paper questionnaires were sent to participants to be returned via mail in instances in which internet access or devices are not available or when paper questionnaires are preferred. Electronic survey links completed remotely were sent to participants and data collected using REDCap (Research Electronic Data Capture). REDCap is a secure, web-based platform supporting data capture for research studies (Harris et al., 2009, 2019). Participants were identified through medical chart review to determine date of transfer to adult facility, as well as contact information for email or mailing questionnaires. Only participants transitioning to the adult facility (Emory University Hospital) partnered with the pediatric institution (Children's Healthcare of Atlanta [CHOA]) were included, given established access to the adult institution's medical record systems.

Data Collection/Measures

Medical Chart Review. Medication adherence information using the Medication Level Variability Index (MLVI) was extracted from the medical charts of all participants taking tacrolimus as their primary immunosuppressant medication. 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 (i.e., lower adherence). In the current study, MLVI was used as both a continuous (i.e., higher MLVI = lower adherence) and a categorical measure, using a predefined threshold of MLVI > 2.5 SD in determining non-adherence. An MLVI cut-off of 2.5 standard deviations has demonstrated clinical relevance in recent studies of non-adherence in both pediatric and adult organ transplant populations (Shemesh et al., 2017; Christina et al., 2014). For calculation of the MLVI, one-year adherence prior to transfer was compared to one-year post-transfer adherence.

Pre-Transfer Measures. All eligible participants completed several psychosocial measures prior to transfer of care. These include the Behavior Assessment System for Children, 2nd Edition (BASC-2 SRP-A) and Pediatric Quality of Life Inventory, 4th Edition (PedsQL 4.0).

Behavior Assessment System for Children – 2nd Edition (BASC-2). Prior to transfer, participants completed 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) to assess pre-transfer mental health and emotional functioning. The Anxiety subscale assesses cognitive and physiological components of anxiety, including “I worry about little things” and “I can never seem to relax.” The Depression subscale assesses endorsement of items such as “Nothing goes my way” and “I don't seem to do anything right.” All items are rated on a four-point scale (i.e., 0=*Never*, 1=*Sometimes*, 2=*Often*, 3=*Almost always*). Raw scores were summed and transformed into *T*-scores based on age and gender norms, with final *T*-scores used in the subsequent analyses. In the current study, the BASC-2 Anxiety subscale achieved an excellent level of internal reliability (α = 0.93) and the BASC-2 Depression subscale achieved an excellent level of internal reliability (α = 0.93).

Pediatric Quality of Life Inventory – 4th edition (PedsQL 4.0). Prior to transfer, participants also completed the Pediatric Quality of Life Inventory, 4th Edition (PedsQL 4.0; (Varni et al., 2003) self-report to assess perceived HRQOL. The PedsQL consists of 23 items across four scales (Physical Functioning, Emotional Functioning, Social Functioning, and School Functioning), which combine into three summary scores (Physical Health Summary Score, Psychosocial Health Summary Score, and Total Scale Score). Items are rated on a four-point scale (i.e., 0=*Never*, 1=*Almost Never*, 2=*Sometimes*, 3=*Often*, 4=*Almost Always*). For scoring, items are reverse scored and linearly transformed to a 0-100 scale (i.e., 0=100, 1=75, 2=50, 3=25, 4=0), such that higher scores indicate greater HRQOL. Within scales and summary scores, item values are averaged based on the number of items completed (i.e., sum of the reverse and linearly transformed items divided by the number of items completed) to account for any missing data. In the current study, the PedsQL Physical subscale achieved an excellent level of internal reliability (α = 1.00) and the PedsQL Psychosocial subscale achieved an excellent level of internal reliability (α = 0.98). The PedsQL Total score achieved excellent internal reliability (α = 0.99).

Post-Transfer Measures. Eligible participants were invited to complete post-transfer psychosocial follow up. These questionnaires include a study-developed demographics form, the 36-Item Short Form Health Survey (SF-36), Brief Symptom Inventory-18 (BSI-18), and PROMIS General Self-Efficacy (GSE) scale.

Demographics Questionnaire**.** Following transfer, participants completed a comprehensive demographics form assessing gender, race, ethnicity, current health insurance, primary policy holder on health insurance, relationship status, years of schooling completed, current employment or educational status and occupation (if applicable) and/or schooling structure (if applicable; i.e., high school, community college/junior college, 4-year college/university, pursuing advanced degree), estimated yearly income, sources of financial support, and current living arrangement. For all questions, participants were given the option to indicate a free response option or provide additional qualitative information if there was not option that most accurately described their experience.

36-Item Short Form Health Survey (SF-36). After transfer, participants also completed the 36-Item Short Form Health Survey (SF-36; (Ware Jr & Sherbourne, 1992) to assess perceived HRQOL after transferring to adult care. The SF-36 is a well-validated measure of HRQOL which includes eight health domains: physical functioning, bodily pain, role limitations due to physical health problems, role limitations due to personal or emotional problems, emotional wellbeing, social functioning, energy/fatigue, and general health perceptions, as well as a single item indicator for perceived changes in health over time. Perceptions of health and impacts on HRQOL are rated based on perceived impacts over the last four weeks. Items are rated anywhere from a two- to six-point scale, depending on item response categories (e.g., 1=*Yes*, 2=*No* versus 1=*All of the time*, 2=*Most of the time*, 3=*A good bit of the time*, 4=*Some of* *the time*, 5=*A little of the time*, 6=*None of the time*). Items are reverse scored and linearly transformed to a 0-100 scale, depending on the number of item response categories (e.g., 1=100, 2=0 versus 1=0, 2=20, 3=40, 4=60, 5=80, 6=100), such that higher scores indicate greater HRQOL. Items within each scale are averaged to obtain domain scores based on the number of items completed (i.e., sum of the reverse and linearly transformed items divided by the number of items completed) to account for any missing data. Physical Component Score and Mental Component Scores are calculated by z-score transformation of the eight subscale domains, multiplying z-scores by established factor coefficients to yield the component score, and, finally, transforming to norm-based *T*-scores (J. E. Ware et al., 1994; M. E. Ware et al., 2001). The SF-36 has demonstrated appropriate validity and reliability in its initial validation (Ware Jr & Sherbourne, 1992), as well as appropriate validity and reliability among adult organ transplant recipients (Feurer et al., 2004; Gómez-Besteiro et al., 2004). In the present study, SF-36 subscale scores achieved acceptable to excellent internal reliability (α's ranging from 0.70 to 0.93).

Brief Symptom Inventory (BSI-18). Following transfer, participants also completed the self-report Brief Symptom Inventory-18 (BSI-18; Derogatis & Derogatis, 2000). The BSI-18 assesses symptoms of anxiety, depression, and somatization across three subscales, respectively, and includes a composite score capturing overall psychological distress (Global Severity Index; GSI). Using a five-point scale (i.e., 0=*Not at all*, 1=*Rarely/Occasionally*, 2=*Sometimes*, 3=*Often*, and 4=*Extremely Often*), participants will rate their psychological symptoms (e.g., "Feeling tense or keyed up") within the past week. Raw subscale and composite scores were converted to gender-normed *T*-scores, with higher scores indicating more distress. Scores were primarily examined via continuous scales, though descriptive information about clinical cut-offs within the sample is also be reported, such that GSI and subscale *T*-scores ≥ 63 indicate clinically elevated levels of psychological distress. The BSI-18 has demonstrated appropriate validity and reliability at initial validation (Derogatis & Derogatis, 2000) and more recently among adult stem cell transplant recipients (Pillay et al., 2015). In the current study, all BSI-18 subscales achieved a good level of internal reliability (Somatization subscale: α = 0.89; Depression subscale: α = 0.89; Anxiety subscale: α = 0.85). The BSI-18 GSI achieved excellent internal reliability (α = 0.94).

PROMIS General Self-Efficacy (GSE) Scale. After transfer, participants also completed the PROMIS General Self-Efficacy (GSE) Scale 4-item short form to assess their perceived ability to problem-solve and confidence in their ability to manage life situations (Salsman et al., 2019). Participants rated their confidence on a five-point scale (i.e., 1=*I am not at all confident*, 2=*I am a little confident*, 3=*I am somewhat confident*, 4=*I am quite confident*, and 5=*I am very confident*) for various statements including "I can manage to solve difficult problems if I try hard enough" and "I can handle whatever comes my way." The raw score for GSE is calculated by summing all items. Raw scores were converted to *T*-scores using freely available PROMIS score conversion tables (available at: https://www.healthmeasures.net/promis-scoring-manuals). The GSE has demonstrated appropriate reliability and validity as an emerging measure of self-efficacy (Salsman et al., 2019), with previously established PROMIS measures across various domains demonstrating appropriate reliability and validity among adult heart transplant recipients (Flynn et al., 2015). In the current study, the PROMIS GSE achieved a good level of internal reliability (α = 0.84)

Analytic Strategy

Data storage and analyses were conducted in SPSS v27. Initial descriptive analyses were run on study variables to assess assumptions of normality.

Aim 1: Comparing Pre- and Post-Transfer HRQOL and Biopsychosocial Functioning. To compare HRQOL and biopsychosocial functioning across pre- and post-transfer among young adult organ transplant recipients, paired sample t-tests were conducted within domains to examine changes in domains across transfer, as well as Pearson bivariate correlations to further characterize the relationship between pre- and post-transfer functioning. To examine changes in HRQOL, PedsQL Physical and Psychosocial Health Summary Scores and SF-36 Physical and Mental Component Summary scores were standardized and expressed as *T*-scores according to established norms and paired sample t-test analyses performed within HRQOL domains (e.g., comparing PedsQL Physical Health Summary *T*-scores to SF-36 Physical Component Summary *T*-scores). To examine changes in mental health symptoms from pre- to post-transfer, BASC-2 and BSI-18 anxiety and depression subscale *T*-scores were compared using paired sample t-tests. Lastly, changes in medication adherence as assessed via blood assay lab values and calculation of the MLVI were examined using a paired sample t-test of MLVI values from pre- to post-transfer. Pearson bivariate correlations were conducted to further characterize the relationship between pre- and post-transfer functioning within domains, including PedsQL Physical and Psychosocial Health Summary Scores and SF-36 Physical and Mental Component Summary scores, BASC-2 and BSI-18 anxiety and depression subscale scores, and pre- and post-transfer continuous MLVI. To further examine adherence pre- and post-transfer, Chi-square analyses were conducted to examine differences in the rates of participants classified as adherent versus non-adherent during the year pre-transfer (i.e., one year prior to the date of transfer) and the year post-transfer (i.e., one year following the date of transfer).

Aim 2: Comparing Health-Related Quality of Life and Psychosocial Functioning to Healthy Norms. To compare HRQOL and psychosocial functioning of young adult organ transplant recipients to healthy norms, one-sample t-tests were conducted among post-transfer assessments with established healthy normative population values or standardized *T*-scores with established mean scores representative of reference population (i.e., *M*=50, *SD*=10). To examine HRQOL among young adult organ transplant recipients compared to healthy norms using the SF-36, one-sample t-tests were conducted to examine HRQOL subscales in comparison to healthy normative scores, using the mean *T*-score value of 50 as normative reference. To examine mental health symptoms among young adult organ transplant recipients compared to healthy norms using the BSI-18 subscale and overall scores, one-sample t-tests were conducted to compare *T*-score results to the normative sample mean of 50. Frequencies of those meeting clinical risk cut-offs (i.e., *T*-score $\geq$ 63) are also reported. Lastly, to examine self-efficacy among young adult organ transplant recipients compared to healthy norms as assessed via the PROMIS Self-Efficacy scale, one-sample t-tests were conducted to compare *T*-score results to the reference sample normative mean of 50.

Aim 3: Explore Biopsychosocial Factors Accounting for Variance in Health-Related Quality of Life. To explore biopsychosocial factors explaining the variance in post-transfer HRQOL during the transition process for young adult organ transplant recipients, hierarchical linear regression modeling was utilized for each HRQOL domain [i.e., SF-36 Physical Component Score (PCS), SF-36 Mental Component Score (MCS)]. Predictors were informed by Ferrans and colleagues' (2005) conceptual model of HRQOL (see Figure 1). Individual variables of interest within the current proposed study aligning with this model and previously established biopsychosocial factors related to HRQOL include a) demographic (i.e., age, gender, race) and social characteristics (i.e., employment status, individual income, living arrangement, having a romantic partner, living with a romantic partner), b) transplant and medical characteristics (i.e., organ type, immunosuppressant medication adherence, time since transplant, time since transfer from pediatric healthcare setting), c) mental health symptoms (i.e., BSI-18 anxiety, depression, and somatization subscales and overall score), and d) young adult functional status (i.e., PROMIS GSE Scale). The primary outcome of interest for these models are post-transfer HRQOL as assessed via the SF-36 PCS and MCS scores. As there are a number of potential predictors for this model, preliminary bivariate correlations and independent sample t-tests were conducted to determine which variables are most applicable for inclusion in the models based on significant associations with HRQOL. HRQOL prior to transfer assessed via the PedsQL 4.0 physical and psychosocial scores will be entered into Step 1 of PCS and MCS models, respectively, to control for HRQOL prior to transfer of care. Emerging significant variables related to post-transfer HRQOL are entered into the model using the following stepwise procedure: Step 2, Demographic and social characteristics, Step 3, transplant and medical characteristics, and Step 4, mental health symptoms and self-efficacy. Non-significant predictors at each step were trimmed for the final model, given the goals of these analyses to predict variation in HRQOL (Peyrot, 1996).

Assessing for Bias in Sampling and Response. To assess for bias in the sampling and response of those participants who are successfully contacted and participated following transfer of care as compared to those who are not, post-transfer demographic variables available from the medical records of those who were eligible for inclusion but not able to be reached were extracted, including gender, race, ethnicity, organ transplant type, age at transplant, and age at last pediatric appointment. Characteristics were compared via Chi-square analyses and independent samples t-tests between those completing psychosocial follow-up and those who did not to determine potential risk for bias in the sampling procedure and inform limitations in generalizability of results. Further, post-hoc analyses were run to examine whether those recruited prior to or during the COVID-19 pandemic experienced significantly different outcomes.

CHAPTER 3

RESULTS

Descriptive Statistics

Table 1 presents full descriptive statistics, including means, standard deviations, ranges, and frequencies of sample characteristics and study variables. Participants were on average 20.70 years of age (*SD* = 0.56; range 18.33 – 21.42) at transfer and 23.19 years (*SD* = 1.68; range 19.50 – 26.17) at the time of survey completion. Approximately half of the sample was male (*n* = 18; 53%), White (*n* = 18; 53%), and the majority were non-Hispanic (*n* = 26; 79%). Participants received their transplant on average 9.80 years before transferring care (*SD* = 5.65; range 1.35 – 20.25), the majority of whom received liver transplants (*n* = 16; 47%) followed by kidney transplants (*n* = 14; 41%) and heart transplants (*n* = 4; 12%).

Approximately half (*n* = 18; 53%) of participants were receiving care through Medicaid, with their parent or caregiver serving as the primary insurance policy holder (*n* = 15; 44%). The majority of participants were single (*n* = 24; 71%) and living with family (*n* = 20; 59%). Fifty percent of participants (*n* = 17) completed some high school or received a high school diploma/GED as their terminal level of education attained. At the time of survey, 33% (*n* = 11) of participants were currently students working towards an advanced degree, 36% (*n* = 12) were working at least part-time, and 33% (*n* = 11) were not working. Notably, of those not working, the majority were not working due to health (*n* = 5; 45%) or due to inability to find a job (*n* = 3; 27%). Seventy percent of the sample (*n* = 24) reported an average individual income of less than $25,000, with only 38% (*n* = 13) reporting they were financially independent.

Aim 1: Comparing Pre- and Post-Transfer HRQOL and Biopsychosocial Functioning.

Paired sample t-tests were conducted to examine changes in pre- and post-transfer HRQOL and biopsychosocial functioning (i.e., mental health, medication adherence), as well as bivariate correlations to further characterize relations over time. Full results of paired sample t-tests and correlations are presented in Tables 2 and 3, respectively.

HRQOL. There was not a significant increase in physical HRQOL from pre- (*M*=45.51, *SD*=15.31) to post-transfer (*M*=47.04, *SD*=5.70; *t*(29) = -.55, *p* = .59). Decreases in psychosocial HRQOL trended towards but did not achieve statistical significance from pre- (*M*=45.65, *SD*=14.61) to post-transfer, with a small effect size (*M*=40.81, *SD*=8.54; *t*(29) = 1.92, *p* = .07). Post-transfer physical HRQOL (PCS) was not significantly related to pre-transfer physical or psychosocial HRQOL (*r*s -.02 to .20). Post-transfer psychosocial HRQOL (MCS) was significantly related to pre-transfer physical HRQOL (*r* = .37, *p* = .04) and psychosocial HRQOL (*r* = .38, *p* = .04).

Mental Health Symptoms. Depression symptoms increased significantly from pre- to post-transfer (pre-transfer depression: *M* = 47.55, *SD* = 12.53; post-transfer depression: *M* = 53.48, *SD* = 11.63; *t*(30) = -2.18, *p* = .04), while anxiety symptoms increased, though not significantly (pre-transfer anxiety: *M* = 46.74, *SD* = 13.22; post-transfer anxiety: *M* = 51.10, *SD* = 11.81; *t*(30) = -1.63, *p* = .11), with small effect sizes for both domains. Post-transfer depression was significantly related to pre-transfer anxiety only (*r* = .37, *p* = .04). Post-transfer anxiety was not significant related to pre-transfer anxiety or depression (*r*s .18 to .20).

Medication Adherence. Among the subsample of participants taking Tacrolimus, there was a non-significant decrease in MLVI from pre- (*M*=2.56, *SD*=1.69) to post-transfer (*M*=2.17, *SD*=1.15; *t*(22) = 1.64, *p* = .12), with a small effect size. Pre- and post-transfer MLVI were significantly, positively related to one another ($r = .59$, $p = .003$). Chi-square test for independence indicated significantly greater percentage of those deemed non-adherent (i.e., MLVI SD $\geq$ 2.5) post-transfer among those who were non-adherent pre-transfer, as well as significantly greater percentage of those deemed adherent post-transfer among those who were adherent pre-transfer ($\chi^2 = 5.06$, $p = .02$).

Aim 2: Comparing Health-Related Quality of Life and Psychosocial Functioning to Healthy Norms.

One-sample t-tests were conducted to compare post-transfer HRQOL and psychosocial functioning among young adult organ transplant recipients to healthy norms using established T-score = 50 normative values and clinical risk cut offs (i.e., BSI-18 only, clinical risk = T-score $\geq$ 63). Full results are presented in Table 4.

HRQOL. Young adult organ transplant recipients demonstrated significantly poorer HRQOL than healthy norms across physical and psychosocial domains (physical: $M = 46.70$, $SD = 5.72$; $t(31) = -3.26$, $p = .003$; psychosocial: $M = 40.67$, $SD = 8.30$; $t(31) = -6.35$, $p < .001$), with medium and large effect sizes, respectively.

Mental Health Symptoms. There were no significant differences in reported mental health symptoms among young adult organ transplant recipients compared to healthy norms across somatization, anxiety, depression, and GSI domains (*p*s .13 to .75, small effect sizes for depression and GSI domains only). The percentage of young adult transplant recipients in the present sample meeting criteria for clinical risk (i.e., T-score $\geq$ 63) ranged from 13% (anxiety) to 28% (somatization).

Self-Efficacy. There were not significant differences in reported self-efficacy among young adult transplant recipients compared to norms ($p = .29$).

Aim 3: Explore Biopsychosocial Factors Accounting for Variance in Health-Related Quality of Life.

To explore biopsychosocial factors accounting for variance in HRQOL among young adult organ transplant recipients following transfer of care, hierarchical regression analyses were utilized based on preliminary analyses to determine variables for inclusion in each step. Given the goals of these analyses to predict variation in HRQOL, non-significant predictors at each step were trimmed in a stepwise manner (Peyrot, 1996).

Physical HRQOL. Physical HRQOL as assessed via the SF-36 PCS score was examined in relation to pre-transfer physical HRQOL, demographic and social variables, post-transfer mental health symptoms, and post-transfer self-efficacy using correlation analyses and independent samples t-tests. Results revealed only post-transfer somatization mental health symptoms was significantly related to post-transfer physical HRQOL ($r = -.39$, $p = .03$). No other study variables were related to post-transfer physical HRQOL (e.g., age, gender, pre-transfer HRQOL, post-transfer mental health symptoms, self-efficacy, adherence) and thus hierarchical regression modeling was not undertaken.

Psychosocial HRQOL. Psychosocial HRQOL as assessed via the SF-36 MCS score was examined in relation to pre-transfer psychosocial HRQOL, demographic and social variables, post-transfer mental health symptoms, and post-transfer self-efficacy using correlation analyses and independent samples t-tests. Results revealed pre-transfer psychosocial HRQOL was significantly, positively related to post-transfer psychosocial HRQOL ($r = .38$, $p = .04$) and post-transfer self-efficacy ($r = .49$, $p < .01$). Significant differences in post-transfer HRQOL were observed across reported gender, such that female young adult transplant recipients reported significantly poorer psychosocial HRQOL ($M = 37.26$, $SD = 8.80$) compared to male recipients

($M = 44.11$, $SD = 6.33$; $t(30) = -2.53$, $p = .02$). Results also revealed significant, negative associations between post-transfer psychosocial HRQOL and age at survey completion ($r = -.47$, $p < .01$), and all BSI-18 domains (somatization: $r = -.37$, $p = .04$; anxiety: $r = -.48$, $p < .01$; depression: $r = -.44$, $p = .01$; GSI: $r = -.47$, $p < .01$). Given the GSI index is a cumulative score across domains, the GSI only was used moving forward. Results from the preliminary analyses informed the inclusion of variables in the following, pre-established hierarchical procedure, with trimming of non-significant predictors at each step: Step 1) pre-transfer psychosocial HRQOL, Step 2) age at survey completion and gender, Step 3) BSI-18 GSI scores, and Step 4) PROMIS self-efficacy. Results of the full initial model and resulting models after trimming of non-significant predictors is presented in Table 5.

In the full model with all included variables, Step 1 pre-transfer psychosocial HRQOL did not account for a significant percent of the variance in post-transfer HRQOL. As such, in subsequent models, pre-transfer psychosocial HRQOL was not included. In the subsequent trimmed model, Step 2 age and gender accounted for a significant 36% of the variance in post-transfer psychosocial HRQOL ($F(2, 28) = 7.94$, $p < .01$, $R^2 = .36$), such that male gender and older age at time of survey was associated with greater psychosocial HRQOL. In Step 3, BSI-18 GSI did not account for a significant variance in post-transfer psychosocial HRQOL beyond age and gender. As such, BSI-18 GSI was not included in subsequent models. Finally, in Step 4, PROMIS self-efficacy explained an additional, significant 10% of the variance in post-transfer psychosocial HRQOL, such that greater perceived self-efficacy was associated with greater psychosocial HRQOL, and resulting in the final model explaining 46% of the variance ($F(1, 27) = 7.60$, $p < .001$, $R^2 = .10$). Age and perceived self-efficacy were significant predictors in the final model.

Risk of Bias Analyses.

Thirty-four participants completed psychosocial follow-up out of the 85 participants who were contacted to participate (40%). Available reasons for non-participation included inaccurate mailing address or email address in medical chart (6%), disinterest in participating in the study (7%), and participant death (2%). The remaining 45% of the eligible sample were contacted but provided no response and thus reasons for not participating were not available. To assess for bias in the sampling and response of those participants who participated following transfer of care as compared to those who were eligible but did not participate, Chi-square and independent samples t-tests were conducted across gender, organ, age at transplant and transfer, and race and ethnicity. There were no significant differences among those who completed psychosocial follow-up compared to those who did not across gender ($\chi^2 = .20$, $p = .66$), race ($\chi^2 = .02$, $p = .87$), age at transplant ($t(82) = .18$, $p = .86$), and age at transfer ($t(83) = -.81$, $p = .42$). There was a significant difference in the proportion of each organ group represented in those completing and not completing follow-up, such that a great percentage of kidney (36%) and liver (60%) participants completed follow-up as compared to heart (21%; $\chi^2 = 7.29$, $p = .03$), as well as a greater portion of participants of Hispanic or Latino ethnicity completing follow-up (78%) as compared to those who did not (36%; $\chi^2 = 5.99$, $p = .03$).

Further, recruitment occurred prior to and throughout the COVID-19 pandemic. As such, post-hoc risk of bias analyses were undertaken to examine whether HRQOL and biopsychosocial outcomes differed between those recruited prior to or during the COVID-19 pandemic using independent samples t-test and Chi square analyses. Fifty-nine percent of participants ($n = 20$) were recruited prior to declaration of the pandemic and public health emergency, occurring through in-person and remote recruitment from May 2019 to March 2020, while 41% ($n = 14$)

participants were recruited entirely through remote methods (i.e., paper questionnaire packets mailed to homes, emails for virtual completion) from April 2020 to August 2021. Post-hoc results revealed significantly poorer emotional well-being related to health among those recruited during COVID-19 (*M* = 52.95, *SD* = 8.92) compared to those who were not (*M* = 44.82, *SD* = 9.94; *t*(30) = -2.42, *p* = .02; *d* = .86), but also significantly lower perceived role limitations due to emotional health among those recruited during COVID-19 (*M* = 36.18, *SD* = 5.00) compared to those who were not (*M* = 46.12, *SD* = 9.83; *t*(30) = 3.45, *p* < .01; *d* = 1.27), both assessed via SF-36 subscales. No other differences emerged in SF-36 subscales, BSI-18, PROMIS GSE, or adherence indicators.

CHAPTER 4

DISCUSSION

The current study sought to examine HRQOL and biopsychosocial functioning among young adult organ transplants during the critical period of transition to adult healthcare and adulthood. The aims of this study were threefold: 1) examine changes in functioning from pre- to post-transfer to adult care, 2) compare functioning among young adult organ transplant recipients to healthy norms, and 3) explore factors related to HRQOL as an indicator of well-being following transfer of care. Results revealed decreases in functioning from pre- to post-transfer (i.e., increases in depression symptoms) as well as significantly poorer HRQOL across domains among young adult transplant recipients compared to healthy norms. Among young adults in the present sample, physical HRQOL was significantly related only to somatization symptoms, while variance in psychosocial HRQOL was significantly accounted for by age and young adult reported self-efficacy. The results from this study inform several future research and clinical directions.

In examining changes in functioning from pre- to post-transfer of care, young adult transplant recipients in the present study reported significantly greater depressive symptoms at post-transfer. Further, while not achieving statistical significance, young adult transplant recipients also reported poorer psychosocial HRQOL at post-transfer when compared to pre-transfer. Findings related to poorer functioning are consistent with the extant literature across chronic illness groups, as well as organ transplantation, and were as hypothesized, though these did not occur consistently across domains, as there were no significant differences in physical

HRQOL or anxiety symptoms. Across several chronic illness groups, including congenital heart disease and Type 1 diabetes, post-transfer HRQOL was significantly lower in physical well-being and social support domains, as compared to pre-transfer HRQOL (While et al., 2017). Further, in examining differences in well-being across those who received heart transplants in childhood as compared to adulthood, those transplanted in childhood reported significantly greater psychological distress across several domains (Cavalli et al., 2019). This suggests specific difficulties associated with transplantation in childhood and navigating the transition period while managing a transplanted organ.

Transition includes the transfer of care to adult healthcare systems in addition to the developmentally normative transitions in education, occupation, and lifestyle changes. As such, it is important to contextualize the current sample's sociodemographic factors, which likely interplay with these outcomes. The majority of this sample was at least partially financially dependent on others, with one-third of these young adults not working or enrolled in higher education, largely due to health reasons or inability to find a job. Socially, the majority of the sample reported living with their family and were single. This sociodemographic make-up is largely consistent with other studies examining these outcomes among young adult organ transplant recipients, such that those experiencing a transplant are more likely to be unemployed, live in their family home, and less likely to have a partner (Hamilton et al., 2017). Further, when comparing young adults who experienced a kidney transplant in childhood compared to adulthood, one study found that those experiencing transplantation in childhood were significantly less likely to have achieved general education requirements, be working, living independently, or living with a partner (Lewis & Marks, 2014). Underscoring the importance of considering sociodemographic factors during and beyond transition, employment status has demonstrated benefits to organ and graft survival among kidney transplant recipients, such that working full time is associated with improved graft and recipient survival (Petersen et al., 2008), possibly through greater financial or insurance stability, or positive social impact. As such, considering sociodemographic factors, including social, educational, and occupational achievements, and the impact that transplantation may have on these outcomes is critical not only to general well-being, but also medical outcomes, particularly when managing a transplant during the critical transition from childhood to adulthood.

Notably, there was no significant difference in adherence as assessed via MLVI from pre- to post-transfer in the present study. This is in contrast to hypotheses and to previous meta-analytic findings which have suggested adolescence and older pediatric patient age, associated with the onset of the transition period in pediatric care, are associated with poorer adherence (Dew et al., 2009). However, it is possible that poorer adherence patterns emerging at the end of pediatric care (i.e., in the year leading up to transfer) have already negatively impacted immunosuppression levels, given observed declines in adherence throughout adolescence in the literature, and thus differences would not be observed immediately pre- and post-transfer. Further, one study has demonstrated a subset of patients may experience improvements in adherence following transfer among kidney transplant recipients, which may be associated with improved psychosocial outcomes, medical stabilization, or improved developmental fit as a result of receiving care in an adult setting, though this has received less attention in the literature (Akchurin et al., 2014). Future research may seek to examine when exactly patterns of adherence shift in order to optimize assessment and intervention, if not during the year leading up to transfer. There was a significant relationship between pre- and post-transfer MLVI and adherence categorization, such that pre-transfer nonadherence was associated with post-transfer nonadherence. However, the individuals comprising the groups deemed adherent versus non-adherent across pre- and post-transfer assessments shifted, such that, while the percentages may be similar, the individuals within each group may not be the same. As such, it is important to consider adherence and shifts in adherence at an individual level. Findings suggest the importance of continuing attention to medication adherence in adult healthcare as a component of transition readiness, as previous adherence patterns generally appear to persist into adult settings. Previous quality improvement interventions support the implementation of transition readiness interventions related to adherence, as well as healthcare knowledge and skills, into pediatric practice, with support for extension of intervention into post-transfer adult care models (Fredericks et al., 2015). A recent meta-analysis suggests several multidisciplinary interventions are effective at optimizing immunosuppressant medication adherence among adult organ transplant recipients (e.g., eHealth/apps, self-management intervention), a combination of which may be incorporated throughout transition and beyond (Shi et al., 2020)

In comparing HRQOL and biopsychosocial functioning of young adult transplant recipients to healthy norms, results revealed only significant differences in HRQOL, such that organ transplant recipients reported significantly poorer HRQOL across domains compared to healthy individuals. This is consistent with previous research comparing transplantation to healthy controls and other chronic illness groups (Endén et al., 2018), as well as a recent meta-analysis across young adult kidney transplant recipients which revealed significantly poorer HRQOL when compared to healthy peers (Hamilton et al., 2017). In examining the portion of the current transplant sample meeting clinical risk cut-off for mental health symptoms according to the BSI-18 (i.e., *T*-score $\geq$ 63, corresponding to the top 9% of healthy norm scores), between 13% and 28% of the current sample were classified as clinical risk. This is above the 9%

expected within the healthy population. While not surprising, given the demands of caring for a transplanted organ and associated life changes, these findings underscore the importance of assessing well-being during transition for these young adults and providing appropriate intervention, based on factors related to these critical outcomes.

Exploration of factors related to physical and psychosocial HRQOL in the present study suggest differing factors impacting well-being across these domains. Physical HRQOL was only related to reported somatization symptoms in the present study, suggesting that greater attention to physical or bodily expressions of stress is associated with poorer physical HRQOL. Experience of greater number of comorbidities or serious medical consequences following transplant may be associated with both greater somatization and poorer physical HRQOL. Prior research among adult heart transplant recipients identified several medical comorbidities associated specifically with SF-36 physical scores, including cardiovascular performance, obesity, and history of severe rejections, suggesting presence of greater medical complications may negatively affect physical HRQOL and functioning (Butler et al., 2003). While medical comorbidities are rarer among young adult transplant recipients, future research is needed to understand how presence of comorbidities or other factors may impact perceived physical HRQOL specifically within this developmental period.

Within psychosocial HRQOL, age and perceived self-efficacy accounted for a significant amount of variance in the final steps of the model, such that older age at survey, and greater perceived self-efficacy were associated with greater psychosocial HRQOL. Gender was no longer significantly accounting for variance in psychosocial HRQOL within the final model. However, it is notable that significant effects of gender dropped out of the final model upon inclusion of self-efficacy as a predictor of HRQOL. This occurrence is largely consistent with findings among adult liver transplant recipients, such that women report poorer overall HRQOL compared to men throughout transplantation across several studies, differences which are posited to relate to specific differences in men and women’s employment rates immediately prior to and following their liver transplant (Cowling et al., 2004; Sarkar et al., 2015). This is also consistent with nationally representative data from the United States which reveals significant gender differences in HRQOL between adult men and women, such that marital status and income have the largest impact on these gender differences (Cherepanov et al., 2010). In considering the role of gender in psychosocial HRQOL of the present sample, it is important to note that several of the female participants in this sample were required to transfer care early (i.e., before age 21) due to requirement from the institution that, if pregnant, pediatric patients can no longer receive care at a pediatric institution, regardless of age. This may have placed additional stress and perceived inability to control life’s challenges on these patients during the transition period, including sudden transfer of care. Consideration of factors specific to female patients during transition that may impact well-being is critical when developing and implementing interventions to improve transition and promote self-efficacy, given established differences in HRQOL across studies.

Young adult age did account for significant variance in post-transfer psychosocial HRQOL within the final model, such that older young adult age at survey was associated with greater reported psychosocial HRQOL. Older age in the present study is likely associated with greater time since completing the transfer from pediatric to adult care and thus greater time to adjust to a different healthcare system and model of care. Among older adult transplant recipients, older age (i.e., > 40 years) has been associated with poorer HRQOL (Dąbrowska-Bender et al., 2018). However, many studies utilize a wide age range (e.g., any adult patient ages 18 years or older) suggesting that, perhaps within the specific transition period associated with young adulthood, older age may be associated with greater HRQOL, a pattern which may shift over time. During young adulthood, older age may be associated with increasingly established or achieved social, educational, or occupational goals, as well as settling in to adult healthcare, prior to the onset of greater risk for comorbidities associated with older age in adulthood (e.g., risk for infections, cardiovascular function; Dharnidharka et al., 2006; Schaenman et al., 2019). Future research is needed to further elucidate these trends, particularly as they relate to psychosocial outcomes and well-being, as well as how these trends may fluctuate over time.

Self-efficacy following transfer also accounted for significant variance in the final model of psychosocial HRQOL and was the only modifiable variable in the final model (i.e., as compared to the non-modifiable variable of age). As such, self-efficacy presents a potentially meaningful opportunity for targeted intervention. Relations between similar constructs of empowerment and autonomy have been observed in other chronic illness groups during adolescence and young adulthood, including positive associations between empowerment and domains of HRQOL among young adults with cancer (Kaal et al., 2017). Further, specifically among organ transplant recipients, self-efficacy has been associated with immunosuppressant medication knowledge and adherence across several recent studies including adolescent, young adult, and older adult samples (Dabirzadeh et al., 2021; Du et al., 2018; Liu et al., 2021). Lower self-efficacy related to managing a chronic medical conditions was also related to lower self-reported recovery among adults following heart transplant, and specifically among those who had not returned to work (Almgren et al., 2021). Self-efficacy has also been related to self-reported mental fatigue and reduced motivation among adult heart transplant recipients (Almgren et al., 2020). Promoting self-efficacy among adult heart transplant recipients has been described as balancing expectations while minimizing disappointments, given the uncertainty of illness and lifestyle adjustments (Almgren et al., 2017). In a recent pilot study examining a condition-specific self-management promotion program among adolescents and young adults who received a kidney or liver transplant, participation in this program (i.e., “Teens Taking Charge” https://teens.aboutkidshealth.ca/kidneytransplant) was associated with significant increases in patient-reported self-efficacy (Korus et al., 2017). Importantly, self-efficacy extends beyond disease management, and includes managing broader daily and life tasks, challenges, and goals. According to Bandura’s theory of self-efficacy, general self-efficacy can be enhanced through several ways, including promoting mastery and use of skills and knowledge, as well as looking to role models (Bandura, 1977). Future research should examine ways to promote self-efficacy through a variety of modalities, including education and peer to peer support, and topics, such as medical disease management and setting and meeting broader life goals, as a way of promoting overall well-being through HRQOL following transplant. This is consistent with efforts in other chronic illness groups (i.e., “18 Steps to 18” within sickle cell disease) to promote self-efficacy in medical management and broader life tasks, such as planning for education and vocational goals, meeting with financial counselors, and promoting a generally healthy lifestyle (Griffin et al., 2013). Additionally, in future studies, self-efficacy should be assessed across several domains, including emotional regulation, managing chronic illness or medication taking, and general life problem solving ability. In the present study, general self-efficacy was assessed; however, future research is needed to elucidate potential differences in various domains of self-efficacy related to HRQOL as an outcome of well-being, as well as other desired outcomes (e.g., medical stability, medication adherence).

The strengths of the present study, including the longitudinal nature of the pre- to post-transfer study design and novelty of this research in the current literature, must be considered in light of several limitations. While every effort was made to recruit all possible participants from the available sample, a lower than expected recruitment rate was observed (40%), which may limit generalizability. Risk of bias analyses revealed that a greater percentage of those receiving a kidney or liver transplant, as well as those of Hispanic or Latino ethnicity, completed psychosocial follow-up as compared to those who did not. It is possible organ group differences are related to differences in establishing research access within each of the adult organ clinics, such that heart clinic was the last clinic to allow access for research staff to recruit during appointments, and thus there were less time for recruitment in person prior to shifting to remote-only recruitment. Additionally, recruitment was undertaken within one institution with an established professional partnership between pediatric and adult settings, in one geographical region of the Southeastern United States. As such, generalizability to different settings and transition experiences may be limited. Future research across institutions and transitional practices is warranted to gain a better understanding of the transition experiences and well-being of a variety of young adults who have received organ transplants in childhood.

Further, it is important to note that recruitment for the present study's psychosocial follow-up began prior to and occurred throughout the COVID-19 pandemic. Recruitment across different periods of public health crises and psychological stressors may further limit generalizability of the present sample. However, post-hoc risk of bias analyses revealed the only significant differences in outcomes across those recruited prior to and during the COVID-19 pandemic were related to emotional well-being and role limitations, such that those recruited during COVID-19 reported poorer emotional well-being related to their health, but fewer role limitations. The COVID-19 pandemic resulted in decreased healthcare access for regular in-person follow-up appointments among organ transplant recipients and reduced access to multidisciplinary care, with in-person medical appointments reserved for the most high-risk or critically ill (Danziger-Isakov et al., 2021). Organ transplant recipients are at increased risk for infection due to immunosuppression, with transplant recipients who contract COVID-19 requiring hospitalization in 80% of cases, and a high mortality rate (~20%) for those hospitalized (Raja et al., 2021). Further, studies have also examined psychological well-being as a result of the COVID-19 pandemic among adult transplant recipients, with results suggesting significantly decreased life satisfaction and lower perceived competence among adult kidney transplant recipients when compared to the months prior to the pandemic (Zgoura et al., 2020); however, the use of active coping strategies during the pandemic were notable for promoting resilience among transplant recipients (McKay et al., 2021). For adolescents and young adults transferring care during the COVID-19 pandemic, some institutions adapted existing in-person transition programming to virtual, interactive formats, with reported increases in access, attendance, and participation (Chandran et al., 2021). As the COVID-19 pandemic persists, research and clinical support regarding ongoing life and psychological stressors, as well as the promotion of optimal health outcomes related to managing a transplant and undergoing the transition to adult healthcare are necessary. This will likely also include supporting young adult transplant recipients in the aftermath of the pandemic, including return to desired social, occupational, and educational goals, and overall well-being.

The current study informs several important research and clinical directions to greater support young adult transplant recipients during the transition to adult healthcare and to adulthood. Findings underscore continued transition support for young adults after transfer of care, given reported increases in mental health symptoms and decreased psychosocial HRQOL throughout transition. Establishing and evaluating efficacy of such transition programs will require institutional and third-party payor support to ensure patient access to these programs and the necessary program personnel (e.g., transition coordinators). In considering assessment and intervention associated with future programs, self-efficacy presents a promising metric for evaluating and promoting positive outcomes associated with well-being. Such interventions may include education and skills-based focus, as well as peer to peer mentorship and role modeling. Additional longitudinal research throughout transition is needed to further understand relations between pre- and post-transfer periods and factors associated with well-being over time. Additionally, while the present study reflects methodology using validated, nationally utilized quantitative measures to compare outcomes to normative data, there is a need to further understand how young adults perceive their well-being and functioning in society, as well as barriers to achieving their desired state of well-being, information which may be best captured using rigorous qualitative methodology. Future research utilizing focus groups and thematic analyses among young adult transplant recipients may improve understanding of this transitional period and perspectives on desired well-being. Further, the present study suggests self-efficacy is uniquely related to HRQOL as an overall measure of well-being. Future research examining potential moderators or mediators of this link (e.g., employment status, social support) and other domains which may explain variance in HRQOL outcomes may further improve understanding of those at greater risk for poorer well-being and inform development of effective interventions. Additionally, future research may also examine additional perspectives regarding young adult well-being on the adult side of healthcare transition, including provider perspectives, partner perspectives, or continued caregiver perspectives. The use of additional perspectives during pediatric care is more widely utilized, given increased access to legal guardians and caregivers, and the transition of responsibility from caregiver to child. However, utilization of varied perspectives during adulthood may present additional information about young adult well-being to inform this critical period.

Conclusion

Given ongoing medical and psychosocial challenges faced by young adult organ transplant recipients during transition, it is of great importance to understand and be responsive to these challenges in order to provide the necessary support for optimal functioning. Results of the present study reveal increases in mental health symptoms from pre- to post-transfer, as well as significantly poorer HRQOL compared to healthy norms. Greater psychosocial HRQOL was significantly associated with older age and greater reported self-efficacy, suggesting promising future directions for assessing and developing targeted clinical intervention aimed at supporting HRQOL during transition. Areas for future research include gaining additional understanding of the transition experience and barriers to well-being through a variety of methodologies, including qualitative and quantitative designs, and systematically assessing the efficacy of current and future transition readiness interventions to support outcomes related to overall well-being among young adult organ transplant recipients.

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Table 1. Sample Demographics and Study Variables

		Descriptives/Frequencies (*N*=34)	
Sample demographics		*M*(*SD*)/n(%)	Range
Age at survey (yrs)		23.19 (1.68)	19.50 – 26.17
Age at transfer (yrs)		20.70 (0.56)	18.33 – 21.42
Time since transplant at transfer (yrs)		9.80 (5.65)	1.35 – 20.25
Days between pediatric and adult care		206.32 (283.96)	0 – 1202
Gender (male)		18 (53%)	
Transplant Type	Liver	16 (47%)	
	Kidney	14 (41%)	
	Heart	4 (12%)	
Race	White	18 (53%)	
	Black	12 (35%)	
	Biracial	1 (3%)	
	Other	3 (9%)	
Ethnicity	Hispanic	7 (21%)	
	Non-Hispanic	26 (79%)	
Insurance	Medicaid	18 (53%)	
	Private	10 (29%)	
	Not insured	4 (12%)	
	Other	2 (6%)	
Primary Insurance Holder	Self	14 (41%)	
	Parent/caregiver	15 (44%)	
	Spouse	1 (3%)	
	N/A (uninsured)	4 (12%)	
Relationship status	Single	24 (71%)	
	Dating/in relationship	5 (15%)	
	Engaged	1 (3%)	
	Married	3 (9%)	
	Other	1 (3%)	
School completed	Some high school	3 (9%)	
	High school diploma/GED	14 (41%)	
	Some college	10 (29%)	
	College/advanced degree	7 (21%)	
Employment status	Student (not working)	6 (18%)	
	Student (working part-time)	5 (15%)	
	Working full time	9 (27%)	
	Working part-time by choice	1 (3%)	
	Working part-time due to health	2 (6%)	

	Not working by choice	1 (3%)
	Not working due to health	5 (15%)
	Not working, unable to find a job	3 (9%)
	On disability	2 (6%)
Annual individual income	$9,999 or less	13 (38%)
	$10,000 - $24,999	11 (32%)
	$25,000 - $49,999	2 (6%)
	$50,000 - $74,999	1 (3%)
	$75,000 - $99,999	1 (3%)
	Not provided	6 (18%)
Sources of financial support	Self only	13 (38%)
	Combination of parents/caregivers and self	11 (32%)
	Parents/caregivers only	7 (21%)
	Other	2 (6%)
	Not provided	1 (3%)
Living situation	With family	20 (59%)
	In college housing	4 (12%)
	In rented housing	8 (24%)
	In self-owned housing	1 (3%)
	Not provided	1 (3%)

Table 2. Comparing Pre- and Post-Transfer HRQOL and Biopsychosocial Functioning

	Pre-Transfer		Post-Transfer		Paired *t* test		
	Mean	SD	Mean	SD	*t* value	*p*	Effect size [d]
HRQOL[a]							
Physical HRQOL T-Score	45.51	15.31	47.04	5.70	-.55	.59	.10
Psychosocial HRQOL T-Score	45.65	14.61	40.81	8.54	1.92	.07	.35
Mental Health [b]							
Anxiety T-Score	46.74	13.22	51.10	11.81	-1.63	.11	.28
Depression T-Score	47.55	12.53	53.48	11.63	**-2.18**	**.04**	**.39**
Medication Adherence [c]							
MLVI	2.56	1.69	2.17	1.15	1.25	.23	.29

	Chi square test				
	Adherent (Post)	Nonadherent (Post)	χ^2	*p*	Effect size [d]
Adherent (Pre), *n* = 10, 43.5%	7 (70%)	3 (30%)	**5.06**	**.02**	**1.09**
Non-adherent (Pre), *n* = 13, 56.5%	3 (23%)	10 (77%)			

Note. PCS = Physical Component Score; MCS = Mental Component Score

[a] Pre-transfer HRQOL measure = PedsQL, post-transfer HRQOL measure = SF-36

[b] Pre-transfer HRQOL measure = BASC-2, post-transfer HRQOL measure = BSI-18

[c] *n*=23 taking Tacrolimus, MLVI able to be calculated

[d] Cohen's *d* interpretation: small effect = 0.20 - 0.49, medium effect = 0.50 - 0.79, large effect ≥ 0.80.

Table 3. Pre- and Post-Transfer HRQOL and Biopsychosocial Functioning Correlations

	1.	2.	3.	4.	5.	6.	7.	8.	9.	10.
1. Physical HRQOL T-Score, PedsQL	1.00									
2. Physical HRQOL T-Score, SF-36 PCS	.196	1.00								
3. Psychosocial HRQOL T-Score, PedsQL	**.662****	-.017	1.00							
4. Psychosocial HRQOL T-Score, SF-36 MCS	**.372***	-.286	**.383***	1.00						
5. Anxiety T-Score, BASC-2	**-.614****	-.186	**-.757****	-.091	1.00					
6. Anxiety T-Score, BSI-18	-.209	.024	**-.406***	**-.483****	.202	1.00				
7. Depression T-Score, BASC-2	**-.545****	-.206	**-.696****	-.087	**.782****	.182	1.00			
8. Depression T-Score, BSI-18	-.271	-.132	**-.382***	**-.443***	**.367***	**.648****	.215	1.00		
9. Medication adherence pre-transfer, MLVI	-.049	-.107	-.023	.172	.246	-.069	.200	-.071	1.00	
10. Medication adherence, post-transfer, MLVI	.221	.086	.247	.110	-.062	-.079	-.042	-.151	**.594****	1.00

Note. PedsQL = Pediatric Quality of Life Inventory, 4th edition; SF-36 = 36-Item Short Form Health Survey; PCS = Physical Component Score; MCS = Mental Component Score; BASC-2 = Behavior Assessment System for Children, 2nd edition; BSI-18 = Brief Symptom Inventory; MLVI = Medication Level Variability Index.

** Correlation is significant at the 0.01 level (2-tailed).

* Correlation is significant at the 0.05 level (2-tailed).

Table 4. Comparing Post-Transfer HRQOL and Psychosocial Functioning to Healthy Norms

			One-sample *t* test[a]			% clinical risk (T-score ≥ 63; BSI-18 only)
	Mean	SD	*t* value	*p*	Effect size[b]	
HRQOL						
SF-36 PCS T-Score	46.70	5.72	**-3.26**	**.003**	**-.57**	
SF-36 MCS T-Score	40.67	8.30	**-6.35**	**<.001**	**-1.12**	
Mental Health						
BSI-18 Somatization T-Score	52.75	15.50	1.00	.32	.18	28%
BSI-18 Anxiety T-Score	50.69	11.84	.33	.75	.06	13%
BSI-18 Depression T-Score	53.22	11.54	1.56	.13	.28	22%
BSI-18 GSI T-Score	53.16	12.83	1.39	.17	.25	22%
Self-Efficacy						
PROMIS GSE Short Form T-Score	48.17	9.71	-1.07	.29	-.19	

Note. BSI-18 = Brief Symptom Inventory; SF-36 = 36-Item Short Form Health Survey; PCS = Physical Component Score; MCS = Mental Component Score; PROMIS GSE = General Self-Efficacy.

[a] Sample compared to T-Score = 50 as normative sample average.

[b] Cohen's *d* interpretation: small effect = 0.20 - 0.49, medium effect = 0.50 - 0.79, large effect ≥ 0.80.

Table 5. Hierarchical Regression, SF-36 Mental Component Score

	Full Model					Trimmed Model (Trimmed non-significant Pre-Transfer PedsQL from Step 1)					Trimmed Model (Trimmed non-significant BSI-18 from Step 3)				
SF-36 MCS	*ß*	*t*	R^2	ΔR^2	*F*	*ß*	*t*	R^2	ΔR^2	*F*	*ß*	*T*	R^2	ΔR^2	*F*
Step 1			.13		3.89										
Pre-Transfer Psychosocial HRQOL (PedsQL)	.22	1.97				--	--				--	--			
Step 2			**.42**	**.30**	**6.07****			**.37**		**7.96****					
Pre-Transfer HRQOL	.14	1.38				--	--				--	--			
Gender	4.20	1.52				**5.84**	**2.27***								
Age	**-2.41**	**-2.97****				**-2.35**	**-2.94****								
Step 3			**.43**	**.01**	**4.46****			**.38**	**.01**	**5.41****			**.36**		**7.94****
Pre-Transfer HRQOL	.12	1.07				--	--				--	--			
Gender	3.90	1.35				5.26	1.94†				**6.22**	**2.50***			
Age	**-2.19**	**-2.28***				**-1.98**	**-2.09***				**-2.15**	**-2.96****			
BSI-18 GSI	-.07	-.45				-.10	-.75				--	--			
Step 4			**.47**	**.04**	**4.04****			**.46**	**.08**	**5.39****			**.46**	**.10**	**7.60*****
Pre-Transfer HRQOL	.07	.65				--	--				--	--			
Gender	3.21	1.11				3.40	1.23				3.72	1.44			
Age	-1.74	-1.74				-1.63	-1.77†				**-1.73**	**-2.44***			
BSI-18 GSI	-.02	-.10				-.05	-.43				--	--			
PROMIS GSE	.29	1.34				.31	1.91†				**.33**	**2.19***			

Note. PedsQL = Pediatric Quality of Life Inventory, 4th edition; BSI-18 = Brief Symptom Inventory; SF-36 = 36-Item Short Form Health Survey; MCS = Mental Component Score; PROMIS GSE = General Self-Efficacy.
$^{\dagger}p < .10$, $^{*}p < .05$, $^{**}p < .01$, and $^{***}p < .001$

Figure 1. Conceptual Model of Health-Related Quality of Life (Ferrans et al., 2005)