EXAMINING RELATIONSHIPS BETWEEN PSYCHOSOCIAL FACTORS AND MEDICAL ADHERENCE IN CHILDREN AWAITING SOLID ORGAN TRANSPLANTATION AND THEIR PARENTS

by

JENNIFER L. LEE

(Under the Direction of Ronald L. Blount)

ABSTRACT

Objective: The study aimed to create a psychological description of parents and children being evaluated for solid organ transplantation compared to normative samples. Parent personality factors were examined as predictors of parent psychological functioning, child health-related quality of life (HRQOL), parent medication knowledge, and child medication adherence. *Method*: Sixty-five caregivers (*M* age = 36.65, 89.2% female) of children (*M* age = 7.94, Range: 0-20 years) undergoing evaluation for a solid organ transplant were recruited. Parents completed questionnaires about their psychological distress, post-traumatic stress (PTSS), personality, medication knowledge, and medication adherence. Parent-proxy report of child HRQOL was collected. *Results*: Parents reported similar levels of psychological distress and PTSS to normative samples. Lower HRQOL for children was reported. Parent conscientiousness (+) and psychological distress (-) were predictors of child HRQOL. Parent neuroticism (+) predicted parent psychological distress. Time since the child's diagnosis (+) predicted medication knowledge. Medication knowledge (+) and parent conscientiousness (+)

predicted medication adherence, also resulting in a significant moderation effect.

Conclusions: A thorough family-focused evaluation during the pre-transplant period would be helpful to determine which families are at risk for negative outcomes. Parent personality significant impacts child functioning and adherence prior to transplant. Parent medication knowledge and parent psychological distress are modifiable factors that would be good targets for intervention during the pre-transplant period.

INDEX WORDS: pediatrics, solid organ transplantation, pre-transplant evaluation, adherence, personality, children, adolescents.

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INTRODUCTION

Pediatric organ transplantation has become a preferred treatment option for children and adolescents with liver, heart and kidney diseases, with the popularity of transplantation steadily increasing over the last 10 years. In 2012, approximately 1,700 liver, heart, or kidney transplants were performed on pediatric patients in the United States. Additionally, there are currently over 1,600 pediatric patients in the U.S. awaiting transplant for these same organ groups (Organ Procurement and Transplantation Network, 2013). The long-term survival rates after transplantation have improved considerably in the past decade, with 80% of pediatric recipients reaching adolescence and young adulthood (LaRosa, Jorge Baluarte, & Meyers, 2011). Although organ transplantation may alleviate disease symptoms and often saves lives, transplantation truly involves trading one life-threatening condition for a different chronic medical condition requiring daily sustained adherence to medication, as well as increased medical monitoring in the form of clinic visits and blood work (Griffin & Elkin, 2001; LaRosa et al., 2011).

Among pediatric populations in general, the rate of medication adherence is approximately 50% (La Greca & Bearman, 2003). Medication regimens for transplant recipients can involve complex administration protocols, and prescriptions that change quickly, varying from week to week in type and dose (Shellmer, Dabbs, & Dew, 2011). Immediately after transplantation, children and adolescents are typically prescribed a minimum of 4 medications for immunosuppression alone, in addition to other specific medications for medical comorbidities and symptoms (Kim, Webster, & Craig, 2013). A recent systematic review of the literature indicated that, on average, 43% of adolescents and 22 % of children with organ transplants are nonadherent to their immunosuppressant medications (Dobbels et al., 2010). Additionally, a meta-analysis by Dew and colleagues (2009) indicated that no significant differences exists in medication adherence between recipients of kidney, liver, or heart transplant recipients, revealing that this is a cross-cutting issue for pediatric transplant recipients.

Nonadherence is particularly problematic as it is a leading cause of organ rejection (Shaw, Palmer, Blasey, & Sarwal, 2003). Adolescents consistently have lower levels of medication adherence (LaGreca & Bearman, 2003) and have one of the lowest organ survival rates, with only 62.9% of organ grafts still functioning 5 years after transplant (Smith, Ho, & McDonald, 2002). Several negative medical complications may follow transplantation, such as susceptibility to infections and post-transplant lymphoproliferative disease, a type of cancer (LaRosa et al., 2011). Other negative medical sequelae that result from nonadherence include hospitalization and death (Simons, McCormick, Mee, & Blount, 2009). Medication nonadherence in pediatric populations is related to greater numbers of visits to the emergency department and inpatient hospitalizations, the most costly types of healthcare service (McGrady & Hommel, 2013). Regarding economic impact, a report published by the United States Government Accountability Office (2007) revealed that treatment for Medicare beneficiaries who experienced organ loss costs $50,398 per year, compared to treatment cost of patients who maintained functioning transplants of only $8,550 per year. The significant health and economic concern regarding organ transplant loss warrants further investigation into the factors associated with poor compliance prior to transplantation.

The Child Health Belief Model (CHBM) can be used to conceptualize factors associated with nonadherence to a medical recommendations and examine mechanisms through which nonadherence occurs in pediatric patients. The CHBM includes factors related to the patient's perceptions of risk, consequences, benefits, barriers, and cues to action (Bush & Iannotti, 1990; Ingerski, Baldassano, Denson & Hommell, 2010). This can consist of non-modifiable factors (i.e., demographics), modifiable factors (e.g., cognitive and environmental), readiness factors (e.g., motivation and perceived benefit), and resulting behaviors (Rapoff, 2010). Of the factors in the model that have been empirically investigated, barriers to adherence have been shown to be the most powerful predictor of a number of health practices in pediatric populations (Marhefka et al., 2008; Modi & Quittner, 2006; Rapoff, 2010) and are related to higher risk for experiencing negative medical outcomes such as rejection episodes, hospitalizations, and/or death (Simons, McCormick, Devine, & Blount, 2010). The types of barriers associated with poor medication adherence in pediatric transplant recipients include cognitive factors (e.g. forgetting, poor planning), aversive medication properties (e.g. hard to swallow, tastes bad), and voluntary resistance to medication-taking (Simons et al., 2009). Dysfunctional parent-child interactions, patient's health status, and elevated parental stress are also factors associated with nonadherence in this population (Gerson, Furth, Neu, & Fivush, 2004; Meyers, Thomson, & Weiland, 1996; Tucker et al., 2002).

The majority of literature on nonadherence in transplant recipients has been conducted in adolescents, due to the well-documented increased risk of organ graft loss during this time (Smith et al., 2002). This period of development represents a vulnerable time when adolescents may be transitioning into more responsible and autonomous roles across all domains of life. While this is a normative and necessary experience, it can be a risky time period for adolescents with transplants, when one misstep in their medical regimen and responsibility can mean the difference between remaining healthy and losing an organ. While the nonadherence literature in pediatric transplantation has primarily focused on the behaviors of adolescents, the literature on children suggests that this problem is not limited by developmental stage. In one study of children with renal transplants, children had lower levels of adherence to immunosuppressant medications when compared to adolescents (Chisholm-Burns et al., 2009). This was similarly shown in a study of liver transplant recipients younger than 10 year of age (Falkenstein, Flynn, Kirkpatrick, Casa-Melley, & Dunn, 2004). While the results of these investigations are at odds with the bulk of the literature, it does indicate that child nonadherence can also be high. It is possible that these differences in adherence between adolescents and children are a result of differences in the measurement methodology. Further investigation into the factors influencing adherence for children is necessary.

For infants and children, it is developmentally necessary for parents to manage the medical regimen and have primary responsibility for medication administration. In fact, parental involvement in the medication regimen is consistently associated with better rates of adherence in transplant recipients (Griffin & Elkin, 2001; Shaw et al., 2003; Simons & Blount, 2007; Simons, McCormick, Mee, & Blount, 2009) and other pediatric populations (Ellis, Podolski, Frey, Naar-King, Wang, & Moltz, 2007; Wysocki & Gavin, 2006), regardless of the patient's age. In an assessment of the approaches utilized by families to manage an adolescent's medication regimen after kidney transplantation, the only strategies related to improved adherence were the use of parents issuing reminders to adolescents to take medications and parental verification of adolescents having done so (Ingerski, Perrazo, Goebel, & Pai, 2011). These finding suggest that parent involvement serves as a protective factor, and is not only critical for medical regimen management in infants and young children, but also critical for adolescents. In an assessment of the relative level of adult caregiver and adolescent regimen responsibility, adult caregivers of adolescent kidney transplant recipients were still primarily responsibility for medication management in 70 percent of cases (Pai et al., 2011). Given that parents have primary responsibility for maintaining adherence for children and adolescents, examining parental factors that may influence adherence in pediatric transplant recipients is pertinent.

Psychological symptoms may be present in both pediatric patients and caregivers (Stuber, 2010). Clinically significant anxiety and depression have been reported in adolescents after receiving a kidney transplant (Berney-Martinet et al., 2009). In one of the few studies comparing depression in children with chronic kidney disease who have not undergone transplantation and transplant recipients, researchers found that patients with transplants were at a higher risk for depression (Kogon, et al., 2013). When compared to healthy same-age peers, both adolescents with chronic kidney disease and adolescents with kidney transplants showed higher levels of learning difficulties and lower levels of overall competence, including school and social competence (Berney-Martinet et al., 2009). While these findings require replication due to the small number of participants in both studies, results suggest that differences in psychological functioning and health-related quality of life (HRQOL) exist in these populations both pre- and post-transplant when compared to healthy same-age peers. Further research to understand the psychological functioning for those awaiting kidney, heart, or liver transplantation is needed. Psychological distress has also been noted in parents and caregivers of transplant recipients. Moderate to severe levels of post-traumatic stress symptoms have been documented in parents of pediatric transplant recipients (Farley et al., 2007; Young et al., 2003), although this has not been measured in parents of children being assessed for transplantation. Many children awaiting transplantation have chronic illnesses that require numerous diagnostic tests and medical procedures prior to undergoing transplantation. Given the prevalence of parental post-traumatic stress symptoms in children with chronic illnesses (Landolt, Vollrath, Ribi, Gnehm, Sennhauser, 2003), it is likely that parents of children awaiting transplantation also experience PTSS. Avoidance symptoms present in post-traumatic stress may also impede a parent's ability to engage in managing their child's health regimen. Parent psychopathology (e.g., depression) has also been related to nonadherence in pediatric transplant recipients (Griffin & Elkin, 2001). In other pediatric populations, feeling overwhelmed in dealing with the child's illness has been shown to impact a parent's ability to manage the health of their child (Auslander, Thompson, Dreitzer, & Santiago, 1997). There is evidence that some patients and their parents may be at risk for negative psychological outcomes post-transplant based upon pre-transplant functioning. Depression and anxiety disorders have been diagnosed in a subset of mothers of pediatric bone marrow transplant recipients 18-months after the procedure, with pre-transplant depression and anxiety symptoms predicting post-transplant psychiatric diagnosis (Manne et al., 2004). This study emphasizes the importance examining parental functioning prior to medical treatment in order to identify risk factors for potential negative long-term outcomes of treatment.

Although more proximal factors, such as general psychological distress or post-traumatic stress, are typically studied in the literature examining predictors of medical adherence behavior and health, more distal factors such as personality may strongly influence the presence and impact of these proximal factors (Chapman et al., 2009; Ferguson, 2013). In children with chronic illnesses, parents often have primary control over the management of the child's illness. As a result, parent personality is more likely to have an influence upon the child's illness management than child personality. Parent personality traits can indirectly influence the social environment and coping (e.g., support-seeking, effective interpersonal interaction) and health-related behaviors (e.g., following medical advice, managing complex medication regimens) to influence long-term health outcomes (Ferguson, 2013; Roberts, Walton, & Bogg, 2005; Roberts, Kuneel, Shiner, Caspi, & Goldberg, 2007). An additional mechanism through which personality may influence a parent's response to the child's illness is through coping styles. In a meta-analysis by Connor-Smith and Flachsbart (2007), personality factors were shown to differentially influence coping styles, with strength of the relationship increasing when individuals were under stress. There is no known literature identifying the impact of parent personality on psychosocial functioning and illness management for children awaiting transplantation. As a result, extrapolations from the literature on other chronic illnesses populations will be reviewed, as well as literature on the broad influence of personality on health and health-related behaviors.

The Five Factor Model (FFM) of personality has been used to conceptualize the five broad factors of personality, including extraversion, neuroticism, openness, agreeableness, and conscientiousness (Caspi, Roberts, & Shiner, 2005; McCrae & Costa, 2008). As will be reviewed below, the existing literature has primarily focused on factors of extraversion, neuroticism, and conscientiousness in relationship to health. As a result, only these three factors' connection to health adherence behaviors will be considered. Extraversion has been described as a personality trait that encompasses the tendency to experience positive moods, typically enjoy social attention, and be sensitive to rewards (Fleeson, Malanos, & Achille, 2002; Ashton, Lee, & Paunonen, 2002). In a study evaluating the influence of maternal mood and affectivity in children with inflammatory bowel disease, maternal positive affectivity was associated with lower levels of child psychological dysfunction and better disease control (Tojek, Lumley, Corlis, Ondersma, & Tolia, 2002). Individuals that are high in positive emotionality may experience better health outcomes due to their ability to nurture social relationships, seek social support, and have strong social networks (Berkman, Glass, Brisette, & Seeman, 2000). Extraversion has also been related to higher quality of life in individuals with chronic illnesses (Penedo et al., 2003), and longevity in healthy individuals (Danner, Snowdon, & Friesen, 2001).

Neuroticism is most often described as a tendency towards negative emotionality, such that individuals high in neuroticism tend to be more anxious, vulnerable to stress, easily frustrated, and prone to experiencing guilt (Caspi, Roberts, & Shiner, 2005; Shiner & Caspi, 2003). Those low on this trait can be described as more emotionally stable and adaptable to social context. Neuroticism has been relatively well studied in its relation to health, but studies with pediatric samples are few. In one study examining pre-treatment parental factors as they relate to post-treatment functioning years later, a study including parents of children diagnosed with leukemia showed that higher maternal trait anxiety, a factor highly related to neuroticism, at diagnosis was predictive of PTSS post-treatment, accounting for 20% of the variance (Best, Streiseand, Catania, & Kazak, 2001). Those with high neuroticism most often use dysfunctional coping skills when placed in a stressful situation (Vollrath, 2001). Neuroticism is also negatively related to medication adherence in adults with chronic illnesses, a relationship that could potentially extend downward to the management of a child's illness (Axelsson, Brink, Lundgren, & Lotvall, 2011).

Conscientiousness represents the capacity of an individual to be attentive, orderly, organized, and planful in their thoughts and actions (Caspi & Roberts, 2005). It has been shown to be related to biological differences in executive functioning across the lifespan and adult effortful attention (Posner & Rothbart, 2000; Rothbart, Ahadi, & Evans, 2000) and is one of the more well-studied personality factors in relation to health variables. Responsibility, a factor particularly relevant to the high-risk management of a child's complex illness, has been shown to be related to conscientiousness (Roberts, Bogg, Walton, Cherynshenko, & Stark, 2004). Conscientiousness is also one of the strongest predictors of delinquency within the FFM (Roberts Cherynshenko, Stark, & Goldberg, 2005). In relation to health behaviors, individuals high in conscientiousness tend to engage in lower levels of risky health behaviors, such as smoking, unhealthy eating habits, not exercising, and driving dangerously (Bogg & Roberts, 2004). Individuals high in conscientious have also been shown to engage in higher levels of healthy behaviors (e.g., eating healthily and sleeping adequately) when under intense stress when compared to individuals lower in conscientiousness (Korotkov, 2008). In adults with chronic illnesses, conscientiousness is positively correlated with medication adherence (Axelsson et al., 2011), including adults undergoing renal dialysis (Christensen & Smith, 1995), and in the general adult population (Hill & Roberts, 2011). In a group of adults with chronic renal insufficiency, a condition typically treated with dialysis until transplantation is an option, patients that were high in neuroticism had a 37.5% higher mortality rate over the course of 5 years, and those low in conscientiousness had a 36.4% higher mortality rate (Christensen et al., 2002). In one of the few studies conducted on adolescents with a chronic illness, adolescents with type 1 diabetes who rated themselves higher in conscientiousness also reported higher levels of self-care, including adherence to medical recommendations (Skinner, Hampson, & Fife-Schaw, 2002). It is important to note that levels of conscientiousness were strongly related to age of the participant and the parent's level of involvement in the child's care was not accounted for. For children with organ transplants, parental involvement is high (Pai et al., 2011), thus parental personality may have a strong influence on medical regimen management and requires further investigation.

It is important to note that the large majority of the research conducted in the area of pediatric transplantation thus far has consisted of individuals studied post-transplant. Few studies have been conducted on families pre-transplant, with even fewer following these individuals longitudinally from pre- to post-transplant. Despite the large number of transplantation centers that conduct pre-transplant evaluations to try to detect families at risk for negative post-transplant outcomes, there are no published studies to date that have prospectively evaluated pre-transplant predictors of post-transplant psychosocial and medical outcomes of patients and their parents/caregivers. The time spent waiting for a transplant can vary from days to months, and even years (Organ Procurement and Transplantation Network, 2013). Many families have been anticipating the date of the transplant evaluation since the child's birth and diagnosis of a congenital disease, while others may have been told their child's needs are emergent and that a transplant is required just days or even hours before the evaluation is scheduled. Pre-transplant evaluations typically consist of a family meeting with numerous providers and support team members, including primary specialists (e.g., nephrologists), surgeons, nurse practitioners, social workers, child life professionals, financial counselors, and psychologists. These evaluations vary greatly in the breadth and depth of their content between transplant centers, but typically include physical, psychological, and social functioning (Streisand & Tercyak, 2001). The goal of these evaluations is not to rule families as eligible or ineligible for transplant based upon psychological factors, as it is in adults (Shemesh, 2008), but to ensure that the patient is medically eligible for transplantation. From a psychosocial standpoint, the evaluation serves to provide information to the family about transplantation, educate them of anticipated stressors and risks, and inform the family of opportunities to seek psychological support should the need arise. Psychologists and others inquire about past adherence behaviors and the family's prior experiences with successfully following the advice of medical providers. Families are provided with appropriate referrals if necessary, although follow-up on these recommendations is not typically systematically tracked. The psychologist gathers information about past psychological difficulties for the family and child, with the expectation that a stressful event such as having a critically ill child and undergoing transplantation may exacerbate pre-existing problems. Likewise, pre-existing problems may serve as risk factors that interfere with a variety of health behaviors and outcomes in the highly stressful and sustained situation into which the patients and families will enter after transplantation. Descriptions of the family's support system and establishment of a plan of care for the remainder of the family members during the acute phase of transplantation are discussed.

Even though pre-transplant evaluations are routinely conducted, there are no standardized batteries or agreed upon psychometrically valid assessment tools for pediatric patients. One study documented the development of a screening instrument, the Pediatric Transplant Rating Instrument, but the measure has yet to be validated and assessed longitudinally to examine predictors of outcomes (Fung & Shaw, 2008). The measure was designed to be administered alongside a psychosocial interview. Scoring of the measure depended on subjective physician ratings of psychosocial distress. When separately evaluated with pediatric populations, the measure showed poor inter-rater reliability between physicians and was published without demonstrated validity criteria, limiting its utility in predicting outcomes for patients and the medical team (Fisher et al, 2011). The measure was also not evaluated in context with other medical and psychosocial criteria. Based on a review of the pediatric transplant literature, Annunziato and colleagues (2010) suggested a number of factors to be considered in the pre-transplant evaluation process and in the development of a standardized pre-transplant screening measure. Patient factors included knowledge of the transplant process, past adherence to medical regimens, cognitive functioning, and levels of psychological functioning. Family factors included financial resources, parental stress, parental personality, and parental mental health. Similar factors have been suggested as predictors of post-transplant outcomes in the adult transplantation literature (Bunzel & Laederach-Hofmann, 2000).

Although relationships between parent psychosocial functioning, child psychosocial functioning, and medical adherence have been described in the literature on individuals post-transplant (e.g., Fredericks, Lopez, Magee, Shieck, & Opipari-Arrigan, 2007; Gerson et al., 2004), limited literature examines these relationships concurrently in the pre-transplant period. Only two published studies to date utilize a prospective design, following between 20 and 35 individuals with heart or heart-lung transplants from the pre-transplant period to 2 years post-transplant (Wray & Radley-Smith, 2004; Wray & Radley-Smith, 2007). It is unclear whether these studies utilize entirely different samples or consist of some of the same individuals being followed over time. Results showed that transplant recipients reported similar levels of depressive symptoms to healthy controls 1 to 2 years after transplant, which reflected a decrease from the pre-transplant period. Similar results were found for their parents' distress pre- to post-transplant (Wray & Radley-Smith 2007). Relationships with medical outcomes or adherence behaviors were not examined in this study, nor were other measures of parent and child psychosocial functioning.

While the above studies can serve to guide this investigation, they provide little information on the pre-transplant predictors of post-transplant functioning in a true experimental manner. Additionally, and pertinent to this investigation, they do not provide a comprehensive and coherent picture of the difficulties patients may face prior to transplant. Knowing what psychosocial symptoms are most likely to be present during a pre-transplant evaluation may facilitate an in-depth examination of these factors. While many studies describe the presence of psychological symptoms and distress in transplant recipients (e.g., Berney-Martinet et al., 2009), few studies describe individuals awaiting transplant and their caregivers. Wray and Radley-Smith (2004) demonstrated that 35 infants and young children awaiting heart or heart-lung transplant had lower levels of emotional and social functioning in comparison to normative samples in the pre-transplant period. In a sample including 28 children from a wider age range of infancy to 14 years also awaiting heart or heart-lung transplant, parents of children awaiting transplant self-reported higher levels of distress, while levels of child emotional distress were similar to those of healthy samples (Wray & Radley-Smith 2007). Although these studies consisted of small samples and only heart or heart-lung transplant recipients, the mixed results suggest that further investigation into pre-transplant functioning of children and adolescents awaiting transplantation and their parents is needed, both for comparison to healthy normative samples and to assess factors related to differential functioning during the pre-transplant period. Further, study of those awaiting kidney and liver transplants, as well as a heart, is needed.

In an attempt to retrospectively examine factors that potentially influenced post-transplant outcomes, Stone and colleagues (2006) categorized families of children who had received heart transplants into risk groups based upon factors such as pre-transplant parental age, education, involvement of child protective services, and psychopathology. Using these categories, they examined differences in post-transplant medical outcomes. Families categorized as “at risk” experienced greater numbers of organ rejections, hospitalizations, and nonadherence. Detailed information on how these risk factors were determined or complied was not provided and the study relied entirely on retrospective chart review. A similar methodology was utilized by DeMaso and colleagues on two studies with recipients of pediatric heart transplants (DeMaso, Kelley, Bastardi, O'Brien, & Blumo, 2004; DeMaso, Twente, Spratt, & O'Brien, 1995). Patients described as having higher levels of psychological functioning pre-transplant experienced fewer hospitalizations in the post-transplant period. (DeMaso et al., 1995). Higher levels of family dysfunction pre-transplant were also related to lower levels of child psychological functioning post-transplant, while better child psychological functioning pre-transplant was related to better adjustment post-transplant (DeMaso et al., 2004). While the methodology of these studies leaves many questions unanswered about patients' and parents' pre-transplant functioning, as well as how they relate to post-transplant outcomes, these studies do suggest that pre-transplant psychosocial functioning is important. Greater methodological rigor is needed in this pursuit.

This study will be the first to investigate pre-transplant functioning in children awaiting kidney, liver, or heart transplantation and their parents to determine relationships between psychosocial functioning and medical adherence during the pre-transplant period. Additionally, this study will include both children and adolescents, with children being a novel population in this research area. Examination of the influence of parent personality on pre-transplant functioning is also a unique contribution to the general pediatric adherence literature, and more specifically to the pediatric transplant literature. Results from this study will be integral for helping to identify individual and family factors associated with psychosocial functioning, disease functioning, and medication adherence prior to organ transplantation. Description of such factors will aid in the development of screening measures for early identification of at-risk individuals in order to provide necessary intervention services prior to developing negative outcomes post-transplant. Conversely, the study will also help to identify protective factors associated with positive outcomes to support and enhance these factors in the pre-transplant period. These factors can be used to inform the creation of a pre-transplant evaluation measure with the most relevant domains of functioning included. It will also serve to guide the development of prevention and intervention programs for the pre-transplant period with potential to influence parent and child outcomes post-transplantation. This knowledge will help to inform practices in pediatric transplant centers, with the goal of improving patient care and reducing financial burden upon the health care system.

It is hypothesized that parents of children awaiting transplant will experience greater amounts of psychological distress in comparison to normative samples, including greater levels of overall psychological distress and post-traumatic stress. Children will experience lower health-related quality of life, as reported via parent proxy-report. It is hypothesized that parent personality factors will be related to medication adherence, as indicated by missed medications, and to medication knowledge. Additionally, parent personality will be related to parent psychological functioning and child HRQOL. Specifically, parent neuroticism will be negatively related to medication adherence, medication knowledge, parent psychological functioning, and child HRQOL. Conscientiousness and extraversion will be positively related to medication adherence, medication knowledge, parent psychological functioning, and child HRQOL. As personality has shown to act as a moderator in the prediction of health behavior (Korotkov, 2008), moderation will be explored with predictive models in which personality factors are significant predictors of adherence and knowledge.

CHAPTER 2

METHOD

Participants

Participants included 65 parents/caregivers who were legal guardians of pediatric patients with kidney, liver, or heart disease who were being evaluated as a part of a standardized treatment protocol in establishing candidacy for solid organ transplantation at Children's Healthcare of Atlanta (CHOA). Caregiver's included 96.6 percent biological parents, 1.5% adoptive parents, and 1.5% grandparents, 89.2% of whom were female. Mean age of parents was 36.65 years (SD = 9.35). Demographic information for children of caregivers who participated is presented in Table 1. Exclusion criteria for parents included parent-reported or documented intellectual disability of the parent and inability to speak or read English fluently. As compensation for their time, parents received a $10 retail store gift card. Families who declined participation in the study were asked to provide basic anonymous demographic information for comparison purposes to those consented. Recruitment rate was 95.6%. No statistically significant differences in demographic information were found between those who declined participation (*n* = 3) and those who participated in the study. Breakdown of the diagnoses serving as the referring concern for the pre-transplant evaluation are presented in Table 2.

Instruments

Measures included in the study are paper and pencil questionnaires. Parents completed a measure reporting on the child's health-related quality of life (PedsQL).

Parents also completed self-report measures of demographics, emotional functioning (BSI-18), personality (NEO-FFI-3), post-traumatic stress (IES-R), and medical adherence (MAM).

Pediatric Quality of Life Inventory (PedsQL; Varni, Seid, & Kurtin, 2001). This 23-item measure assesses health-related quality of life. Parents of children 2-21 years old completed the proxy-report version. The PedsQL is intended for use only with children ages 2-18, and the upper age range is often extended for pediatric samples given the differential development of children with a chronic illness. As a result, only children ages 2-20 were utilized for analyzes including the PedsQL, comprising 72.30% of our sample. The PedsQL has been used to assess parent-reported HRQOL in pediatric kidney and liver transplant recipients (Anthony et al., 2010; Fredericks et al., 2008). Age-based format for the PedsQL includes 4 versions: Toddler (2-4 years), Young Child (5-7 years), Child (8-11 years), and Adolescent (12-18 years). HRQOL includes four dimensions of functioning: physical, emotional, social, and school. A Total Score is created from these domains. Respondents are asked to indicate how much each item has been a problem in the past month using a 5-point Likert scale from 0 – "Never a problem" to 4 – "Almost always a problem." Established internal consistency and construct validity have been shown to be good, with scores of HRQOL being correlated with illness morbidity and burden (Varni et al., 2001). For this sample, internal consistency was acceptable for all age-based formats of the PedsQL (Cronbach's $\alpha = .91 – .95$). Data for 10,241 healthy comparison families exists for the PedsQL. A cut-off score of 65.42 has also been shown to differentiate those who may be at risk for impaired HRQOL (Varni, Burwinckle, Seud, & Skarr, 2003).

Background Questionnaire. Completed by the parent, this measure assesses patient and parent/caregiver demographic characteristics. Data collected include age, sex, race/ethnicity, educational history, socioeconomic status, employment status, and family structure.

Brief Symptom Inventory-18 (BSI-18; Derogatis, 2000). The BSI-18 is an 18-item measure designed to assess psychological distress in adults. It contains a Global Severity Index composite indicative of overall psychological distress comprised of components of anxiety, depression, and somatization. Items are rated on a Likert scale from 0 – "Not at all" to 4 – "Extremely often." A cut-off T-score of 63 has been shown to differentiate individuals with significant psychological distress. The BSI-18 has shown strong concurrent validity with the well-established and validated Symptom Checklist-90-R (SCL-90-R) from which the BSI-18 was derived (Recklitis & Rodriguez, 2007). For this sample, internal consistency was acceptable (Cronbach's α = .95).

NEO-Five Factor Inventory-3 (NEO-FFI-3; McCrae & Costa, 2010)**.** The 60-item NEO-FFI-3 measures the five factors of normal personality. Neuroticism, extroversion, and conscientiousness factors will be utilized. Parents self-report on their own personality, responding to descriptive statements of behavioral and emotional tendencies on a Likert scale from 1 – "Strongly disagree" to 4 – "Strongly agree." Normed t-scores were obtained. The NEO-FFI-3 has been shown to have good internal consistency (α = .78 to .86 for factors) and is a reliable assessment of personality, showing convergence with the longer NEO-Personality Inventory (McCrae & Costa, 2007). For this sample, internal consistency was acceptable for all factors utilized (Cronbach's α = .82 for neuroticism, .63 for extraversion, and .84 for conscientiousness).

Impact of Event Scale-Revised (IES-R; Weiss & Marmar, 1997). The IES-R is a 22-item self-report measure of posttraumatic stress symptoms (PTSS). The standardized prompt for the IES-R asks individuals to respond to the questions with respect to stressful life events. Unique to this study, parents will be asked to provide a rating for how distressing each item was during the past seven days with respect to their experience with their child's medical condition. Responses are rated on a 5-point Likert scale from 0 – "Not at all" to 4 – "Extremely." The modified prompt on the IES-R has been used to reliably assess ($\alpha = .96$) PTSS among caregivers of several pediatric populations, including solid organ and bone marrow transplant candidates (Ingerski, Shaw, Gray, & Janicke, 2010). IES-R has shown adequate validity and internal consistency. For this sample, internal consistency was acceptable (Cronbach's $\alpha = .89$). A cutoff of 1.5 for the mean item endorsement of the subscales comprising the Total Score has been shown to be clinically significant (Creamer, Bell, & Failla, 2003). A normative sample mean of 1.08 was developed using parents of healthy children and was used for comparison purposes (Jurbergs, Long, Ticona, & Phipps, 2004).

Medical Adherence Measure (MAM; Zelikovsky & Schast, 2008). The Medication module of the MAM was administered to parents/caregivers. The MAM is a semi-structured interview that assesses medication adherence, as indicated by the percentage of reported doses missed in the past seven days for each prescribed medication. It also assesses knowledge of the medication regimen, including names of medications, indications, frequency, and dosages. Averaging the percent of correct information provided on the different elements comprising medication knowledge resulted in a variable computing the mean level of knowledge. Rates of medication adherence (i.e., missed doses) were calculated by dividing the number of doses missed by the number of prescribed doses, and subtracting that value from 1. The MAM has shown good convergent validity, with a systematic review of the adherence literature (Dobbels et al., 2010) reporting that higher rates of nonadherence on the MAM were positively correlated with rates of nonadherence calculated with electronic monitoring (e.g., Medication Event Monitoring Systems). Adherence reported with the MAM has also been associated with barriers to adherence and clinical outcomes, such as organ rejection two years post-transplant (Simons et al., 2010; Zelikovsky, Schast, Palmer, & Meyers, 2008).

Medical Chart Review. The patient's Electronic Medical Record (EMR) was accessed to gather information related to the patient's medical diagnosis, time since diagnosis, and prescribed medication regimen. Participants were prescribed varying medication regimens. In this sample, 76.9% (*n* = 50) were prescribed medications and able to report on adherence, 10.7% (*n* = 7) had knowledge only assessed due to the child being hospitalized at the time of the evaluation and therefore out of their usual medication taking routine, 6.1% percent of children (*n* = 4) were not prescribed medications in the 7 days before the transplant evaluation, and 6.1% (*n* = 4) of participants have missing adherence data for other reasons (e.g., unable to complete on day of evaluation and unable to contact parent for adherence data). Children were prescribed between 0 and 18 medications at the time of the transplant evaluation (*M* =6.19*, SD* =3.38). Of those prescribed medications, participants were required to take between 4 and 222 doses of medication each week (*M* = 68.19, *SD* = 42.85).

Procedure

Prior to initiating data collection, Institutional Review Board approval was obtained from participating institutions. Potential participants were recruited from a large pediatric transplant center in the southeastern United States. Patients who were scheduled for a pre-transplant evaluation were identified by the Transplant Coordinators. Research personnel were notified of the date and time of the scheduled pre-transplant evaluation, as well as the patient's age. On the day of the evaluation, the patient's parent/caregiver was approached by a research assistant or staff member in their clinic room and provided a brief description of the study. Interested families were asked to provide informed consent and HIPAA authorization. During recruitment and consent, it was heavily emphasized that the parent's responses would remain confidential, would not be shared with the team conducting the evaluation, and would in no way impact the likelihood of their child being approved and listed for transplantation. Parents who provided consent completed self- and proxy-report paper-and-pencil questionnaires while attending the pre-transplant evaluation for their child.

Table 1.

Demographic Information

Factor	*M*	*SD*
Age	7.94	6.48
	Frequency	%
Sex		
Male	32	50.80
Female	33	49.20
Organ Type		
Kidney	25	38.46
Heart	18	27.69
Liver	22	33.85
Ethnicity		
Caucasian	37	59.90
African American	20	30.80
Hispanic/Latino	2	3.10
Biracial	6	9.20
Family income		
Less than $10,000	7	10.80
$10,000-24,999	7	10.80
$25,000-49,999	12	18.50
$50,000-74,999	16	24.60
$75,000-99,999	9	13.80
$100,000 or greater	9	13.80
Parent Education Level		
Less than high school diploma	5	7.70
High school diploma/GED	7	10.80
Some college	24	36.90
Associate’s degree	5	7.70

Bachelor’s degree	17	26.20
Advanced degree	7	10.80
Family marital status		
Married	51	78.50
Single, never married	9	13.80
Divorced	3	4.60
Separated	2	3.10

Note. *N* = 65

Table 2.

Medical Information: Diagnosis by Organ Group

	Frequency	%
Kidney		
Glomerular diseases	5	7.7
Polycystic kidneys	2	3.1
Congenital, familial, and metabolic	16	24.6
Other kidney disease	2	3.1
Liver		
Acute hepatic necrosis	3	4.6
Cholestatic liver disease/cirrhosis	3	4.6
Biliary atresia	8	12.3
Metabolic diseases	3	4.6
Malignant neoplasms	3	4.6
Other liver disease	2	3.1
Heart		
Cardiomyopathy	12	18.5
Congenital heart disease	6	9.2

CHAPTER 3

RESULTS

Data Analytic Plan

Analyses were conducted in accordance with hypotheses stated in the Introduction. For all analyses, assumptions and requirements for each statistical test were examined prior to performing analyses.

Power analyses. Sample size was determined using the G*POWER program (Faul, Erdfelder, Buchner, & Lang, 2009). For correlational analyses, the sample size needed to achieve a recommended power of .80 in a one-tailed test at $\alpha = .05$ for correlation with a presumed medium effect size ($r = .30$) is 67 participants. For examining predictors of medical regimen adherence, the sample size needed to achieve a recommended power of .80 with $\alpha = .05$ for a presumed medium effect size ($f^2 = .20$) including a maximum of 4 predictors using multiple linear regression is 65 participants. For single sample t-tests comparing to normative samples, the sample size needed to achieve a recommended power of .80 in a one-tailed test at $\alpha = .05$ for a t-test with a presumed medium effect size ($d = .50$) is 27 participants. Analyses were conducted utilizing the Statistical Package for Social Sciences, Version 22.0.

Comparison of Psychological Functioning in Parents and Children Awaiting Transplantation to Normative Samples.

For the BSI, normed T-score means of 50 were utilized as population means for comparison purposes. Normative sample means for the IES-R and PedsQL are presented with the analyses. T-test results are presented in Table 3. Descriptive data on percentages of parents and children with clinically significant elevations are provided below.

Parents of children awaiting transplantation reported similar levels of general psychological distress compared to normative samples. Despite no differences in mean level of psychological distress, 23.1% of parents (*n* = 15) reported general psychological distress in the clinically significant range. Parents of children awaiting transplantation reported similar levels of post-traumatic stress compared to parents of healthy children. Despite no differences in mean level of psychological distress, 18.5% of parents (*n* = 12) reported clinically significant levels of PTSS. Results comparing children awaiting transplantation on parent proxy-reported HRQOL to normative samples (Varni et al., 2003) are presented in Table 3. Significantly lower HRQOL was found for the entire pre-transplant sample when compared to the normative sample, as well as for the toddler and adolescent pre-transplant age groups. Using a cut-off score derived by Varni and colleagues (2003) to differentiate those who may be at risk for impaired HRQOL, 46.8% of the sample (*n* = 22) fell in that at risk range.

Relationships Between Parent Personality, Parent Psychosocial Functioning, Child HRQOL, and Medical Adherence. Pearson product moment correlations were utilized to examine the relationships between the 3 factors of parent personality and their relationship with: parent psychological distress and PTSS, parent-report of child HRQOL, and medical regimen adherence (i.e., knowledge, adherence). Medical factors, including time elapsed since diagnosis of the disease necessitating transplantation and the number of medications the child was taking at the time of the pre-transplant evaluation, were also included. Results of correlational analyses are presented in Table 4.

Parent psychological distress was negatively related to the child's age, time since diagnosis, and parent extraversion. Psychological distress was also positively related to parent neuroticism and parent PTSS. Parent PTSS was negatively related to time since diagnosis and child HRQOL. Positive relationships were found between PTSS with regards to parent neuroticism, psychological distress, and medication knowledge. Medication knowledge was negatively related to the child's age, time since diagnosis, and number of prescribed medications. Positive relationships were found between medication knowledge with parent PTSS and medication adherence. Neuroticism showed a trending positive relationship with medication knowledge (p = .08). Medication adherence was positively related to medication knowledge. Conscientiousness showed a trending (p = .06) positive relationship with adherence. Number of medications prescribed was positively related to the child's age, time since the child's diagnosis, and negatively related to child HRQOL.

Predictors of Parent Psychological Distress, Child HRQOL, Medication Knowledge, and Medication Adherence.

Hierarchical multiple linear regression was utilized to examine predictors of parent psychological distress, child HRQOL, and medication adherence and knowledge. Correlational analyses were used to guide selection of predictors for entry. For all regression analyses, assumptions for multiple linear regression were met and multicollinearity diagnostics for multiple regression models did not reveal concerns with multicollinearity within the tested models, with all tolerance values $\geq .2$ and all VIF values ≤ 3. Relevant demographic factors and medical factors were entered in Step 1. Child age and time since diagnosis were both significantly correlated with outcomes, with identical direction and similar correlation strength. The two were also very strongly correlated with each other ($r = .65, p < .01$). In cases where both the child's age and time since diagnosis were correlated, the factor with the strongest correlation with the outcome being predicted was entered to avoid entering potentially multicollinear relationships. In Step 2, factors correlated with relevant outcomes were entered.

Predictors of Child Health Related Quality of Life.

In selecting factors for entry into the model, parent psychological distress and parent post-traumatic stress were highly correlated ($r = .76, p < .01$). Collinearity diagnostics indicated that these two variables reflected a similar construct and should not be included in the same models (Cohen, Cohen, West, & Aiken, 2002). Results are presented in Table 5. Number of medications was entered on the first step and accounted for a statistically nonsignificant amount of the variance. When parent neuroticism and conscientiousness were entered in the second step of the model, number of medications and parent neuroticism emerged as significant predictors, accounting for an additional 31% of the variance in child health related quality of life. Parent psychological distress was added in the third step of the model, resulting in the removal of neuroticism as a statistically significant predictor from the model. Conscientiousness emerged as a significant predictor, joining number of medications and parent psychological distress in predicting 40% of the variance in child HRQOL.

Predictors of Parent Psychological Distress.

Although parent PTSS was correlated with parent psychological distress, it was again removed from the model predicting psychological distress, as collinearity diagnostics indicated they reflected a similar construct. Hierarchical regression analyses for parent psychological distress are presented in Table 6. Time since diagnosis was entered on the first step, emerging as a statistically significant predictor and accounting for 8% of the variance in parent psychological distress. When parent neuroticism and parent extraversion were entered in the second step of the model, only parent neuroticism remained a significant predictor, with the full model accounting for 42% of the variance in parent psychological distress.

Predictors of Medical Regimen Knowledge.

In predicting the level of a parent's medication knowledge, time since diagnosis and the number of medications were entered in the first step, predicting 16% of the variance (Table 7). Time since diagnosis emerged as a significant negative predictor. Parent neuroticism and parent PTSS were added in the second step. Time since diagnosis remained the only significant predictor, with the overall model predicting 19% of the variance in medication knowledge.

Predictors of Medical Regimen Adherence.

The relationship between medication knowledge and parent conscientiousness predicting medication adherence was examined in the first model (Table 8). Despite only a trending statistical relationship with medication adherence, parent conscientiousness was entered into the model due to its well-documented relationship with adherence in prior literature with adults. Predictors were mean centered prior to conducting analyses. Medication knowledge was entered on the first step and accounted for 15% of the variance ($p \leq .01$). In the second step of the model, parent conscientiousness added significantly to the variance in medication adherence ($\Delta R^2 = .07, p \leq .05$). Given that conscientiousness emerged as a significant predictor, the potential for interaction between parent personality factors in predicting medical adherence was examined. The interaction of medication knowledge and parent conscientiousness was entered on the third step and contributed an additional 16% of the variance predicting medication adherence ($p \leq .01$). In the final model, medication knowledge, parent conscientiousness, and the interaction of medication knowledge and conscientiousness were significant predictors, accounting for 38% of the variance in medication adherence. Following the recommendations of Holmbeck (2002), moderational analyses examined the simple effects of the interaction for parents with high (+1 *SD*) and low (-1 *SD*) levels of conscientiousness and followed procedures of Hayes (2013) using the PROCESS macro for SPSS. Results indicated that the slope was nonsignificant for high levels of conscientiousness ($t[43] = .09$, $p = .931$), but significant for low levels of conscientiousness ($t([43] = 2.37$, $p < .05$). This interaction is shown in Figure 1. For parents with high levels of conscientiousness, similar levels of adherence were reported at low ($M = 98.23$) and high ($M = 98.43$) levels of knowledge. For parents with low levels of conscientiousness, adherence levels were significantly lower for parents with low knowledge ($M = 87.22$) than for parents with high ($M = 100.00$) levels of knowledge.

Table 3.

Psychosocial Functioning Compared to Normative Samples

	Pre-transplant		*Normative*				
Variable	*M*	*SD*	*M*	*SD*	*t*	*df*	*d*
Child HRQOL							
Toddler (2-4 years)	68.90	20.11	87.42	12.49	-3.44**	13	1.10
Young child (5-7 years)	61.02	18.72	78.02	16.44	-2.22†	5	0.96
Child (8-12 years)	67.93	18.24	78.86	16.61	-1.20	3	0.63
Adolescent (13-20 years)	62.26	21.03	79.45	16.40	-3.92**	22	0.91
Full sample norms	64.56	19.92	81.34	15.92	-5.78**	46	0.93
Parent Psychological Distress	51.61	12.92	50	10	1.00	64	0.14
Parent Post-traumatic Stress	0.97	0.67	1.08	0.80	-1.24	64	-0.15

Note. * $p \le .05$, ** $p \le .01$, $^{\dagger}p \le .10$; *d* represents Cohen's effect size, *d* for which the ranges are small: 0 - 0.2, medium = 0.3 - 0.5, and large = 0.6 - 2.0.

Table 4.

Correlates of Parent Personality and Medication Adherence

Variable	2	3	4	5	6	7	8	9	10	11
1. Child Age *n* = 65 (*M* = 7.94, *SD* = 6.98) Range: .07–20.44	.65**	-.20†	-.23*	-.06	-.28**	-.19†	-.13	-.30*	.32**	-.07
2. Time Since Diagnosis in Months *n* = 65 (*M* = 53.74, *SD* = 64.88) Range: .10–243.30	--	-.20†	.09	-.02	-.28*	-.21*	-.00	-.37**	.30*	-.02
3. Neuroticism *n* = 65 (*M* = 46.23, *SD* = 9.52) Range: 23.00–67.00	--	--	-.26*	-.45**	.63**	.52**	-.36**	.19†	-.17†	-.05
4. Conscientiousness *n* = 65 (*M* = 51.23, *SD* = 8.32) Range:30.00–66.00	--	--	--	.11	-.08	-.01	.36**	-.12	.02	.22†
5. Extraversion *n* = 65 (*M* = 52.49, *SD* = 8.32) Range: 29.00–75.00	--	--	--	--	-.25*	-.34**	.21†	.15	-.17†	.09
6. Parent Psychological Distress *n* = 65 (*M* = 51.62, *SD* = 12.92) Range: 33.00–81.00	--	--	--	--	--	.76**	-.42**	.15	-.19†	.04
7. Parent Post-traumatic Stress *n* = 65 (*M* = 0.98 , *SD* = 0.67) Range: 0–3.42	--	--	--	--	--	--	-.36**	.23*	-.03	.04
8. Child Health Related Quality of Life *n* = 47 (*M* = 64.56, *SD* = 19.92) Range: 21.74–100.00	--	--	--	--	--	--	--	-.03	-.29*	.03
9. Medication Knowledge *n* = 57 (*M* = .88 , *SD* = .17) Range: .40–1.00	--	--	--	--	--	--	--	--	-.27*	.39**
10. Number of Medications *n* = 57 (*M* = 6.19, *SD* = 3.38) Range:1.00–18.00	--	--	--	--	--	--	--	--	--	.01
11. Medication Adherence *n* =50 (*M* = .96 , *SD* = .08) Range: .64–1.00	--	--	--	--	--	--	--	--	--	--

Note. Pearson product moment correlations were used with *r*; * $p \le .05$, ** $p \le .01$, $^{\dagger}p \le .10$

Table 5.

Hierarchical Regression of Child Health Related Quality of Life

Child HRQOL	B^{a}	SEB^{b}	β^{c}	R^2	ΔR^2	*F*
Step 1:				.08	.08	3.61†
Number of Medications	-1.65	.87	-.29†			
Step 2:				.31	.23**	5.81**
Number of Medications	-2.15	.79	-.38**			
Parent Neuroticism	-.73	.31	-.35*			
Parent Conscientiousness	.62	.36	.24†			
Step 3:				.40	.08*	6.11**
Number of Medications	-2.10	.75	-.37**			
Parent Neuroticism	-.17	.38	-.08			
Parent Conscientiousness	.75	.35	.29*			
Parent Psychological Distress	-.63	.28	-.38*			

Note. $N = 42$; ^{a}B, unstandardized coefficients; ^{b}SEB, standard error of unstandardized coefficients; $^{c}\beta$, standardized coefficients; $^{*}p \leq .05$, $^{**}p \leq .01$, $^{\dagger}p \leq .10$

Table 6.

Hierarchical Regression of Parent Psychological Distress

Parent Psychological Distress	B^a	SEB^b	β^c	R^2	ΔR^2	F
Step 1:				.08	.08	5.15*
Time Since Diagnosis	-.06	.02	-.28*			
Step 2:				.42	.34**	14.67**
Time Since Diagnosis	-.03	.02	-.16			
Parent Neuroticism	.82	.15	.61**			
Parent Extraversion	.03	.17	.02			

Note. N=65*;* ^{a}B, unstandardized coefficients; ^{b}SEB, standard error of unstandardized coefficients; ^{c}β, standardized coefficients; * $p \leq .05$, ** $p \leq .01$

Table 7.

Hierarchical Regression of Medication Knowledge

Medication Knowledge	B^{a}	SEB^{b}	β^{c}	R^2	Δ R^2	*F*
Step 1:				.16	.16	5.33**
Time Since Diagnosis	.00	.00	-.33**			
Number of Medications	.00	.00	-.16			
Step 2:				.19	.03	3.13*
Time Since Diagnosis	.00	.00	-.29*			
Number of Medications	.00	.00	.17			
Parent Neuroticism	.00	.00	.01			
Parent Post-traumatic Stress	.04	.04	.17			

Note. N=57*;* ^{a}B, unstandardized coefficients; ^{b}SEB, standard error of unstandardized coefficients; ^{c}β, standardized coefficients; $^{*}p \leq .05$, $^{**}p \leq .01$, $^{\dagger}p \leq .10$

Table 8.

Hierarchical Regression of Medication Adherence

Medication Adherence	B[a]	SEB[b]	β[c]	R^2	Δ R^2	F
Step 1:				.15	.15	8.46^{**}
Medication Knowledge	.19	.06	$.39^{**}$			
Step 2:				.22	$.07^{*}$	6.66^{**}
Medication Knowledge	.20	.06	$.42^{**}$			
Parent Conscientiousness	.00	.00	$.27^{*}$			
Step 3:				.38	$.16^{**}$	9.44^{**}
Medication Knowledge	.19	.09	$.41^{**}$			
Parent Conscientiousness	.00	.00	$.25^{*}$			
Knowledge X Conscientiousness	-.02	.01	$-.40^{**}$			

Note. N=50; [a]B, unstandardized coefficients; [b]SEB, standard error of unstandardized coefficients; [c]β, standardized coefficients; $^{*}\ p \leq .05$, $^{**}\ p \leq .01$, $^{\dagger}p \leq .10$

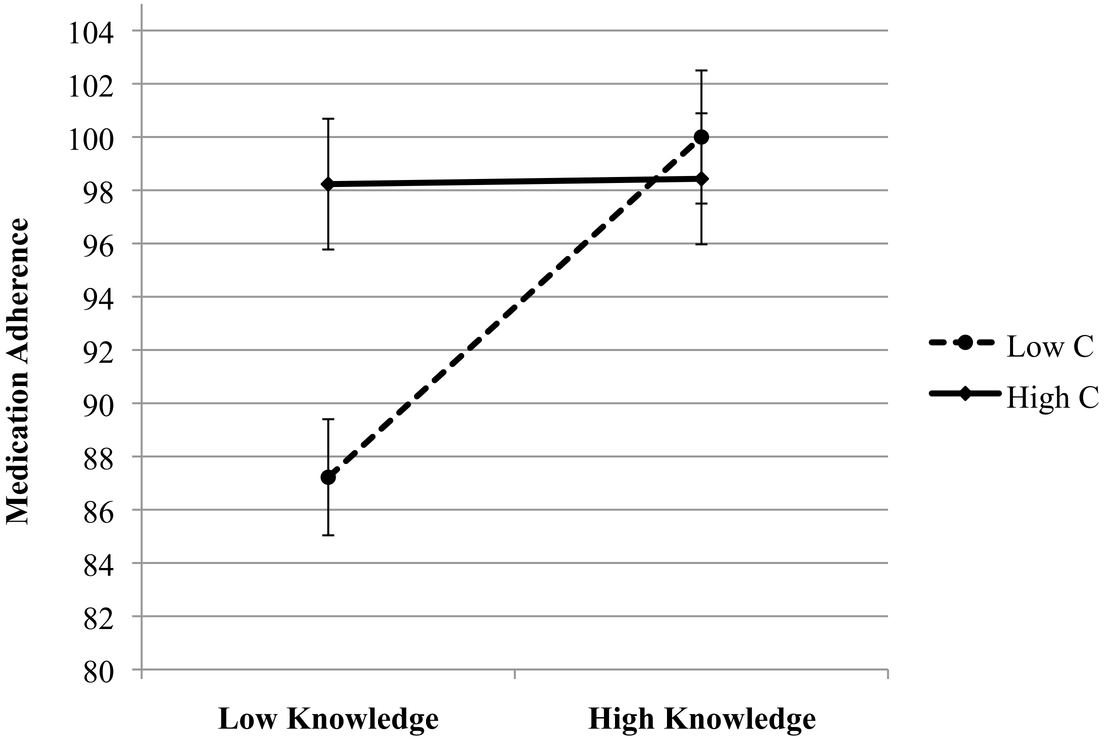

Figure 1. Moderation of Knowledge and Adherence by Conscientiousness

CHAPTER 4

DISCUSSION

This investigation assessed the psychological distress and HRQOL of parents and pediatric patients awaiting organ transplantation. Additionally, this investigation examined the association between parent psychological distress, parent personality factors, children's HRQOL, parents' medication knowledge, and the children's medication adherence. This is the first investigation to attempt creating an accurate description of the presence of psychological distress in children being evaluated for an organ transplant and their parents. It is also unique in measuring medication knowledge and adherence in these parents prior to transplantation, while examining their relationship with parent personality and psychological factors for the parent and child.

Consistent with hypotheses, parents reported significantly lower health-related quality of life for their children compared to normative samples. Almost half of the children fell in the at-risk range for impaired HRQOL. Given the level of severe medical illness required to become a candidate for solid organ transplantation, these levels of impairment are not surprising. One of the goals of transplantation is not only to increase the quantity of life, but the quality of life by trading a terminal illness for a chronic illness. Despite this goal, it has been demonstrated that adolescents receiving liver (Fredericks et al.. 2008; Taylor, Franck, Gibson, Donaldson, & Dhawan, 2009) and kidney transplants (Dobbels, Decorte, Roskams, & Van Damme-Lombaerts, 2010) experience HRQOL post-transplant that remains lower than healthy normative samples, suggesting that factors contributing to lower HRQOL in these children are present both pre- and post-transplant. It remains to be seen whether HRQOL improves following transplantation.

In contrast to the findings of lower HRQOL for children awaiting transplantation, their parents reported similar levels of psychological distress for themselves when compared to normative samples. One study of parents of children being evaluated for heart or heart-lung transplantation showed higher levels of psychological distress compared to a sample of parents of healthy children (Wray & Radley-Smith, 2007), but that study focused on a small samples from a single primary organ group. However, prior research with parents of transplant recipients showed no differences in mean levels of anxiety and depression, two of the domains that comprise the psychological distress index of the BSI used in this study (Young et al., 2003). In spite of the lack of mean differences for the parents in the current study when compared to normative samples, approximately 23% of the participating parents expressed clinically significant levels of psychological distress. These rates are higher than those of parents whose children have already received organ transplants, 13% of whom have been shown to report clinically significant depression (Young et al., 2003). In parents of children awaiting bone marrow transplants, 20% of mothers met criteria for either major depressive disorder, generalized anxiety disorder, or panic disorder (Manne et al., 2001). In the normative sample for the BSI-18, 10% of individuals fall in the clinically significant range (Derogatis, 2000). Therefore, although mean levels of psychological distress were not elevated in the current study, levels of severe psychological distress for some parents were at the higher end of what would be expected in parents of children with chronic illnesses and those in the normative sample.

Similar to findings for depression and anxiety, parents of children awaiting transplantation reported similar mean levels of post-traumatic stress symptoms compared to normal adult samples. These findings are consistent with literature on parents of children who have received solid organ transplants (Young et al., 2003). Prior work examining the prevalence of clinically significant PTSS in parents of children who received transplants demonstrates prevalence rates between 14.3 and 27 percent (Farley, et al., 2007; Ingerski, Shaw, Gray, & Janicke, 2010; Young et al., 2003). This suggest the results of the current study in which 18.5% of parents had elevated levels of PTSS are similar to what might be expected post-transplant. In community samples, the prevalence rates of PTSD is estimated to be 3.5 percent (Kessler, Chiu, Demier, Ellen, & Waters, 2005), suggesting that these parents may be experiencing higher rates of elevated PTSS.

As hypothesized, parent personality was correlated with child HRQOL, with neuroticism showing a negative relationship and conscientiousness showing a positive relationship. Extraversion showed a statistically trending positive relationship. It is possible that extraversion would emerge as a correlate of HRQOL with a larger sample size. Neuroticism showed a statistically trending negative relationship with medication knowledge. While neuroticism is negatively related to adherence in the adult literature (Axellson et al., 2011), there is no known literature investigating its relationship with medication knowledge. Given the statistically underpowered nature of this finding, further research is required to clarify this relationship. Similar to children who are post-transplant (Simons & Blount, 2007), the number of medications prescribed was negatively related to medication knowledge. A greater number of medications require a greater burden upon the parent for accurate recall, likely resulting in recall errors or omissions. Conscientiousness showed a statistically trending positive relationship with medication adherence and extraversion showed no statistically significant relationship with knowledge or adherence, consistent with their relationships in the literature on adults with chronic illnesses (Axelsson et al., 2011; Korotkov, 2008).

Commensurate with literature demonstrating neuroticism as a robust predictor of the development of psychopathology across the lifespan (Widiger, 2011), parent neuroticism was positively related to parent psychological distress and post-traumatic stress. Neuroticism is also a strong predictor of post-traumatic stress for parents who have a child diagnosed with a chronic, potentially terminal illness (Cox, MacPherson, Enns, & McWilliams, 2004). The current study is unique in demonstrating these relationships in parents of children awaiting transplantation. The finding that conscientiousness showed no statistically significant relationship with parent psychological distress or PTSS is relatively consistent with the existing literature in which conscientiousness demonstrates a small to very small relationship with psychopathology (Lamers, Westerhof, Kovács, & Bohlmeijer, 2012). Extraversion's negative relationship with parent psychological dysfunction suggests that it could act as a protective factor against developing psychopathology in prolonged stressful situations, such as those experienced by the parents in this study. Extraversion may enhance engagement-focused coping, including seeking social support (Connor-Smith & Flachsbart, 2007), potentially serving as a buffer against developing psychological symptoms.

These relationships were then examined further using regression to identify unique predictors. In regression analyses, number of medications was a significant negative predictor of child HRQOL. In children who are post-transplant, the number of prescribed medications is related to both the frequency and intensity of medication side effects (Simons & Blount, 2007), which have been shown to be associated with poorer physical and mental health in adolescents with transplants (Simons et al., 2008). Number of medications may also be an indication of illness severity, which would significantly impact a child's quality of life. Parent conscientiousness was positively related to child HRQOL, suggesting that parents who are conscientious impact their children's environment in a way that is protective. In children with sickle cell disease, parent problem-solving capabilities, a component of conscientiousness, served as a barrier from impaired HRQOL (Barakat, Daniel, Smith, Robinson, & Patterson, 2014). A parent with high conscientiousness will more likely demonstrate the ability to plan around their child's physical condition and accommodate for their child's limitations in a flexible manner (Belsky & Barends, 2002), which may reduce the potential impairment caused by a chronic illness, resulting in higher HRQOL. Similarly, parent psychological distress was predictive of lower HRQOL (Connell & Goodman, 2002; Davis, Davies, Waters, & Priest, 2008). Parent psychological distress may interfere with a parent's ability to engage emotionally and effectively with the child and their environment.

Neuroticism was as a strong predictor of parent psychological distress in children undergoing solid organ transplant evaluations. Parenting a child with a chronic illness creates greater levels of parenting stress than parenting a healthy child (Cousino & Hazen, 2013). The association between neuroticism and parent psychological distress may be due to dysfunctional coping skills present in parents with higher levels of neuroticism (Vollrath, 2001). As the study was cross-sectional, directionality cannot be determined. It is possible that parents who are high in neuroticism are more at risk for developing psychopathology under these stressful circumstances or that psychological distress causes one to respond to questions in a way that raises neuroticism on personality inventories.

In predicting medication knowledge, the time since the child's diagnosis necessitating transplant was the only significant predictor, with parents of children for whom less time had elapsed since diagnosis demonstrating higher levels of knowledge. Parents whose children were recently diagnosed may demonstrate greater knowledge, as the diagnosis is potentially more novel and salient. These parents may also be more vigilant to changes in the regimen than those whose children were diagnosed further in the past. Contrary to expectation, the number of medications that the child was prescribed did not significantly impact the level of the parent's knowledge. It is possible that parents of children that are prescribed greater number of medications develop systems to cope with such complexity out of necessity and possess equal knowledge to parents whose children take fewer medications.

Medication adherence was predicted by medication knowledge, supporting the conceptualization that knowledge is necessary, though perhaps not sufficient for medication adherence. Parent conscientiousness was also positively predictive of adherence, accounting for an additional 7% of the variance. Conscientiousness moderated the relationship between medication knowledge and adherence, with low levels of knowledge and low levels of conscientiousness resulting in the lowest reported levels of adherence. Despite the low levels of organization and lack of planfulness that characterizes individuals with low conscientiousness (Caspi & Roberts, 2005), parents with high levels of knowledge reported significantly higher levels of adherence than those with lower levels. It is possible that these parents' higher levels of knowledge allow them to adapt flexibly and quickly to the demands of their child's medication regimen without as much structure and organization. As it is unlikely that intervention will change a parent's personality, identifying parents with low levels of conscientiousness and providing additional medication education could result in higher levels of adherence. Interventions focused on enhancing medication knowledge and related skills might result in changes in parenting behavior specific to their child's medication adherence. This possibility is supported by results from a qualitative study of parents who were returning home in the weeks after their child received a transplant, as these parents identified that consistent, hands-on education helped them to feel confident about caring for their child (Larret et al., 2014).

There are several limitations to this investigation. This study is cross-sectional in nature, eliminating the possibly of examining how these relationships change over time, particularly post-transplant. Future research should follow patients longitudinally to assess the causal relationships of factors that are present at the pre-transplant evaluation that predict psychosocial and medical outcomes post-transplant. As this is one of the first pediatric studies to examine parent personality in pediatric populations, it would be beneficial for future research to include additional personality factors and determine how they may interact to create an adaptive profile for managing a chronic illness. This study also consisted of a mixed chronic illness population. While this adds to the external validity of these findings, there is a possibility that illness type influences these results in ways that were unmeasured in this study. During recruitment, it was emphasized that the parent's responses would remain confidential, would not be shared with the team conducting the evaluation, and not impact the likelihood of their child being approved and listed for transplantation. Despite this, it is possible that parents may have minimized their reports of psychological difficulties or dysfunction out of concern that such report might reduce their child's likelihood of receiving a transplant. Future research should include a measure of social desirability to determine if this had an effect on the responses of parents. Additionally, the study collected parent-report of the child's functioning, primarily due to the wide age range of the sample. Efforts to collect child self-report of psychological functioning would be beneficial in bolstering the results of this study. Finally, while the overall sample size of children undergoing a pre-transplant evaluation was relatively large, and recruitment took place at one of the largest organ transplant centers in the country, the sample size of patients for whom adherence data was obtained was relatively small. Future studies should aim to collect data from multiple sites in order to bolster sample size and statistical power, as well as generalizability.

As lower family functioning pre-transplant has been shown to negatively impact psychological functioning post-transplant (DeMaso et al., 2004), screening for psychological functioning of parents would be beneficial to help identify the higher number of parents who present with psychological distress at the time of the pre-transplant evaluation. Additionally, given the negative relationship between parent psychological distress and PTSS, providing mental health care referrals for parents identified as at risk during the pre-transplant period would likely result in improved psychological outcomes for both the child and the parent post-transplant. Focusing on increasing parent medication knowledge prior to transplant would also be helpful in bolstering the likelihood of adherence. A strong family-focused assessment and conceptualization of functioning prior to transplant would inform intervention in the waiting period, potentially increasing positive outcomes post-transplant.

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