ASSESSING PARENTS' PERCEIVED BARRIERS TO THEIR CHILD'S MEDICATION ADHERENCE: MEASURE DEVELOPMENT AND VALIDATION WITH PEDIATRIC SOLID ORGAN TRANSPLANT CANDIDATES

by

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(Under the Direction of Ronald L. Blount)

ABSTRACT

Objective: Pediatric solid organ transplant recipients must adhere to complex medical regimens to ensure graft survival. Despite the consequences of inconsistent medication taking, nonadherence is prevalent in this population. Parents serve an important role in supporting adherence; however, there may be factors that interfere with their ability to do so. This study aimed to evaluate a novel measure, Barriers to Pediatric Adherence for Parents (BPAP), for assessing parents' perceived barriers to facilitating adherence to their child's medication regimen. *Method:* Fifty-five parents of solid organ transplant candidates completed the BPAP and measures of psychosocial functioning and medication adherence. *Results:* Item reduction and principal components analysis revealed a 19-item, unidimensional measure of parents' perceived barriers. Scores on the BPAP were positively associated with parent internalizing symptoms and perceived impact of the illness on the family, and the presence of aggression in the child. *Discussion:* The factor structure and validity of the BPAP should undergo further evaluation in other pediatric populations. Addressing endorsed items from the BPAP may be useful to help parents overcome perceived barriers to their child's medication adherence.

INDEX WORDS: Adherence, barriers, parents, solid organ transplantation

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A Dissertation Submitted to the Graduate Faculty of The University of Georgia in Partial Fulfillment of the Requirements for the Degree

DOCTOR OF PHILOSOPHY

ATHENS, GEORGIA

2014

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August 2014

ACKNOWLEDGEMENTS

I would like to thank my major professor, Dr. Ronald Blount, for his guidance throughout the course of this project. I would also like to thank members of the Pediatric Psychology Research Laboratory for their support and assistance with data collection. I would also like to acknowledge the members of my committee, Drs. Anne Shaffer and Cynthia Suveg for their time and contributions to this project. Finally, I would like to thank the providers and patients of Transplant Services at Children's Healthcare of Atlanta as this project would not have been possible without them.

TABLE OF CONTENTS

Page

LIST OF TABLES

Page

CHAPTER 1

INTRODUCTION

Solid organ transplantation has become a preferred treatment option for many children with end-stage pediatric liver, heart, and kidney diseases, and the rate of organ transplant is steadily increasing (Organ Procurement and Transplantation Network, 2010). In 2011, approximately 1,800 solid organ transplants were performed on pediatric patients in the United States, with kidney, heart, and liver transplants being the most common among all organ groups. Currently, there are over 1,600 pediatric patients on the waiting list for a solid organ transplant. Additionally, the long-term survival rates have improved considerably in the past decade, as 80% of pediatric recipients reach adolescence and young adulthood (LaRosa, Jorge Baluarte, & Meyers, 2011).

While organ transplantation has resulted in numerous saved lives and improved quality of life for many children, it requires daily, sustained adherence to immunosuppressants and other medications, as well as increased medical monitoring in the form of clinic visits and blood work (Griffin & Elkin, 2001). Medical regimens for transplant recipients can be complex, which often results in the necessity of support from family members. Despite the importance of medication adherence for maintaining organ function, up to 80% of organ transplant recipients do not take their medication as prescribed (Fredericks & Dore-Stites, 2010). A recent systematic review of the literature on adherence to the immunosuppressive regimen among pediatric kidney transplant recipients revealed that an average of 22.4% of younger children were nonadherent, while 43.2% of adolescents did not take their immunosuppressant medication as prescribed (Dobbels et al.,

2010). Although graft rejection can be related to physical factors (e.g., infection), medication nonadherence is a leading cause of complications after transplant (Hansen, Seifeldin, & Noe, 2007; Shaw, Palmer, Blasey, & Sarwal, 2003).

Despite a large body of literature suggesting that rates of adherence decrease as children reach adolescence, some research involving younger children has been conducted. In contrast to caregivers of adolescents, parents are presumed to have a greater role in adherence for younger children. Since parents report generally high rates of adherence for children, there has been less research investigating correlates of nonadherence among this group. However, among younger renal transplant recipients, the presence of psychiatric illness (e.g., Major Depressive Disorder, Oppositional Defiant Disorder) is associated with greater nonadherence (Shaw et al., 2003). Additionally, among pediatric renal transplant recipients, one study demonstrated that children had significantly lower rates of adherence to immunosuppressant therapy when compared to adolescents (Chisholm-Burns et al., 2009). There was a similar finding in a study of pediatric liver transplant recipients, where children less than 10 years old had lower rates of medication adherence when compared to adolescents (Falkenstein, Flynn, Kirkpatrick, Casa-Melley, & Dunn, 2004). These conflicting findings likely resulted from variation in measurement, but suggest that children at various ages may be at risk for nonadherence.

Due to the importance of adherence in children and adolescents, parental involvement in the child's prescribed regimen is necessary. Parental involvement may be necessary for different reasons depending on the child's developmental stage. For example, younger patients are unable to administer their own medications, and depend on a caregiver to complete this task. However, adolescent patients may face different challenges (e.g., autonomy development, greater reliance on peers) with sustaining adherence. In fact, parental involvement in the medication regimen is

consistently associated with better rates of adherence in transplant recipients (Griffin & Elkin, 2001; Simons, McCormick, Mee, & Blount, 2009) and other pediatric populations (Ellis et al., 2007; Wysocki & Gavin, 2006). These findings suggest that parental involvement serves a protective function in regards to pediatric adherence.

The potential for grave consequences resulting from nonadherence, particularly among transplant recipients, has led to the investigation of risk factors associated with this behavior. When considering adherence as an issue that involves and is influenced by the entire family system, there may be risk factors for nonadherence that are present at multiple levels. At the child level, past research with pediatric transplant recipients has elucidated psychosocial correlates of nonadherence, including poor planning and organizational skills (Simons & Blount, 2007), behavior problems (Fredericks, Magee, Opipari-Arrigan, Shieck, Well, & Lopez, 2008), inattention (Gerson, Furth, Neu, & Fivush, 2004), depressive symptoms (Maikranz, Steele, Dreyer, Stratman, & Bovaird, 2007), and low health-related quality of life (Fredericks et al., 2008). While these constructs point to areas that put children at risk for being nonadherent, they do not specifically point to how they interfere with medication taking.

Past research has also identified factors that are associated with child medication adherence at the broader family level. Parent and family factors associated with nonadherence among pediatric transplant recipients include the presence of parent psychopathology (e.g., depression) and low parental involvement in the medical regimen (Griffin & Elkin, 2001). There are additional factors that may negatively impact a parent's ability to ensure their child's adherence, such as feeling overwhelmed by managing their child's illness, as has been documented in research with other pediatric groups (Auslander, Thompson, Dreitzer, & Santiago, 1997), but not investigated in transplant recipients. Given that parents of solid organ

transplant recipients may experience PTSD (Young et al., 2003), avoidance-related symptoms associated with this disorder may also enhance risk for not ensuring their child's adherence.

As suggested above, there may be several sources of interference when it comes to adherence with a child's medical regimen. Some factors may indirectly interfere with the child's medication taking, such as the presence of parental depressive symptoms or family conflict, while others, such as the medication having a bad taste or the child forgetting about the medication, may have direct interference with the regimen. The Health Belief Model (HBM; Janz & Becker, 1984) was developed to conceptualize people's failure to follow through with recommendations for preventive medicine, and has been extended to include noncompliance with prescribed medical regimens. The HBM consists of four basic tenets, one of which includes *perceived barriers* to compliance with recommendations from medical providers. According to the HBM, barriers are, "the potential negative aspects of a particular health action that may act as impediments to undertaking the recommended behavior" (Janz & Becker, 1984, p. 2). The broad scope of this definition permits the consideration of closely or distantly related barriers.

In an attempt to identify specific, behavioral barriers to adherence based on documented psychosocial risk factors, past studies have led to the creation and validation of measures that assess adolescents' barriers to medication taking (Logan, Zelikovsky, Labay, & Spergel, 2003; Simons & Blount, 2007). While this research has elucidated cognitive and behavioral barriers to adherence from an adolescent's perspective, it provides an incomplete picture of factors that interfere with adherence among the entire family system, as well as factors that may be more distally associated with adherence. Past research has assessed parents' perceived barriers to their child's medical adherence for patients with other chronic medical conditions including asthma, cystic fibrosis, and HIV (Mansour, Lanphear, & DeWitt, 2000; Modi & Quittner, 2006; Roberts,

2005; Steele et al., 2001). However, no empirical investigations have been conducted with the solid organ transplant population. Results from these studies have elucidated factors that parents perceive as interfering with their ability to ensure their child's adherence. For example, participants in a study conducted by Mansour and colleagues (2000) identified multiple sources of barriers to adherence. Specifically, barriers were present at the individual (e.g., lack of knowledge about the child's medications), health care provider (e.g., satisfaction with and trust in provider), health care system (e.g., type of insurance), and environmental (e.g., social support from friends and community) levels. Additionally, Modi and Quittner (2006) found that parents of children with cystic fibrosis and asthma frequently identified characteristics of the child (e.g., oppositional behavior) and the child's response to medication (e.g., bad taste, side effects) as factors that interfered with adherence. This research reveals that parents commonly report barriers to ensuring their child's medication adherence.

Although the development of tools to assess parent-perceived barriers to their child's medical regimen is an important step, there have been no published follow-up studies supporting the validity of these instruments. Specifically, scores yielded on the barriers interviews utilized in these studies were either not assessed in relation to actual adherence (Mansour et al., 2000; Roberts, 2005), or the results did not demonstrate relationships with rates of child medical adherence (Modi & Quittner, 2006; Steele et al., 2001). Additionally, these newly developed measures were not evaluated in relation to other validity indices, with the exception of Steele and colleagues (2001) who examined the relationship between parent barriers and how vulnerable they perceived their child was to negative consequences of their illness. Further, in these studies, parent-perceived barriers were assessed through unstructured interview only, yielding qualitative data. In addition to a lack of quantitative data to compare level of barriers with adherence and

medical outcomes, parents may be reluctant to disclose or unable to articulate the adherence-related challenges they face in an open-ended interview format. A self-report, validated, quantitative measure may be more useful for identifying barriers from a parent's perspective, and have increased utility in research and clinical contexts.

The current study evaluated the factor structure and validity of a novel quantitative measure, Barriers to Pediatric Adherence for Parents (BPAP), which assesses parents' perceived barriers to ensuring their child's medication adherence among a sample of parents of pediatric solid organ transplant candidates. A measure of parents' perceived barriers to ensuring their child's medication adherence would fill a gap in the literature, and provide clinicians and researchers with a parsimonious tool for assessing barriers. Additionally, items on the BPAP were developed to assess parents' emotions, thoughts and behaviors that may be amenable to intervention to reduce or overcome their own barriers to helping ensure their child's adherence.

It was hypothesized that the BPAP would demonstrate adequate internal consistency, and that a reliable factor structure would be identified. Further, it was posited that scores on the BPAP would be related to concurrent parent and child psychosocial factors. Specifically, higher perceived barriers as measured on the BPAP would be significantly and positively associated with higher levels of parent internalizing symptoms (e.g., depression, anxiety, somatization), posttraumatic stress symptoms, perceived burden from the child's medical condition, as well as with higher levels of child emotional and behavior problems, lower child health-related quality of life, and greater medication nonadherence.

CHAPTER 2

METHOD

Participants

Participants in the final sample included 55 parents (98.2%) or legal guardians (1.8%) of pediatric patients with kidney (43.6%), liver (32.7%), or heart (23.6%) disease who were evaluated for solid organ transplant candidacy at a children's hospital in the southeastern United States. The mean time from medical diagnosis to pre-transplant evaluation was 5.1 years (*SD* = 5.6). Characteristics of the sample are described in Table 1. Parents were eligible if their child was less than 21 years old and was prescribed at least one medication. Two parents were not eligible since their child was not prescribed daily medication. Parents were excluded from participation in the study if they did not speak or read English fluently (*n* = 6), had significant cognitive disability (*n* = 2), or did not reside with the transplant candidate (*n* = 2). Three families (1 kidney, 1 liver, 1 heart) declined participation in the study due to lack of interest. There were no significant demographic (i.e., child age, child gender, parent education level, family income) differences between families who accepted and declined participation in the study.

Measures

Background Questionnaire. This questionnaire assessed child factors, including age, sex, and race. Parent and family factors were also assessed, including parent age, sex, race, relationship to the transplant candidate, highest level of education obtained, current marital status, employment status, and income.

Barriers to Pediatric Adherence for Parents (BPAP). The original version of the BPAP was a 39-item measure designed to systematically assess potential barriers perceived by parents in relation to facilitating their child's medication adherence. Items were developed based on a thorough review of domains that have shown a strong association with child adherence. Items are based on behavioral or cognitive aspects of factors shown to be associated with child nonadherence. Each item is rated on a 5-point Likert scale from "Strongly disagree" to "Strongly agree." Higher scores represent more barriers. The measure is provided in Appendix A.

Brief Symptom Inventory-18 (BSI-18; Derogatis, 2000). The BSI-18 is a brief, 18-item assessment of the frequency of internalizing symptoms experienced in the past seven days. The Global Severity Index (GSI) consists of items assessing anxious, depressive, and somatic symptoms. Each item is rated on a 5-point Likert scale from 0 ("Not at all") to 4 ("Extremely often"). Scores are presented as standardized *T* scores based on community norms. The BSI-18 has a strong correlation with the Symptom Checklist-90, which is a well-established measure of internalizing symptoms (Recklitis & Rodriguez, 2007). In the current sample, Cronbach's alpha for the GSI was .95. Sixteen percent of the current sample had a GSI *T* score $\geq$ 65, indicating clinically significant internalizing symptoms.

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) resulting from a specific life event. For the present study, participants were 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 on a 5-point Likert scale from 0 ("Not at all") to 4 ("Extremely"). The IES-R has documented psychometric properties (Creamer, Bell, & Failla, 2003). For the current study, Cronbach's alpha was .94 for the total score.

Impact on the Family Scale-Revised (IOF-R; Stein & Jessop, 2003). The IOF-R is a 15-item measure of a parent's perception of the effects of a child's ongoing health condition on the family. Each item is rated on a 4-point Likert scale from 1 ("Strongly agree") to 4 ("Strongly disagree"). Past evaluation of the IOF has found adequate construct validity, as scores on the IOF were significantly associated with related domains, including maternal psychiatric symptoms, child's health status, and rates of the child's health care utilization (Stein & Jessop, 2003). Reliability for the current study was consistent with past studies (α = .90).

Behavior Assessment System for Children-Second Edition (BASC-2; Reynolds & Kamphaus, 2004). The BASC-2 is a validated measure of behavioral and emotional functioning, and offers parent-proxy report forms. Parents completed the proxy-report version if their child was 2 years old or above. For the purposes of this study, items from the following subscales were administered: Anxiety, Depression, Aggression, Attention Problems, and Hyperactivity. Parents rated the frequency (Never, Sometimes, Often, Always) of each behavior within the past several months. Scores are presented as standardized *T* scores. The BASC-2 has been used extensively with children with chronic medical conditions, including pediatric liver and kidney transplant recipients (Wu, Aylward, Steele, Maikranz, & Dreyer, 2008). In the current sample, Cronbach's alphas for the subscales ranged from .57 to .94.

Pediatric Quality of Life Inventory (PedsQL; Varni, Seid, & Kurtin, 2001). The PedsQL is a 23-item measure, which assesses health-related quality of life. Parents of children over two years old completed the proxy-report version. HRQOL is assessed along four dimensions of functioning, including physical, emotional, social, and school. Respondents are asked to indicate how much each item has been a problem in the past month using a 5-point Likert scale from "Never a problem" to "Almost always a problem." Ratings of internal

consistency have been good, and construct validity has been established with correlations of illness morbidity and burden (Varni et al., 2001). The PedsQL has been used to assess parent-reported HRQOL in pediatric kidney (Anthony et al., 2010) and adolescent liver (Fredericks et al., 2008) transplant recipients. Internal consistency for the total score was excellent ($\alpha = .94$) in the current sample.

Medical Adherence Measure (MAM; Zelikovsky & Schast, 2008). The Medication module of the MAM is a semi-structured interview which assesses medication adherence, as indicated by the percentage of reported doses taken late or missed in the past seven days for each prescribed medication. It also assesses knowledge of the medication regimen, including medication doses. Rates of medication nonadherence (i.e., missed doses) and late doses were calculated by dividing the number of doses missed or taken late by the number of prescribed doses, and multiplied by 100 to obtain a percentage. In a study with kidney transplant recipients, percent of missed medication doses identified on the MAM was associated with the number of documented acute rejection episodes by two years post-transplant, providing evidence for the predictive validity of the MAM (Zelikovsky et al., 2008). Adherence was calculated as a continuous variable to describe percent of medications missed or taken late in the past seven days. The range of possible scores was 0 (no medications taken) to 100 (all medications taken). The mean, standard deviation, median, and range were calculated for missed and late prescription medications as well as missed and late other (e.g., over the counter) medications. Characteristics of the medication regimen for the current sample are provided in Table 2.

Medical Chart Review. The patient's Electronic Medical Record (EMR) was accessed to collect health information, including medical diagnosis, time since diagnosis, and prescribed medication regimen.

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. The Transplant Coordinators identified patients who were scheduled for a pre-transplant evaluation and subsequently notified research personnel. On the day of the pre-transplant evaluation, the patient's parent 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. Parents who declined participation in the study were asked to complete an anonymous demographics questionnaire.

After providing consent, parents completed self- and proxy-report paper-and-pencil questionnaires during the pre-transplant evaluation for their child, which took 30-45 minutes. As compensation for their time, parents received a hospital parking voucher or a $10 retail store gift card.

Approach to statistical analyses

The underlying factor structure of the BPAP was evaluated with principal components analysis (PCA). Parallel analysis (PA) was used to determine the number of factors to retain (Hayton, Allen, & Scarpella, 2004; Horn, 1965). Although there are other commonly used criteria for determining the number of factors to retain, such as Kaiser's (K1) criterion and scree plot analysis, these methods have been criticized for their subjectivity and are only appropriate with larger sample sizes. Additionally, Kaiser's criterion tends to provide over-factored solutions and the cut-point of eigenvalues greater than one is considered trivial (Ruscio & Roche, 2012).

PA has been credited for overcoming some of the limitations of the K1 criterion because it accounts for the proportion of variance that results from sampling error (Zwick & Velicer, 1986).

The first step for conducting PA was to generate a random data set. Then, the mean and 95th percentiles of each eigenvalue extracted from the random data set were compared to the eigenvalues generated from the BPAP. Factors from the current sample's data that had larger eigenvalues than those from the random data set were retained (Hayton et al., 2004). A cutoff of ≥ 0.3 was used to determine which BPAP items loaded on each factor (Floyd & Widaman, 1995). The reliability of the BPAP was evaluated using Cronbach's alpha.

Construct validity of the measure was evaluated by calculating correlation coefficients between parent (e.g., psychopathology, perceived illness burden) and child (e.g., emotional and behavioral problems, health-related quality of life) factors and BPAP scores. All analyses were conducted with the Statistical Package for the Social Sciences, Version 21.0 (SPSS 21).

Table 1

Participant Characteristics (n = 55)

Factor	*M* (*SD*)	Range	*n*	%
Child's age	8.51 (6.4) years	25 days – 20 years		
Child's sex				
Female			26	47.3
Child's race				
White			30	54.5
Black			19	34.5
Hispanic			2	3.6
Biracial			4	7.3
Parent's age	37.22 (9.2) years	20 – 68 years		
Parent's sex				
Female			48	87.3
Parent's race				
White			32	58.2
Black			20	36.4
Hispanic			3	5.5
Parent's marital status				
Single			8	14.5
Married			43	78.2
Divorced			3	5.5
Other			1	1.8

Parent's education level		
Less than high school	4	7.3
High school diploma/GED	5	9.1
Some college	23	41.8
College degree	23	41.8
Parent's employment status		
Full-time	27	49.1
Part-time	6	10.9
Not working due to child's health	13	23.6
Not working for other reasons	8	14.5
Family income		
< $9,999	5	9.1
$10 – 24,999	6	10.9
$25 – 49,999	11	20.0
$50 – 74,999	12	21.8
$75 – 99,999	8	14.5
> $100,000	8	14.5

Table 2

Description of medication adherence

Variable	Mean	*SD*	Range	Median
Medications prescribed	6.4	3.1	1 – 16	6.0
Prescription medication				
% Missed	2.4	6.6	0 – 33	0
% Late	1.4	3.5	0 – 16	0
Other medication				
% Missed	6.1	18.3	0 – 100	0
% Late	2.7	7.2	0 – 29	0
All medications				
% Missed	4.2	9.4	0 – 36	0
% Late	1.7	9.4	0 – 20	0

CHAPTER 3

RESULTS

Preliminary analyses

Pearson correlation and one-way analyses of variance (ANOVA) were used to assess the relationship between demographic and medical factors and BPAP scores. There was a significant relationship between BPAP scores and race, with parents of Hispanic children (n = 2) reporting significantly more barriers (M = 110.0, SD = 55.2) than parents of both White (M = 66.6, SD = 17.7) and Black (M = 64.1, SD = 19.7), but not biracial (M = 68.0, SD = 23.7), children ($F_{3,54}$ = 3.15, p = .033). Upon further examination, this difference was driven by one outlying BPAP score (Z score = 3.82). This score was transformed using a procedure described by Field (2009), where a new score was created by adding three times the standard deviation to the mean (Z score = 3). Given the extremely low number of Hispanic participants and that the significant relationship between BPAP and race was driven by a single outlying score, race was not entered as a covariate for subsequent analyses. There was no significant relationship between BPAP scores and additional demographic (e.g., child age, family income) or medical (e.g., organ group, time since diagnosis) factors.

Due to the high report of medication adherence for the sample, the Kolmogorov-Smirnov (K-S) test was calculated to evaluate the normality of the data. Parent report of medication adherence, $D(38) = 0.43$, $p < .001$ was significantly non-normal. Thus, non-parametric statistics were used (Spearman's correlation coefficient) to examine the relationship between medication adherence and parents' perceived barriers.

Item reduction

Following item reduction, 19 out of 39 questions on the BPAP were retained. Eighteen (46.2%) items were dropped from the measure based on infrequent endorsement (> 90% of respondents choosing "Disagree" or "Strongly Disagree"). Two (5.1%) items were eliminated because they did not have a significant correlation with the total BPAP score. Finally, no questions were removed based on the final criterion, since all remaining items (n = 19, 48.7%) had a significant factor load. Refer to Appendix A for a copy of the BPAP.

Factor structure

To determine if PCA was an appropriate analysis, two statistical tests were conducted. First, Bartlett's test of sphericity was significant (χ^2 = 465.026, p = .000), which indicates that the correlations among the data were appropriate for the analysis. Second, the Kaiser-Meyer-Olkin (KMO) measure of sampling adequacy was .72, suggesting an adequate sample size for factor analysis (Hutcheson & Sofroniou, 1999; Kaiser, 1974).

Parallel analysis (PA) revealed one factor after comparing eigenvalues obtained from the current sample to the random data set. This solution accounted for 38.68% of the total variance in BPAP scores. The remaining 19 items (after item reduction) on the BPAP had factor loadings greater than .30. Factor loadings and the results of PA are presented in Table 3.

Reliability and validity

The internal consistency of the 19-item BPAP was assessed with Cronbach's alpha. For the current sample, the alpha was .904, demonstrating good internal consistency of the measure.

To further explore how child and parental psychosocial factors relate to parent-reported barriers, correlations were conducted. In terms of parent factors, as shown in Table 4, perceived impact of the child's illness on the family had a significant positive association with the total

BPAP score (r = .47, p < .001). Additionally, higher levels of parent report of their own internalizing symptoms was significantly and positively correlated with higher BPAP barrier scores (r = .27, p = .045). Parental posttraumatic stress was not significantly related to parent-reported barriers.

When considering child factors, the presence of aggression (r =.39, p = .012) was positively associated with BPAP scores. As shown in Table 4, other child factors, including internalizing symptoms, attention problems, hyperactivity, and health-related quality of life, did not demonstrate significant relationships with parent-reported barriers. Further, parent report of the child's adherence to prescription or other medications was not related to BPAP scores.

Table 3

Summary of principal components analysis results for the BPAP

Item	Factor Loading
Sometimes I forget to make sure my child takes his/her medicine.	.303
Sometimes I feel bad that my child has to take medicine.	.488
My life can become so busy that it is difficult for me to make sure my child took his/her medicine.	.797
It is difficult for me to get to the pharmacy to pick up refills for my child.	.657
I can't always afford my child's medicine.	.558
Sometimes I don't realize when my child has run out of medicine.	.583
I don't like to wake my child up to make sure he/she takes medicine.	.822
Sometimes I feel like my child is too sick to take medicine.	.528
My child tells me they don't want to take medicine.	.693
I worry about the long-term effects of the medicine on my child's health.	.474
When I'm away from my child, there is nobody to rely on to make sure my child takes his/her medicine.	.648
Sometimes my child refuses to take medicine.	.660
Sometimes my child gets upset when I try to give him/her medicine.	.627
My child and I have arguments about taking medicine.	.727
I'm not always there to remind my child to take his/her medicine.	.510
I have responsibilities outside of my family (jobs, organizations, etc.) that sometimes get in the way of making sure my child takes his/her medicine.	.773
I sometimes feel overwhelmed with my child's medical condition and just don't want to think about giving my child his/her medicine.	.551
I don't believe that all the medicines my child is prescribed are helpful.	.611

It upsets me to see my child have difficulty taking medicines that taste bad or are hard to swallow.	.571
Eigenvalue	7.348
% of variance	38.675
α	.904

Table 4

Intercorrelations among parent factors and BPAP scores

	1	2	3	4	Mean (*SD*)
1. BPAP	-	.27*	.12	.47**	67.10 (20.24)
2. Internalizing symptoms[a]		-	.75**	.58**	51.18 (13.07)
3. PTSS			-	.41**	2.77 (1.94)
4. Impact on the family				-	34.11 (8.93)

Note. $^{**}p \leq .01$; [a] Displayed as a *T* score for the BSI-18 Global Severity Index; BPAP = Barriers to Pediatric Adherence for Parents; PTSS = posttraumatic stress symptoms.

Table 5

Intercorrelations among child factors and BPAP scores

	1	2	3	4	5	6	7	8	9	Mean (*SD*)
1. BPAP	-	.12	.28	.39*	.24	.29	-.16	-.04	.18	67.10 (20.24)
2. Anxiety[a]		-	.77**	.48**	.20	.59**	-.50**	.30	.03	49.78 (14.44)
3. Depression[a]			-	.69**	.20	.69**	-.52**	.19	-.11	52.44 (13.50)
4. Aggression[a]				-	.12	.73**	-.31*	.20	-.01	45.93 (8.07)
5. Attention problems[a]					-	.46**	-.21	-.02	.17	51.73 (10.17)
6. Hyperactivity[a]						-	-.45**	-.15	-.04	49.14 (12.45)
7. HRQOL							-	-.02	-.01	64.21 (19.04)
8. % meds missed[b]								-	-.10	4.17 (9.44)
9. % meds late[b]									-	1.66 (4.06)

Note. $*p \leq .05$, $**p \leq .01$; [a] Displayed as *T* scores; [b] Spearman's correlations; BPAP = Barriers to Pediatric Adherence for Parents; HRQOL = Health-related quality of life.

CHAPTER 4

DISCUSSION

The present study evaluated the psychometric properties of a novel measure, Barriers to Pediatric Adherence for Parents (BPAP), which was designed to assess parents' perceived barriers to their child's medication regimen. This measure was tested among a sample of parents of children with kidney, liver, or heart disease who were undergoing evaluation for solid organ transplant candidacy. Item reduction and factor analysis procedures revealed a 19-item, single factor measure. Some aspects of parent and child functioning were related to BPAP scores; however, other domains that were expected to be associated with barriers scores, including parent and child internalizing symptoms, and rates of medication adherence, did not demonstrate a significant relationship. Overall, the BPAP is a promising new measure that is one of the first quantitative measures of parents' perceived barriers.

Results of principal components analysis confirmed the presence of a unidimensional barriers scale and internal consistency of the 19-item measure was adequate. Twenty items were eliminated from the measure because of infrequent endorsement or because responses did not correlate with the total BPAP score. Items that were retained reflected the presence of barriers that were specific to the parents themselves as well as characteristics and behaviors of the child. In terms of barriers that were specific to parents, themes included forgetting to administer medication, financial concerns, and emotional impact (e.g., feeling overwhelmed). Parents also endorsed that worry about long-term effects of medication interferes with their ability to facilitate adherence. Respondents also endorsed barriers related to their child's functioning,

including refusal, argumentative behavior, and emotional distress. Participants were permitted to provide open-ended feedback about other potential barriers. The open-ended response option yielded two additional barriers, which included a change in the family's routine (e.g., vacation) and certain characteristics of the medication regimen itself (e.g., amount of medication, frequency of administration) that were not captured in the original iteration. Future versions of the BPAP should include items that capture these concerns to determine if they are frequently endorsed by other parents and if they relate to other barriers.

Hypotheses regarding the validity of the parent barriers measure were partially supported. As hypothesized, parents who reported that they experienced greater internalizing symptoms endorsed more barriers to the child's medication regimen. Parents who experience higher depressive or anxiety symptoms may feel too overwhelmed to manage their child's medical condition. Additionally, perceived impact of the child's illness on the family was related to total BPAP scores. Specifically, parents who perceived that their child's illness had a greater impact on the family system reported more barriers to the medication regimen. This suggests that parents who, in general, have greater difficulty adjusting to managing family responsibilities in light of the various challenges associated with their child's chronic medical condition may be ones who also have most difficulty facilitating medication administration.

Parental self-report of posttraumatic stress symptoms was not related to BPAP scores. Examination of mean symptom scores revealed that parents endorsed relatively low levels of posttraumatic stress compared to other chronic illness populations. In the current sample, the mean IES-R score was 2.77, which was significantly lower than past research with caregivers of children who were solid organ or stem cell transplant candidates (M = 17.6), HIV positive (M = 11.4), or diagnosed with sickle cell disease (M = 14.5; Ingerski, Shaw, Gray, & Janicke, 2010).

Low endorsement of posttraumatic stress symptoms in the current sample could be related to the time lag between parents' completion of inventories and the child's initial diagnosis, as an average of five years had passed from diagnosis to the pre-transplant evaluation. It is also possible that posttraumatic stress symptoms were not endorsed because the parents did not view the diagnosis as traumatic.

When considering how child functioning relates to parent-reported barriers, only symptoms of aggression demonstrated a significant positive relationship with BPAP scores. This finding is consistent with past research, which shows that externalizing behaviors can interfere with medication taking (Fredericks et al., 2008; Modi & Quittner, 2006). Contrary to expectation, there was no significant association between parent-reported barriers and other measures of child functioning, including anxiety, hyperactivity, attention problems, and health-related quality of life. The lack of significant findings for some of these factors may be due to low reported levels of these symptoms.

Finally, the results of this study did not support a relationship between parent-reported barriers and adherence to their child's medication regimen. Although this was not anticipated, this finding is consistent with past research using other measures of parent barriers (Modi & Quittner, 2006; Steele et al., 2001). Failure to find a relationship was likely related to the fact that the average reported adherence was 96%, with many parents reporting perfect (100%) adherence to their child's medication regimen in the past week. This rate is significantly higher than estimates of adherence among pediatric populations in general (LaGreca & Bearman, 2003), as well as pediatric solid organ transplant recipients specifically (Fredericks & Dore-Stites, 2010). It is possible that the medication regimens that are prescribed for kidney, liver, and heart disease are less complex and burdensome compared to the post-transplant period, which could

explain high adherence rates in this sample. Additionally, it is possible that parents reported an over-estimate of actual adherence because of the context of the research study, which was during the course of evaluation for transplant candidacy. Parents may have over-reported adherence because the family's ability to manage medical regimens is involved in helping to determine suitability for transplantation.

Results from this study must be considered within the context of limitations. First, analyses were completed with a sample that varied with regard to the child's age and underlying disease requiring evaluation for solid organ transplant. However, families who present for pediatric solid organ transplant evaluation have a variety of illnesses and can range from infancy to late adolescence. Second, parents in the current sample were highly educated, as over 80% of participants had greater than high school education. Results may not be generalizable to families with lower educational attainment. Third, principal components analysis was selected as the method of factor analysis. Although preliminary statistical analyses showed that PCA was appropriate for the current sample, there is a risk that the final solution was not the best fit for the data. Fourth, some questions from the original version of the BPAP were eliminated based on item reduction procedures. Although these items were infrequently endorsed by the current sample or not correlated with the total score, they may be clinically meaningful for some families. Additionally, although respondents were permitted to identify additional barriers in the open-ended section of the measure, there may been other barriers that interfere with parents' ability to ensure their child's adherence that are not yet known. Fifth, interview was employed as the method of assessing parent report of medication adherence. It is possible that parents were not accurate, either intentionally or unintentionally, when reporting their child's adherence over the past week. Future research should employ more than one adherence measure to obtain a more

reliable picture of medication taking. Finally, there are unique factors to consider when conducting research and interpreting findings with families in the pre-transplant period. Even though parents were assured that their responses on questionnaires would remain anonymous and not affect their child's eligibility for transplantation, they may have tried to present themselves in a positive light to increase the child's chance of being listed for transplant. This could have impacted their willingness to endorse barriers, disclose details about their psychological functioning, or report less than perfect medication adherence.

Future research in this area should focus on validation of the BPAP with other samples of pediatric patients. Specifically, the BPAP should be administered to parents of children who are more homogeneous in terms of age or medical diagnosis. Additionally, future research protocols should include more than one adherence measure, as multiple measures is considered the gold standard in the literature. Further, the BPAP could be expanded to include barriers that were pertinent to other aspects of medical care, including adherence to dietary restrictions (e.g., low sodium, hydration) and attendance at clinic appointments. This would help capture the complexity of sustaining adherence to regimens for chronic medical conditions, above and beyond medications. Finally, the predictive validity of the BPAP should be evaluated by comparing barriers scores to future adherence scores and other medical markers (e.g., hospitalizations).

Overall, results from this study suggest that parents of potential solid organ transplant candidates experience barriers to ensuring their child's medication adherence. However, endorsement of barriers by parents did not coincide with some measures of parent psychosocial functioning, child emotional functioning, or rate of parent proxy-reported medication adherence. Of note, there was a ceiling effect and restricted range for several of the validity measures, which

likely prevented identification of significant associations with BPAP scores. The BPAP should undergo further psychometric evaluation with parents of children with larger samples and with other chronic medical conditions. Additionally, the BPAP could serve as a useful tool for initiating dialogue about barriers to adherence with parents in clinical settings. These discussions could lead to specific targets for intervention to improve pediatric adherence and health outcomes.

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Appendix A.

Barriers to Pediatric Adherence for Parents (BPAP)

Having a child who must take medication on a daily basis can be challenging. Check the box that reflects how much you agree or disagree with each statement.

Italicized items are **not included in the final measure

	Strongly Disagree	Disagree	Not Sure	Agree	Strongly Agree	Correlation with total score
1. I don't understand the purpose of the medicines my child is prescribed.	*74.5%*	*21.8%*	*1.8%*	-	*1.8%*	*.032*
2. I don't like the side effects that the medicine has on my child.	*23.6%*	*21.8%*	*32.7%*	*16.4%*	*5.5%*	*.195*
3. Sometimes I forget to make sure my child takes his/her medicine.	64.8%	24.1%	3.7%	7.4%	-	.394**
4. Sometimes I feel bad that my child has to take medicine.	3.6%	7.3%	10.9%	52.7%	25.5%	.407**
5. I have trouble finding time to make sure my child takes his/her medicine.	*64.8%*	*29.6%*	-	*3.7%*	*1.9%*	*.791**
6. Sometimes I just don't feel like making my child take his/her medicine.	*77.8%*	*16.7%*	*1.9%*	*3.7%*	-	*.752**
7. I think that my child should be responsible for taking his/her own medicine.	*55.8%*	*15.4%*	*5.8%*	*17.3%*	*5.8%*	*.272*
8. I don't have the support I need to make sure my child takes his/her medicine.	*72.7%*	*25.5%*	-	*1.8%*	-	*.799**
9. My life can become so busy that it is difficult for me to make sure my child took his/her medicine.	60.0%	23.6%	1.8%	14.5%	-	.746**
10. It is difficult for me to get to the pharmacy to pick up refills for my child.	60.0%	23.6%	-	16.4%	-	.571**

11. I can't always afford my child's medicine.	42.6%	24.1%	14.8%	18.5%	-	.566**
12. Sometimes I don't realize when my child has run out of medicine.	60.0%	27.3%	5.5%	7.3%	-	.436**
13. I don't feel comfortable talking to the medical team about my child's medicines.	*72.7%*	*25.5%*	-	*1.8%*	-	*.700***
14. Sometimes I'm too tired to make sure my child takes his/her medicine.	*70.9%*	*25.5%*	-	*3.6%*	-	*.775***
15. I don't like to wake my child up to make sure he/she takes medicine.	54.5%	23.6%	1.8%	16.4%	3.6%	.651**
16. Sometimes I feel like my child is too sick to take medicine.	59.3%	25.9%	7.4%	7.4%	-	.598**
17. My child tells me they don't want to take medicine.	55.8%	21.2%	3.8%	17.3%	1.9%	.554**
18. I feel like I can't make my child take medicine.	*76.4%*	*16.4%*	-	*5.5%*	*1.8%*	*.604***
19. The system my family uses for organizing my child's medication doesn't always work well.	*64.8%*	*25.9%*	*5.6%*	*3.7%*	-	*.721***
20. I worry about the long-term effects of the medicine on my child's health.	11.3%	13.2%	13.2%	43.4%	18.9%	.321*
21. When I'm away from my child, there is nobody to rely on to make sure my child takes his/her medicine.	46.3%	38.9%	11.1%	3.7%	-	.675**
22. Sometimes my child refuses to take medicine.	47.2%	26.4%	3.8%	22.6%	-	.567**
23. Sometimes my child gets upset when I try to give him/her medicine.	37.0%	20.4%	1.9%	35.2%	5.6%	.490**
24. My child and I have arguments about taking medicine.	60.0%	14.0%	10.0%	16.0%	-	.610**
25. Sometimes I don't feel well, which makes it hard to make sure my child take his/her medicine.	*67.3%*	*23.6%*	-	*9.1%*	-	*.790***
26. I'm not always there to remind my child to take his/her medicine.	50.9%	26.4%	3.8%	17.0%	1.9%	.568**
27. I find it difficult to stick to my child's fixed medication	*60.0%*	*32.7%*	*1.8%*	*5.5%*	-	*.808***

schedule.						
28. I get confused about how my child's medicine should be taken (e.g., with or without food).	*65.5%*	*27.3%*	*3.6%*	*3.6%*	-	*.708***
29. I believe that my child's prescribed dosages and schedules are too difficult to understand.	*74.5%*	*23.6%*	-	*1.8%*	-	*.725***
30. Sometimes I feel sad and I don't have the energy to get my child to take his/her medicine.	*74.5%*	*18.2%*	*1.8%*	*5.5%*	-	*.784***
31. Sometimes I feel so anxious that it is hard to focus on getting my child to take his/her medicine.	*76.4%*	*16.4%*	*3.6%*	*3.6%*	-	*.687***
32. I have too many other family responsibilities that get in the way of getting my child to take his/her medicine.	*76.4%*	*18.2%*	*3.6%*	*1.8%*	-	*.826***
33. I have responsibilities outside of my family (jobs, organizations, etc.) that sometimes get in the way of making sure my child takes his/her medicine.	67.3%	21.8%	1.8%	9.1%	-	.797**
34. My spouse/partner and I don't always work well together to make sure our child takes his/her medicine.	*70.4%*	*20.4%*	*1.9%*	*5.6%*	*1.9%*	*.644***
35. My spouse/partner and I argue sometimes, which makes it hard for me to make sure my child takes his/her medicine.	*72.2%*	*18.5%*	*3.7%*	*1.9%*	*3.7%*	*.550***
36. I sometimes feel overwhelmed with my child's medical condition and just don't want to think about giving my child his/her medicine.	72.7%	16.4%	1.8%	7.3%	1.8%	.650**
37. My family has been through a lot of changes (moving, jobs, etc.), which sometimes makes it hard to make sure my child takes his/her medicine.	*74.5%*	*16.4%*	*1.8%*	*5.5%*	*1.8%*	*.661***
38. I don't believe that all the medicines my child is	56.4%	29.1%	10.9%	3.6%	-	.572**

prescribed are helpful.						
39. It upsets me to see my child have difficulty taking medicines that taste bad or are hard to swallow.	35.2%	22.2%	3.7%	29.6%	9.3%	.475**

Is there anything else that makes it hard for you to make sure your child takes their medication on schedule every day? _____

_____