

# Longitudinal Stability of Specific Barriers to Medication Adherence

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**Objective** Higher levels of barriers are related to lower medication adherence and negative medical outcomes in pediatric transplant recipients. Although total number of barriers appears to be stable over time, it is unclear whether the same is true for specific barriers. This study examined the frequency of endorsement and the stability of specific barriers over 18 months. **Method** Participants included 63 parents and 51 adolescents and young adults. Transplant types included 39 kidneys, 16 livers, 10 hearts, and 1 double lung. Participants completed measures of perceived barriers to adherence at Time 1 (T1) and Time 2 (T2). **Results** The majority of parent- and adolescent-reported specific barriers showed a positive relationship from T1 to T2. Few specific barriers showed significant differences in the level of endorsement between time points. **Conclusion** Specific barriers to medication adherence tend to be stable over time. Patients' specific barriers appear unlikely to change without targeted intervention.

**Key words** adherence; adolescents; barriers; pediatric; transplantation.

Pediatric solid organ transplantation has become an increasingly common treatment for children with a variety of severe medical conditions, including liver, kidney, and heart disease. Medical progress in the domain of pediatric transplantation, along with advancements in the safety and efficacy of immunosuppressive therapy, has significantly increased the life expectancy of children with an organ transplant (Agarwal & Pescovitz, 2006). However, along with increased life expectancy comes the responsibility of lifelong adherence to a complex medical regimen necessary to maintain the viability of the transplanted organ and to ensure the health of the recipient after surgery (Griffin & Elkin, 2001). Adherence to medical advice and regimens may be burdensome for patients and their families, and nonadherence is common. A recent systematic review of the literature indicated that, on average, 43% of children with organ transplants are nonadherent to their immunosuppressant medications (Dobbels et al., 2010).

The consequences of nonadherence are significant. Failure to follow prescribed medical recommendations can result in organ rejection, death, decreased patient quality of life, and increased cost to the individual (Butler, Roderick, Mullee, Mason, & Peveler, 2004; Fredericks et al., 2008; Fredericks, Lopez, Magee, Shieck, & Opiari-Arrigan, 2007; Pinsky et al., 2009). Specifically, medication nonadherence in pediatric populations is related to greater numbers of visits to the emergency department and inpatient hospitalizations, both of which are the most costly types of health care (McGrady & Hommel, 2013). The U.S. Government Accountability Office (2007) revealed that treatment cost for Medicare beneficiaries who experienced organ loss was \$50,398 per year. In contrast, treatment costs for patients who maintained functioning transplants was only \$8,550 per year. Therefore, maintaining a healthy organ graft may not only improve medical and

psychosocial status, but also help reduce economic burden on the health-care system.

According to the Health Belief Model, perceived barriers represent potentially difficult or unpleasant aspects of health behaviors (e.g., side effects; Janz & Becker, 1984) that may interfere with adherence to prescribed treatment recommendations (Rapoff, 2010). A substantial body of literature in pediatric populations has shown that greater levels of barriers are associated with increased difficulty in following prescribed medical regimens (Marhefka et al., 2008; Modi & Quittner, 2006; Rapoff, 2010). In adolescent transplant recipients, higher numbers of barriers are associated with greater risk for experiencing negative medical outcomes such as rejection episodes, hospitalizations, and/or death (Simons, McCormick, Devine, & Blount, 2010). Barriers to adherence have similarly been associated with negative psychosocial outcomes, including less family cohesion, less emotional expression, and greater conflict among family members (Simons & Blount, 2007). The types of barriers associated with poor medication adherence in pediatric patients include cognitive factors (e.g., forgetting, poor planning), aversive medication properties or difficulties ingesting medication (e.g., hard to swallow, tastes bad), and voluntary resistance (e.g., defiance) toward medication taking (Hommel & Baldassano, 2010; Simons, McCormick, Mee, & Blount, 2009; Zelikovsky, Schast, Palmer, & Meyers, 2008). Low family adjustment (Logan, Zelikovsky, Labay, & Spergel, 2003), as well as high adolescent responsibility and low parent supervision (Modi, Marciel, Slater, Drotar, & Quittner, 2008; Zelikovsky et al., 2008), have also been shown to be associated with poor adherence.

Our previous work with pediatric transplant recipients demonstrated that the total overall number of barriers and barriers subscale scores for the entire sample are stable over time. This study also reported significant associations between specific barriers at baseline assessment and nonadherence and negative health outcomes at long-term follow-up. As these data are part of a larger study from which the current article is derived (Simons et al., 2010), we will review selected results below to support the established relationship between individual barriers to medication adherence and medical outcomes. The relationship between specific barriers at Time 1 (T1) and adherence 18 months later at Time 2 (T2) showed that parent-reported barriers at T1 were positively related to nonadherence at T2 at the specific barrier item level. Being forgetful, disorganized, and the lack of parent reminder were significantly associated with parent-reported nonadherence. Parents' belief that the medication has too many side effects was related to more out-of-range serum

immunosuppressant levels. Adolescent-reported barriers (e.g., negative side effects, being tired of taking medications, being tired of living with a chronic medical condition) at T1 were also related to adolescent-reported nonadherence at T2, as indicated by both self-report of missed and late doses, as well as out-of-range serum immunosuppressant levels. With regards to medical outcomes, parents and adolescents reporting more ingestion-related barriers (e.g., difficulties swallowing medications) and not wanting others to see the child taking medications at T1 had more instances of organ rejection and death between T1 and T2. Greater numbers of hospitalizations between T1 and T2 were experienced by children who, at T1, reported difficulties with having too many pills to take and experiencing too many medication side effects.

Even though results from this investigation provided answers to important questions about barriers and their relationship to adherence and health, fundamental questions remain about the nature of barriers to medication adherence. First, it is unclear which specific barriers are most frequently endorsed. Data on the relative percentage of patients and parents who endorse specific barriers more frequently than others may help guide clinicians' assessment and intervention efforts. Second, there are no data to indicate whether individual patient's specific barriers to medication adherence are stable or variable over time. If specific barriers, which appear to function as obstacles to adherence, are stable over time, their negative effects on adherence would likely persist. Effective, focused, early intervention to reduce what might otherwise be stable barriers could help patients overcome specific barriers, minimize continual adverse effects, and enhance adherence and health outcomes. These interventions could provide lasting benefits. Conversely, if barriers are unstable over time, interventionists' efforts become more complicated. Unstable barriers would require continual monitoring over time to know how intervention efforts should be directed. Empirical evidence is needed to provide support for the necessity of intervening on specific adherence barriers, which, if stable, would continue to promote nonadherence and poor health outcomes.

To inform intervention design more precisely, a better understanding of which specific barriers are endorsed and whether barriers remain stable or change over time is critical. The current study addresses these fundamental and important gaps in the study of barriers to adherence by examining specific patient- and parent-reported barriers to medication adherence at an initial data collection time point (T1) and 18 months later (T2). The relative percentage of specific adolescent- and parent proxy-reported

barriers to medication adherence will be presented to identify highly endorsed barriers. The stability of endorsement for specific barriers will then be determined through varied analytic methods. It is hypothesized that the majority of specific adolescent- and parent proxy-endorsed specific barriers will be stable over an 18-month period.

## Method

### Participants

Inclusion criteria specified that participants (1) be solid organ transplant recipients who were at least 4 months post-transplant; (2) live with at least one parent; (3) be English speaking; and (4) be  $\geq 11$  years of age. If adolescents and young adults (AYAs) were developmentally delayed, per parent report, only parent-reported data were collected. A consort diagram in Figure 1 demonstrates recruitment and retention over time.

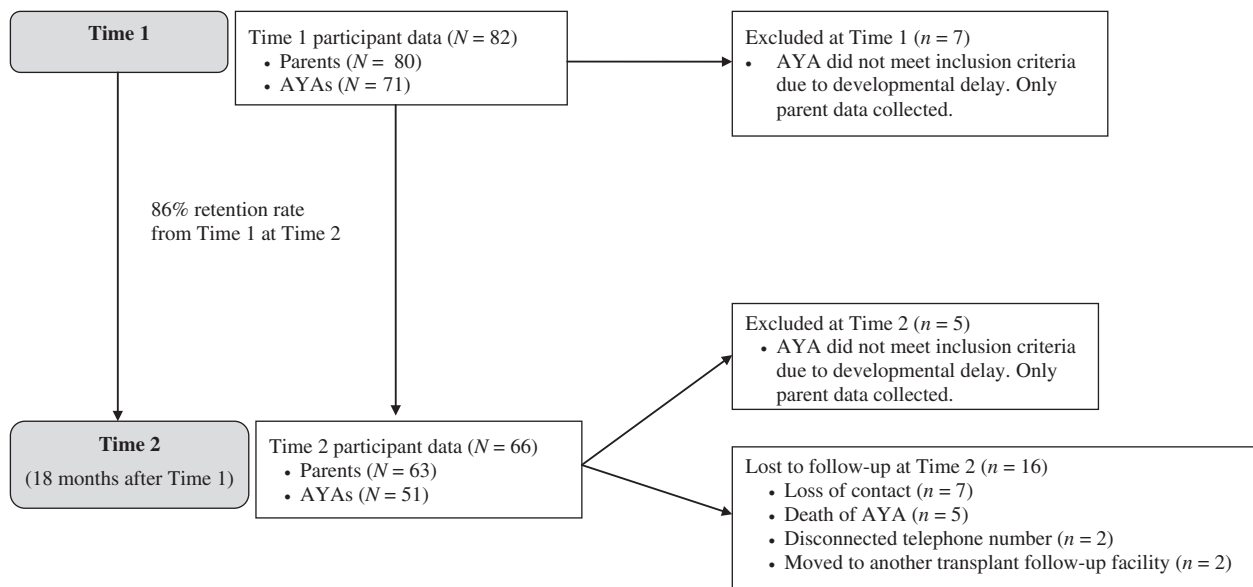
**Time 1.** Detailed demographic information for both time points is presented in Table I. The original sample included data for 82 AYA patients, aged 11–20 years. Parents alone, AYAs alone, or parent–AYA dyads participated. In all, 80 parents and 71 AYAs completed measures at T1. Ninety-three percent of parent participants were female caregivers ( $n = 74$ ). Nine percent of AYAs ( $n = 7$ ) were developmentally delayed per parent report and excluded from participation. Approximately 57.3% of AYAs received kidney transplants, 24.4% received liver

transplants, 17.1% received heart transplants, and 1% received double lung transplants.

**Time 2.** At the 18-month follow-up, the sample included 66 of the original AYA participants from T1 who were between 12 and 22 years of age at the time of data collection. Sixty-three parents and 51 AYAs completed measures at T2. Ninety-seven percent of parent participants were female caregivers ( $n = 62$ ). Eight percent of adolescents ( $n = 5$ ) who participated at T1 and T2 were developmentally delayed per parent report and excluded from participation. Approximately 59.1% of adolescents received kidney transplants, 24.2% received liver transplants, 15.2% received heart transplants, and 1.5% received a double lung transplant. Sixteen families were lost to follow-up between T1 and T2, with 86% of living participants retained. Reasons for discontinuing participation included loss of contact ( $n = 7$ ), death of the participant ( $n = 5$ ), disconnected phone number ( $n = 2$ ), and movement to another transplant follow-up location ( $n = 2$ ). No significant differences in demographic or medical factors were found between families of participants who participated at T1 only and those who participated at both time points. Time between initial recruitment data collection at T1 and follow-up at T2 ranged from 12 to 20 months ( $M = 16.5$ ,  $SD = 1.5$ ).

### Measures

AYAs completed a measure of barriers to medication adherence and reports of adherence. Parents completed



**Figure 1.** Flow of participants enrolled from Time 1 (T1) to Time 2 (T2): This figure illustrates the number of participants at both T1 and T2 and, the number of participants excluded at T1 or lost to follow-up at T2.

Table 1. Demographic Information

Factor	Time 1		Time 2	
	N = 82		N = 66	
	M	SD	M	SD
Age	15.80	9.67	17.17	2.36
	Frequency	%	Frequency	%
Sex				
Male	46	56.10	36	45.50
Female	36	43.90	30	54.50
Ethnicity				
Caucasian	50	62.50	41	62.10
African American	26	31.70	19	28.80
Asian-East Indian	1	1.20	1	1.50
Other	5	6.10	5	7.60
Family income				
<\$10,000	11	14.10	10	15.60
\$10,000–24,999	13	16.70	10	15.60
\$25,000–49,999	21	26.90	15	23.40
\$50,000–74,999	11	14.10	9	14.10
\$75,000–99,999	6	7.70	6	9.40
\$100,000–149,999	7	9.00	7	10.90
\$150,000+	9	11.50	7	10.90
Family marital status				
Married	50	62.50	40	60.60
Single	11	13.80	10	15.20
Divorced	11	13.80	9	13.60
Separated	5	6.30	4	6.10
Widowed	2	2.50	2	3.00
Partnered	1	1.30	1	1.50

demographic information, a measure of parent-reported adolescent barriers to medication adherence, and a measure of adolescent adherence. Information on medical outcomes was collected from medical records. The same AYA- and parent-report measures were completed at T1 and T2.

#### Adolescent Medication Barriers Scale

The 17-item Adolescent Medication Barriers Scale (AMBS; Simons & Blount, 2007) is a factor-analytically derived measure of adolescents' report of their own barriers to taking medications as prescribed by their physician. Criterion-related validity is strong, with nonadherent adolescents receiving solid organ transplants reporting higher barrier scores on the AMBS than adherent adolescents (Simons & Blount, 2007). AYAs were asked to endorse the extent to which they agreed with statements about specific barriers (e.g., "I don't like how the medicine tastes") using a 5-point Likert-like scale ranging from 1 (*strongly disagree*) to 5 (*strongly agree*). There are three factor analytically derived subscales: Disease Frustration/

Adolescent Issues (eight items), Regimen Adaptation/Cognitive Issues (six items), and Ingestion Issues (four items). The AMBS has shown acceptable internal consistency in the current study with Cronbach's alpha of .86.

#### Parent Medication Barriers Scale

The 16-item Parent Medication Barriers Scale (PMBS; Simons & Blount, 2007) is a factor-analytically derived measure of parents' report of their AYA's barriers to taking medications as prescribed by the physician. Criterion-related validity is strong, with parents of nonadherent solid organ transplant recipients reporting higher barrier scores on the PMBS than parents of adherent adolescents (Simons & Blount, 2007). Parents were asked to endorse the extent to which they agreed with a statement about a specific barrier for their child (e.g., "My child does not like how the medicine tastes") using a 5-point Likert-like scale ranging from 1 (*strongly disagree*) to 5 (*strongly agree*). There are four factor analytically derived subscales: Disease Frustration/Adolescent Issues (seven items), Regimen Adaptation/Cognitive Issues (five items), Ingestion Issues (three items), and Parent Reminder (one item).

The PMBS showed acceptable internal consistency in the current study with Cronbach's alpha of .87.

#### Procedures

This study was part of a larger investigation. Participants were recruited from a pediatric transplant follow-up clinic in the United States. Approval of the institutional review board was obtained before study commencement. Informed parental consent and child assent were obtained at T1, along with Health Information Portability and Accountability Act (HIPAA) release before participating. At T2, participants were contacted either in clinic or by telephone, and new consent, assent, and HIPAA release were obtained either in person in the clinic or via mail if families were contacted by telephone. Measures, including demographic information and parent and adolescent report of barriers and adherence, were collected using a structured interview format. A medical chart review was used to determine diagnosis and relevant medical history. Participation in the study was voluntary, and participants were compensated for their time with \$20 gift cards at both T1 and T2. Standardized measures were completed via telephone interviews.

#### Statistical Analyses

Descriptive statistics were used to examine the frequency of specific barriers endorsed by each participant at T1 and those who continued to endorse the same barriers at T2.

For each participant, specific barriers endorsed as 1 (*strongly disagree*) to 3 (*not sure*) were coded as 0 for a “not endorsed” barriers category. Specific barriers endorsed as 4 (*agree*) or 5 (*strongly agree*) were coded as 1 for an “endorsed” barriers category. This criterion for coding barriers as “endorsed” or “not endorsed” was used to categorize specific barriers for adolescent and parent proxy reports at both T1 and T2. Each individual’s response was then examined to determine whether the same individual who endorsed the barrier at T1 also endorsed the same barrier at T2, indicating stability of a specific barrier for that individual over the 18-month follow-up period. If a specific barrier was endorsed by  $\geq 20\%$  of the sample at T1, the barrier was described as being “highly endorsed.”

The stability of specific barriers was then further examined by two additional methods. First, Pearson product moment correlations were conducted using the entire 5-point Likert scale for each specific barrier from the ABMS and PMBS to examine the strength and direction of associations between specific barrier items from T1 to T2. Cohen’s criteria (1988) were used to examine the magnitude of the correlations (small:  $r = .10-.29$ , moderate:  $r = .30-.49$ , large:  $r = .50-1.00$ ). Second, paired samples *t*-tests were conducted using the entire 5-point Likert scale to examine changes in levels of specific barrier items across time. Analyses were conducted using IBM Statistical Package for the Social Sciences, Version 20.

## Results

### **How Frequently Were Specific Barriers Endorsed at T1 and Re-endorsed at T2?**

Descriptive statistics for specific barrier endorsement (i.e., responding [*agree*] or [*strongly agree*] to a particular barrier) at T1, as well as individuals who continued to endorse each specific barrier at T2 are presented in Table II. Percentages of AYAs reporting (*agree*) or (*strongly agree*) for a particular barrier at T1 ranged from 5.9 to 35.3%. The percentage of AYAs endorsing a barrier at T1 who continued to endorse the same barrier at T2 ranged from 0 to 87.50% per barrier ( $M = 47.32\%$ ,  $SD = 26.48$ ). The lowest percentages of re-endorsement at T2 were for those barriers with the lowest level of endorsement at T1. AMBS barriers receiving the highest endorsement at T1 included “forgetful and [doesn’t] remember to take medication,” “tired of taking medication,” “tired of living with a medical condition,” “don’t realize when I run out of pills,” “don’t like how the medication tastes,” and “don’t like what medication does to appearance.” The percentage of AYAs who continued at T2 to endorse these most

highly endorsed barriers from T1 ranged from 41.2 to 86.7% ( $M = 64.05\%$ ,  $SD = 16.07$ ).

Percentages of parents reporting (*agree*) or (*strongly agree*) for a particular barrier at T1 ranged from 6.3 to 38.1%. The percentage of parents who endorsed a barrier at T1 who continued to endorse the same barrier at T2 ranged from 20 to 85.7% ( $M = 47.93\%$ ,  $SD = 17.14$ ). Again, those barriers with the lowest percent re-endorsement were the least frequently endorsed barriers at T1. PMBS barriers receiving the highest endorsement at T1 were similar to those on the AMBS, with both AYAs and parents highly endorsing four of the same six barriers. Parents, like AYAs, endorsed “forgetful and [doesn’t] remember to take medication,” “tired of taking medication,” “tired of living with a medical condition,” and “doesn’t like what the medication does to appearance.” Additionally, there were two more highly endorsed barriers that only appear on the PMBS, including “parent not always there to remind child to take medication” and “child relies on parent reminder to take medication.” The percentage of parents who continued to endorse these most highly endorsed barriers from T1 to T2 ranged from 46.2 to 85.7% ( $M = 61.38\%$ ,  $SD = 13.97$ ).

### **What Are the Correlations Between Specific Barrier Endorsements at T1 and T2?**

Results of correlational analyses, paired samples *t*-tests, and effect sizes are shown in Table III. In correlational analyses of specific items on the AYA-reported AMBS, 1 barrier showed a small relationship ( $r = .28$ ), 10 barriers showed a medium relationship ( $r = .30-.48$ ), and 3 barriers showed a strong relationship ( $r = .53-.78$ ) over 18 months. Only three barriers showed no statistically significant relationship over time. For correlational analyses of specific items on the parent-reported PMBS, 11 barriers showed a medium relationship ( $r = .34-.48$ ) and 3 barriers showed a strong relationship ( $r = .54-.60$ ) over 18 months. Only two barriers showed no statistically significant relationship over this period.

### **Are There Significant Differences in Specific Barrier Endorsement Between T1 and T2?**

Differences in levels of endorsement for specific barriers between T1 and T2 based on paired samples *t*-tests showed significant changes for only 2 of the 17 barriers on the AMBS (i.e., “gets in the way of activities” and “hard to make it to the pharmacy to refill”). These two barriers demonstrated significant increases in ratings over time. Significant changes in levels of endorsement were found for only 2 of the 16 parent-reported barriers on the PMBS between T1 and T2. One barrier demonstrated an average

Table II. Stability of Individuals' Barriers Endorsed at Time 1 (T1) and Time 2 (T2)

Item:	Adolescent (AMBS)		Parent (PMBS)	
	T1 n (%)	% persisted at T2 n (%)	T1 n (%)	% persisted at T2 n (%)
<b>Disease Frustration/Adolescent Issues</b>				
Child very busy with other things that get in the way of taking medication	–	–	11 (17.5)	6 (54.5)
Child sometimes feels sick and can't take the medicine	–	–	11 (17.5)	4 (36.4)
Doesn't want other people to notice them taking the medicine	7 (13.7)	3 (42.9)	9 (14.3)	5 (55.6)
Doesn't like what the medication does to appearance <sup>a</sup>	12 (23.5)	7 (58.3)	23 (36.5)	12 (52.2)
Tired of taking medicine <sup>a</sup>	17 (33.3)	10 (58.8)	18 (28.6)	12 (66.7)
Tired of living with a medical condition <sup>a</sup>	15 (29.4)	13 (86.7)	14 (22.2)	12 (85.7)
Medicine has too many side effects	7 (13.7)	3 (42.9)	8 (12.7)	4 (50.0)
Don't want to take the medicine at school	9 (17.6)	3 (33.3)	–	–
Just don't feel like taking the medicine	8 (15.7)	7 (87.5)	–	–
<b>Regimen Adaptation/Cognitive Issues</b>				
Forgetful and doesn't remember to take medication <sup>a</sup>	18 (35.3)	14 (77.8)	13 (20.6)	6 (46.2)
Not organized about when and how to take medication	4 (7.8)	0 (0.0)	7 (11.1)	2 (28.6)
Gets in the way of activities	4 (7.8)	3 (75.0)	7 (11.1)	2 (28.6)
Hard to stick to a fixed medication schedule	7 (13.7)	2 (28.6)	10 (15.9)	2 (20.0)
Parent not always there to remind child to take medication <sup>a</sup>	–	–	20 (31.7)	11 (55.0)
Don't realize when I run out of pills <sup>a</sup>	13 (25.5)	6 (41.2)	–	–
Hard to make it to the pharmacy to refill	5 (9.8)	1 (20.0)	–	–
<b>Ingestion Issues</b>				
Medicine is hard to swallow	4 (7.8)	2 (50.0)	4 (6.3)	1 (25.0)
Too many pills to take	10 (19.6)	4 (40.0)	11 (17.5)	6 (54.5)
Doesn't like how the medicine tastes <sup>a</sup>	13 (25.5)	8 (61.5)	11 (17.5)	5 (45.4)
Confused about how the medicine should be taken	3 (5.9)	0 (0.0)	–	–
<b>Parent Reminder</b>				
Child relies on parent reminder to take medication <sup>a</sup>	–	–	24 (38.1)	15 (62.5)

Note. N = 51 for AMBS; N = 63 for PMBS; % for T1 = % of total sample; % of T1 and T2 = % of Time 1 endorsers who continue to endorse at T2.

<sup>a</sup>Barriers with  $\geq 20\%$  of sample endorsement at T1.

decrease (i.e., “child sometimes feels sick and can't take the medicine”) and one barrier demonstrated an average increase (i.e., “tired of living with a medical condition”). No other significant changes over time were found.

## Discussion

The current study extends prior research by identifying the relative frequency of endorsement for specific barriers to medication adherence using both AYA and parent proxy-reports. Specifically, we found that particular barriers appear to remain stable over an 18-month period. Barriers with the greatest stability between T1 and T2 were those from the Disease Frustration/Adolescent Issues subscale. Barriers on the Regimen Adaptation/Cognitive Issues subscale were also among the most frequently endorsed barriers at both time points. Overall, findings suggest that adolescents with specific adherence barriers will continue to experience similar levels of the same barriers in the absence of targeted intervention.

In general, parents and adolescents tended to endorse the same barriers as most frequently occurring. Both parents and AYAs endorsed relatively high levels on “tired of taking medication,” “tired of living with a medical condition,” and “doesn't like what it does to my appearance,” which were also among the most stable barriers across 18 months. The first two barriers may be reflective of the persistent challenges of having a transplant. Caring for a transplanted organ can be burdensome and tax the emotional resources of even well-adjusted AYAs. Internalizing symptoms have been shown to be associated with lower adherence. Additionally, prior research has shown that Regimen Adaptation/Cognitive barriers, the factor to which these highly endorsed specific barriers belong, mediate the relationship between both anxiety and depression and medication adherence (McCormick King et al., 2014). AYAs also appear to be sensitive to the effects of prescribed treatment on appearance. Adolescence is a time when social evaluations become increasingly important (Collins, Maccoby, Steinberg, Heatherington, & Bornstein, 2000), and for

Table III. Relationships and Change in Barriers From Time 1 to Time 2

Item endorsed	AMBS from Time 1 to Time 2				PBMS from Time 1 to Time 2					
	r	t	T1 M (SD)	T2 M (SD)	d	r	t	T1 M (SD)	T2 M (SD)	d
Disease Frustration/Adolescent Issues										
Child very busy with other things that get in the way of taking medication	—	—	—	—	—	.40**	-1.17	2.11 (1.03)	2.30 (1.29)	-0.16
Child sometimes feels sick and can't take the medicine	—	—	—	—	—	.47**	2.23*	2.11 (1.05)	1.81 (1.03)	0.29
Doesn't want other people to notice them taking the medicine	.20	.09	1.90 (1.15)	1.88 (1.19)	0.02	.43**	-0.60	2.02 (1.04)	2.11 (1.27)	-0.08
Doesn't like what the medication does to appearance	.41**	-1.70	2.22 (1.20)	2.53 (1.21)	-0.26	.59**	1.79	2.63 (1.30)	2.37 (1.34)	0.20
Tired of taking medicine	.59**	-1.11	2.59 (1.16)	2.61 (1.46)	0.05	.54**	-1.00	2.43 (1.24)	2.59 (1.36)	-0.12
Tired of living with a medical condition	.78**	-0.66	2.51 (1.32)	2.59 (1.20)	-0.02	.60**	-2.44*	2.40 (1.09)	2.75 (1.38)	-0.27
Medicine has too many side effects	.37**	-0.64	2.29 (1.10)	2.41 (1.24)	-0.10	.45**	1.16	2.13 (1.04)	1.95 (1.22)	0.16
Don't want to take the medicine at school	.30*	.32	2.16 (1.22)	2.09 (1.22)	0.06	—	—	—	—	—
Just don't feel like taking the medicine	.35*	-1.61	2.14 (1.15)	2.45 (1.29)	-0.25	—	—	—	—	—
Regimen Adaptation/Cognitive Issues										
Forgetful and doesn't remember to take medication	.46**	-1.51	2.69 (1.30)	2.98 (1.36)	-0.22	.48**	-1.14	2.17 (1.16)	2.37 (1.41)	-0.15
Not organized about when and how to take medication	.33*	.56	1.88 (.93)	1.80 (.78)	0.09	.35**	-0.20	2.00 (.97)	2.03 (1.26)	-0.03
Gets in the way of activities	.39**	-4.33**	1.73 (.98)	2.43 (1.22)	-0.63	.37**	-0.75	1.86 (.98)	1.97 (1.11)	-0.11
Hard to stick to a fixed medication schedule	.18	-.88	2.02 (.99)	2.18 (.99)	-0.16	.26	-0.17	2.05 (1.10)	2.08 (1.25)	-0.03
Parent not always there to remind child to take medication	—	—	—	—	—	.34**	-1.17	2.65 (1.30)	2.60 (1.30)	0.04
Don't realize when I run out of pills	.30*	.30	2.39 (1.17)	2.33 (1.21)	0.05	—	—	—	—	—
Hard to make it to the pharmacy to refill	.28*	-2.90**	1.86 (.94)	2.37 (1.13)	-0.49	—	—	—	—	—
Ingestion Issues										
Medicine is hard to swallow	.53**	1.53	1.84 (.99)	1.65 (.89)	0.20	.19	0.68	1.52 (.82)	1.43 (.93)	0.10
Too many pills to take	.33*	.39	2.27 (1.33)	2.20 (1.18)	0.06	.37**	-0.46	2.00 (1.15)	2.08 (1.30)	-0.07
Doesn't like how the medicine tastes	.48**	-.33	2.37 (1.25)	2.43 (1.27)	-0.05	.34**	1.04	2.06 (1.09)	1.89 (1.23)	0.15
Confused about how the medicine should be taken	.19	-1.40	1.80 (.83)	2.02 (.91)	-0.25	—	—	—	—	—
Parent Reminder										
Parent not always there to remind child to take medication	—	—	—	—	—	.34**	-1.17	2.35 (1.27)	2.57 (1.35)	-0.17

Note. *d* < .05; \**d* < .01; N = 51 for AMBS; N = 63 for PMBS; Pearson correlation and dependent samples *t*-tests were used; *d* represents Cohen's effect size, *d*.

AYA transplant recipients, normative social concerns may be exacerbated by feeling self-conscious about taking medications in public. These emotional and social concerns related to having a transplant may in turn result in a general lack of motivation to take medications as prescribed.

Given the frequency of endorsement and stability of specific social and emotional barriers, cognitive-behavioral and problem-solving interventions may be helpful. The literature has reported that interventions containing cognitive-behavioral elements are most effective in increasing adherence (Graves, Roberts, Rapoff, & Boyer, 2010; Kahana, Drotar, & Frazier, 2008). Additionally, training in how to manage social pressures and enlist peer support (La Greca & Mackey, 2009) may offer potential avenues for encouraging AYAs to take medications even in social settings. Both parents and AYAs also frequently endorsed “forgetful and doesn’t remember to take medication.” Adolescents additionally endorsed “don’t realize when I run out of pills” (AMBS item only), and parents endorsed “parent not always there to remind child to take medication” and “child relies on parent to take medication” (PMBS items only). These four highly endorsed and stable barriers potentially represent difficulties with AYAs’ executive functioning (EF), which could impede their ability to follow complex medication regimens. In adolescents with diabetes, for example, better EF was associated with better parent-reported treatment adherence (Bagner, Williams, Geffken, Silverstein, & Storch, 2007).

Deficits in AYAs’ EF may be addressed by increasing developmentally appropriate parental responsibility and supervision. A previous study examining the allocation of regimen responsibility in transplant recipients reported that adolescents whose parents assumed greater responsibility for medication taking had better adherence than adolescents who were solely responsible for taking medications (Zelikovsky et al., 2008), lending support for the protective role of parental monitoring against nonadherence. AYA’s difficulties in remembering to take or refill medications may be addressed via regimen adaptations, reminders, cues, or parental scaffolding of greater AYA responsibility for taking medications contingent on performance (La Greca & Mackey, 2009; Masten, 2004). Technology-based approaches (Miloh et al., 2009) and eHealth interventions (Cushing & Steele, 2010) may also be viable methods for targeting specific barriers related to EF. From the Ingestion Issues subscale, one specific barrier, “doesn’t like how the medicine tastes,” demonstrated relatively frequent and stable endorsement by adolescents. These barriers may be addressed by masking undesirable tastes using pleasant-tasting beverages or foods. Patients and their families

may also discuss with their medical providers the possibility of being prescribed alternative medications with less unpleasant tastes.

Previous research has shown that specific barriers are associated with poorer adherence and greater number of future negative health outcomes (Simons et al., 2010). Based on findings from the current study, it is likely that individuals who continue to experience barriers will also continue to be at higher risk for experiencing negative health outcomes. Interventions aimed at reducing targeted adherence barriers may prove effective in helping to reduce nonadherence and negative health outcomes. Established intervention strategies have not been adequately tested with pediatric solid organ transplant recipients (Graves et al., 2010; Kahana et al., 2008), and to date, no empirically supported treatments for nonadherence in pediatric solid organ recipients exist (Fredericks & Dore-Stites, 2010). To help develop manualized interventions and inform direct clinical practice, brief measures of barriers, such as the AMBS and PMBS, may be used to assess specific adherence-related challenges.

Despite the useful information provided by this study, it is not without limitations. Participants included a relatively small number of AYA transplant recipients recruited from a single institution. Future studies should attempt to recruit larger and multisite samples. The inclusion of additional medical variables would strengthen the findings of this study. The ethnic composition of participants was also limited to predominantly Caucasian and African American adolescents, and findings may not generalize to patients of other races/ethnicities. Additionally, patients from diverse socioeconomic backgrounds and of different ages may have unique barriers that are more or less problematic than those reported in this investigation.

Overall, this study contributes to the literature by addressing the fundamental question of which specific barriers are most frequently experienced by AYA transplant recipients and demonstrating that, overall, specific barriers to adherence appear to be stable over an 18-month period. This information may prove useful in guiding intervention efforts to address specific obstacles to medication adherence. Assessing patients’ specific barriers to adherence and selecting appropriate interventions to interrupt the otherwise stable trajectory of specific barriers may vastly improve clinical care and outcomes.

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