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A preliminary investigation of sleep quality and patient-reported outcomes in pediatric solid organ transplant candidates

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Abstract

The current cross-sectional, single-center study aimed to examine sleep quality in a sample of adolescents awaiting solid organ transplantation and to explore associations between sleep quality and both health-related quality of life and barriers to adherence. Thirty adolescents between the ages of 12 and 18 years (*M* age = 15.26, SD = 1.89) who were awaiting transplantation participated in this study. Participants completed measures of sleep quality, health-related quality of life, and barriers to adherence. T test and correlational analyses were performed to examine study aims. Adolescents awaiting transplantation had significantly lower levels of overall sleep quality compared to published norms of healthy peers. Domains of sleep quality were positively related to emotional and psychosocial health-related quality of life. Sleep quality domains were also negatively related to adherence barriers. This study provides preliminary evidence demonstrating that sleep quality among transplant candidates is compromised, and that poor sleep quality is related to adolescents' functioning across a number of domains during the pretransplant period. Results highlight the clinical importance of assessing and targeting sleep functioning in adolescents awaiting transplantation in order to reduce the negative influence of suboptimal sleep on functioning during this vulnerable period.

Keywords

adherence barriers; health-related quality of life; patient-reported outcomes; pretransplant; sleep

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AUTHORS' CONTRIBUTIONS

Gutierrez-Colina, Cushman, Eaton, Quast, Lee, Rich, and Reed-Knight: Conceived/designed study; Gutierrez-Colina, Eaton, Lee, Rich, and Reed-Knight: Collected data; Gutierrez-Colina and Cushman: Analyzed data; Gutierrez-Colina, Cushman, Eaton, Quast, Lee, Rich, Reed-Knight, Mee, Romero, George, Mao, and Blount: Interpreted data; Gutierrez-Colina, Cushman, and Quast: Drafted the article; Eaton and Lee: Involved in funding; Gutierrez-Colina, Cushman, Eaton, Quast, Lee, Rich, Reed-Knight, Mee, Romero, George, Mao, and Blount: made a critical revision of the article and approved the article.

Ana M. Gutierrez-Colina has moved from The University of Georgia to Cincinnati Children's Hospital Medical Center.

1 | INTRODUCTION

Medical advancements in pediatric transplantation have given patients with life-threatening conditions the opportunity for an extended life. Despite the steep rise in survival rates,[1] the prospect of transplantation can be daunting and overwhelming for pediatric patients and their families. The waiting period, which can last anywhere from days to years, has been described as one of the most stressful stages of transplantation because of the uncertainty, apprehension, and vulnerability that characterizes this period.[2,3] Given the potential for unique stressors endured during the pretransplant phase, pediatric patients awaiting transplantation are at risk for mental health and behavior problems.[4,5] As a result, clinicians and researchers have increasingly focused on identifying modifiable factors that may help alleviate the challenges endured by patients and their families during this vulnerable period. Sleep has been proposed as a key malleable factor with wide clinical implications for the promotion of adjustment and coping in chronically ill populations.

Unfortunately, inadequate sleep in youth is common, with approximately 87% of high school students getting suboptimal sleep.[6] Among children and adolescents with chronic illness, the risk for sleep problems is particularly high compared to healthy youth.[7,8] In a sample of pediatric patients undergoing dialysis, 86% endorsed sleep disturbances and 25% endorsed less than 7 hours of total sleep time during week or weekend nights.[9] Sleep problems in the pre-transplant population are likely multifactorial and influenced by neurobiological, cognitive, and behavioral factors. Few studies to date, however, have examined the prevalence or role of sleep problems in adolescent patients awaiting transplantation. Thus, a better understanding of the role of sleep in the pretransplant phase remains a fundamental area of inquiry, as nearly every aspect of child functioning (eg, quality of life, psychosocial well-being, physical health) has been linked to sleep.[10]

Sleep difficulties are also associated with a wide array of psychosocial problems (eg, emotional, social, academic), with children who have persistent sleep problems having a 16-fold greater risk of experiencing psychosocial symptoms in subclinical or clinical ranges compared to those without sleep problems.[11] Delahaye et al[12] found that sleep variables (eg, daytime sleepiness, sleep onset delay, sleep duration) were negatively correlated with HRQOL in pediatric patients. Poor sleep quality has also been associated with cognitive problems in other pediatric groups.[11] Despite the significant lack of literature on sleep functioning during the pretransplant phase, research conducted with patients post-transplantation has shown that sleep accounts for more variance than age, time since transplantation or health status in children's HRQOL.[13] Thus, while empirical evidence reveals that disruptions in sleep are both present post-transplantation and also associated with a wide variety of negative psychosocial outcomes, further research is needed to investigate whether similar problems exist pretransplantation, an important gap in the transplant literature.

The role of sleep in promoting health and self-management has received increasing attention in the pediatric literature. Worse sleep quality in children with diabetes, for example, has been linked to more self-regulatory failures and greater risk of high blood glucose levels,[14]

suggesting that sleep may be a significant risk factor for barriers related to disease management. The adequate management of medications prior to transplantation is a critical aspect of maximizing organ function and minimizing morbidity pretransplantation. Past research has demonstrated that sleep variables, such as sleep schedule, influence how likely pediatric transplant recipients are to take their medications as prescribed.[15] Few studies to date, however, have investigated how sleep may relate to barriers that affect the successful management of medications in pediatric patients awaiting transplantation.

In summary, while the scientific community has begun to consider the role of sleep in emotional and behavioral functioning, few studies to date have examined the interrelations between sleep quality, psychosocial functioning, and barriers to medication management in adolescents awaiting a solid organ transplant. The objective of this study was to further our understanding of sleep quality during the pretransplant period and its relationship to aspects of psychosocial functioning to provide new avenues for identifying patients who may benefit from clinical interventions targeting sleep during the pretransplant phase. Based on these objectives and guided by previous literature, the following hypotheses were examined: (a) Patients awaiting transplantation will have significantly lower levels of sleep quality compared to previously published norms in healthy peers; (b) sleep quality will be positively related to HRQOL and negatively related to adherence barriers.

2 | METHOD

2.1 | Participants

A total of 30 adolescents awaiting solid organ transplant between the ages of 12 and 18 years (*M* age = 15.26, SD = 1.89) were included. This cross-sectional, single-center, observational study is part of a larger investigation of infants, toddlers, children, adolescents, and young adults awaiting transplantation. Eligibility criteria for the larger investigation specified that patients must be (a) a potential candidate for a solid organ transplantation (ie, kidney, liver, heart), (b) younger than 21 years of age, (c) able to speak and read English, and (d) attending a pretransplant evaluation with an English-speaking primary caregiver. Participants with a significant history of developmental or cognitive delay were excluded from the study. Given that the sleep measure used has not been validated in children younger than 12 or older than 18, and only adolescents completed this questionnaire, the previously stated inclusion criteria were narrowed for this particular investigation and only participants 12–18 years were included in analyses. See Figure 1 for a detailed recruitment diagram. All eligible participants were identified by a trained staff research assistant via medical chart review prior to the clinic visit. There were no differences on demographic and medical variables between the adolescents who were enrolled in the study and those who declined to participate. Additional characteristics of the sample are presented in Table 1.

2.2 | Procedure

All data collection was completed at one large tertiary medical center in the southeastern United States. All study procedures were in full compliance with HIPAA regulations and were approved by the Institutional Review Board for the study site. Potential pre-transplant adolescent participants were approached in clinic by a study investigator during their

outpatient pretransplant evaluation appointment. Informed consent/assent and HIPAA authorization were obtained from each participant or their caregiver. To minimize disruption of clinic flow and patient care, adolescents completed paper and pencil measures at the beginning, during, or at the end of their clinic visit. Data collection took place from July 2012 to April 2016. All participants received a retail store gift card as compensation for their time and effort. Previously published norms of sleep quality in a control sample of healthy adolescents were used to compare transplant recipients with healthy peers.[16]

2.3 | Measures

Participants or their caregivers provided sociodemographic information from a standard demographic questionnaire. Medical data (eg, type of transplant, time since transplantation) were collected via retrospective review of the electronic medical record.

2.3.1 | Sleep—Adolescents completed the ASWS,[17] a 28-item measure of subjective sleep quality validated for adolescents. Participants responded to items describing the frequency of various sleep behaviors over the previous month on a 6-point Likert scale ranging from *Always* to *Never*. These items yield five subscale scores: (a) Going to Bed (eg, "I am ready to go to bed at bedtime."), (b) Falling Asleep (eg, "I fall asleep quickly."), (c) Maintaining Sleep (eg, "I sleep soundly through the night."), (d) Reinitiating Sleep (eg, "After waking up during the night, I have trouble getting comfortable."), and (e) Returning to Wakefulness (eg, "In the morning, I wake up feeling rested and alert."). The psychometric properties of the ASWS are well established.[18] In the current study, the Going to Bed and Maintaining Sleep subscales were excluded from the analyses due to low reliability. Internal consistency for overall sleep quality was 0.83, while the alphas for the three retained subscales ranged from 0.64 to 0.75.

2.3.2 | HRQOL—Adolescents reported on their HRQOL using the PedsQL, version 4.0 (PedsQL).[19] The PedsQL is a 23-item measure used to assess HRQOL in pediatric populations and healthy children. The PedsQL assesses four domains of HRQOL: Social Functioning, School Functioning, Emotional Functioning, and Physical Functioning. A Psychosocial Functioning composite score can be obtained by averaging the scores from the Social, School, and Emotional Functioning subscales. Scores on each subscale or composite scale can range from 0 to 100, with higher scores indicating better HRQOL. The construct validity and internal consistency of the PedsQL are acceptable in the literature.[19] In the current study, Cronbach's alphas for the Physical, Emotional, Social, School, and Psychosocial subscales were 0.81, 0.81, 0.74, 0.68, and 0.78, respectively.

2.3.3 | Adolescent medication barriers—The AMBS[20] is a 17-item measure used to assess adolescents' self-report of barriers to following their medication regimen as prescribed. To complete this measure, adolescents endorse the extent to which different barriers get in the way of medication taking on a 5-point Likert scale ranging from *Strongly disagree* to *Strongly agree*. Barriers are categorized into three subscales, including (a) Regimen Adaptation/Cognitive Issues, (b) Disease Frustration/Adolescent Issues, and (c) Ingestion Issues. In previous literature, the criterion-related validity of the AMBS has been demonstrated to be strong.[20] In the current study, Cronbach's alphas for the three subscales

and the total score were 0.76 (Regimen Adaptation/Cognitive Issues), 0.84 (Disease Frustration/Adolescent Issues), and 0.58 (Ingestion Issues). The Ingestion Issues subscale was not included in analyses due to poor reliability.

2.4 | Statistical analyses

This paper contains data analyses of the adolescent subset of a larger longitudinal study of a wider age range (birth to young adulthood) of pediatric patients awaiting transplantation. All data analyses were conducted using the IBM Statistical Package for the Social Sciences, version 24.0. Descriptive statistics were calculated for all sociodemographic variables. For hypothesis, statistical significance was set at $P < 0.05$. To evaluate significant differences between the demographics of those who participated in the study and those who declined, Mann-Whitney U tests and chi-square tests were used. To compare sleep quality scores with previously published norms,[16] t tests were conducted and Cohen's d was calculated for effect size. Non-parametric Spearman's correlation analysis (rs) was performed to investigate the relation between various aspects of patient-reported sleep quality and the outcome variables of interest (ie, HRQOL and adherence barriers).

3 | RESULTS

3.1 | Patient-reported sleep quality in adolescents awaiting transplantation

As shown in Table 2, results revealed significantly lower levels of overall sleep quality in adolescents awaiting transplantation compared to healthy peers ($t = -18.31$, $P \leq 0.001$, $d = 2.36$). Significant differences between groups were also found for the Falling Asleep ($t = -9.48$, $P \leq 0.001$, $d = 1.38$) and Reinitiating Sleep ($t = -9.48$, $P \leq 0.001$, $d = 1.38$) subscales, with adolescents awaiting transplantation experiencing lower sleep quality in these domains. No significant differences were found for the Returning to Wakefulness subscale ($t = -0.81$, $P = 0.86$, $d = 0.10$).

3.2 | Sleep quality and HRQOL

Bivariate correlations were conducted to examine associations between domains of sleep quality and HRQOL. The ASWS Falling Asleep subscale was significantly and positively correlated with the PedsQL Emotional (rs = 0.43, $P \leq 0.01$), Psychosocial (rs = 0.38, $P \leq 0.05$), and Social (rs = 0.34, $P \leq 0.05$) functioning subscales, such that better sleep quality in this domain was related to higher levels of quality of life. Similarly, the ASWS Returning to Wakefulness subscale was significantly and positively correlated with the PedsQL Social (rs = 0.31, $P \leq 0.05$) functioning subscale. The ASWS Reinitiating Sleep subscale was significantly and positively correlated with the PedsQL Psychosocial (rs = 0.35, $P \leq 0.05$) and Total (rs = 0.31, $P \leq 0.05$) subscales. Lastly, higher levels of overall sleep quality, as captured by the ASWS Total score, were correlated with better psychosocial (rs = 0.38, $P \leq 0.05$) and total (rs = 0.32, $P \leq 0.05$) quality of life. No other significant correlations were found between domains of HRQOL and sleep quality.

3.3 | Sleep quality and medication barriers

The ASWS Falling Asleep (rs = −0.33, $P \leq 0.05$), Reinitiating Sleep (rs = −0.31, $P \leq 0.05$), and Total (rs = −0.35, $P \leq 0.05$) subscales were significantly and negatively related to the

AMBS Regimen Adaptation/Cognitive Issues subscale, with adolescents experiencing poorer sleep quality in the assessed domains endorsing greater adherence barriers. There were no significant associations between sleep quality and Disease Frustration/Adolescent Issues barriers.

4 | DISCUSSION

The current study aimed to evaluate sleep quality in a sample of adolescent patients awaiting transplantation and to examine associations between sleep quality and domains of HRQOL and barriers to medication adherence. Consistent with study hypotheses, results indicated that adolescents in the pretransplant phase experience significantly lower levels of sleep quality compared to healthy age-matched peers across a number of sleep domains. Specifically, adolescents waiting for a transplant reported significantly more difficulties falling asleep, reinitiating sleep, and returning to wakefulness than their healthy counterparts. Effect sizes were large for these subscales. These results replicate previous findings in the post-transplant literature[13] and build upon this body of research by demonstrating that sleep problems can also be present prior to transplantation. Given that disruptions in sleep have been related to worse psychosocial functioning across a number of domains,[10] poor sleep quality before transplant may place adolescents at increased risk of adjustment difficulties during the early stages of the transplantation process. Further, poor sleep quality may also place adolescents at higher risk for slower transplant surgery recovery and decreased physical health when inadequate sleep continues posttransplantation. These findings also raise questions about the continuity and discontinuity of sleep problems throughout the transplant journey. It is possible that susceptibility to sleep difficulties starts early in patients' transplantation journey, and that some of the same mechanisms (eg, poor sleep hygiene, cognitive rumination) that affect sleep quality during the pretransplant period are in play post-transplantation. If this is the case, sleep problems pretransplantation may not resolve post-transplant without targeted behavioral, medical, and/or pharmacological interventions. The side effects of medications (eg, steroids) or the timing of drug administration known to affect sleep are some other possible factors that may remain problematic as children move through the transplantation journey.[9]

The current findings revealed a positive association between sleep quality and HRQOL scores among adolescents awaiting transplantation, with medium effect sizes. Specifically, adolescents' ability to fall asleep was associated with higher levels of both emotional, social, and psychosocial HRQOL scores. These results replicate previous work concluding that sleep plays a significant role in emotional processing and regulation, while also extending these findings to pediatric patients awaiting transplantation.[21,22] Higher levels of overall sleep quality and ability to reinitiate sleep were correlated with better psychosocial and overall HRQOL, further supporting the previously established association between sleep and HRQOL among pediatric patients with chronic kidney disease[23] and a variety of other pediatric populations.[24,25] Poor sleep quality may affect adolescents' HRQOL by increasing their susceptibility to stress or by limiting their abilities to engage in adaptive coping strategies to manage the stressors associated with the prospect of transplantation. Psychological distress, particularly depressive symptoms, is often associated with insomnia or poor sleep quality.[26] Alternatively, poor sleep quality may trigger psychological distress

by impairing emotion regulation and limiting engagement in enjoyable or social activities, functioning as a potential risk factor for depression.[26,27] Interestingly, none of the sleep quality domains were associated with physical HRQOL scores. Sleep problems in this population may be more related to psychosocial issues rather than physical functioning. However, the small sample size of this preliminary investigation may be a limiting factor in our ability to detect significant relations of small effect size between sleep and physical functioning.

In the current sample, adolescents' overall sleep quality, ability to fall asleep, and ability to return to wakefulness were negatively associated with medication barriers related to Regimen Adaptation/Cognitive Issues, including forgetfulness, difficulties with memory, organization, attention, and problem-solving skills. Because executive functions are emerging during this developmental period, it is not uncommon for adolescents to report forgetfulness as a significant barrier to medication taking.[28,29] Poor sleep quality, combined with emerging executive functioning skills, may exacerbate forgetfulness, distraction, or the likelihood that an adolescent will sleep through scheduled medication doses. This is consistent with past work demonstrating the crucial role of sleep quality for optimal cognitive functioning,[22,23,30,31] which has important implications not only for self-management but also for scholastic achievement during the transplant journey.

Taken together, our findings highlight the importance of assessing patient-reported sleep quality in adolescents awaiting transplantation and demonstrate that preliminary findings indicate sleep quality during the pretransplant period relates to important clinical outcomes, including HRQOL and barriers to adherence. Assessing pediatric sleep problems during the pretransplant evaluation may provide clinicians with valuable information to promote the well-being of adolescents as they prepare for transplantation. Among those patients struggling with sleep problems, brief interventions, such as psychoeducation to promote appropriate sleep hygiene practices (eg, bedtime routine, dark cool sleep space, no use of electronics 30 minutes before bedtime), could be delivered during routine clinical appointments to target sleep problems. For sleep problems with more complex presentations, cognitive behavioral interventions, referrals to sleep medicine clinics, and consideration of pharmacotherapy may be successful multidisciplinary approaches to targeting sleep problems in this vulnerable population.[25,26] Additional research is needed to evaluate the short- and long-term effectiveness of sleep interventions during the pretransplant period and their possible implications post-transplantation.

Despite the novelty of these findings, this study has limitations. The small sample size limits statistical power to detect significant relations among the variables examined. Although results comparing adolescents awaiting transplantation to published norms of healthy peers were robust with large effect sizes, conclusions about specific associations with patient-reported psychosocial variables and adherence barriers at this stage are preliminary. These findings await further replication with larger sample sizes that will provide increased statistical power. Further, the sample was collected from a single transplant center, which may limit generalizability of our findings to other geographical locations. Despite these issues with external validity, the racial and ethnic composition of the sample in our study was diverse. However, future multi-site investigations are needed to address concerns with

generalizability of the results. The cross-sectional nature of our study also limits causal conclusions, as poor psychosocial functioning may affect sleep quality, or sleep problems may affect psychosocial functioning. Most likely, the associations documented in this study reflect complex and bidirectional relations that exist among the variables examined. Lastly, while adolescent report provides unique insight into adolescents' perceptions of their own sleep quality and psychosocial functioning, there are limitations to reliance on self-reports, including response bias influenced by social desirability. Future inclusion of objective physiological measures of sleep (ie, actigraphy, polysomnography, serum iron levels) would provide a more comprehensive assessment of sleep and its role in adaptation during the pretransplantation period.[32]

Overall, this study documents patient reported of sleep quality among adolescents awaiting a solid organ transplant and provides preliminary evidence demonstrating that poor sleep quality is related to adolescents' functioning across a number of domains during the pretransplant period. Results highlight the clinical importance of assessing sleep functioning and providing appropriate interventions when indicated to reduce the potential negative influence of sleep problems on functioning during the pretransplant period.

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Abbreviations:

AMBS	Adolescent Medication Barriers Scale
ASWS	Adolescent Sleep-Wake Scale
HIPAA	Health Insurance Portability and Accountability Act
HRQOL	health-related quality of life
PedsQL	Pediatric Quality of Life Inventory

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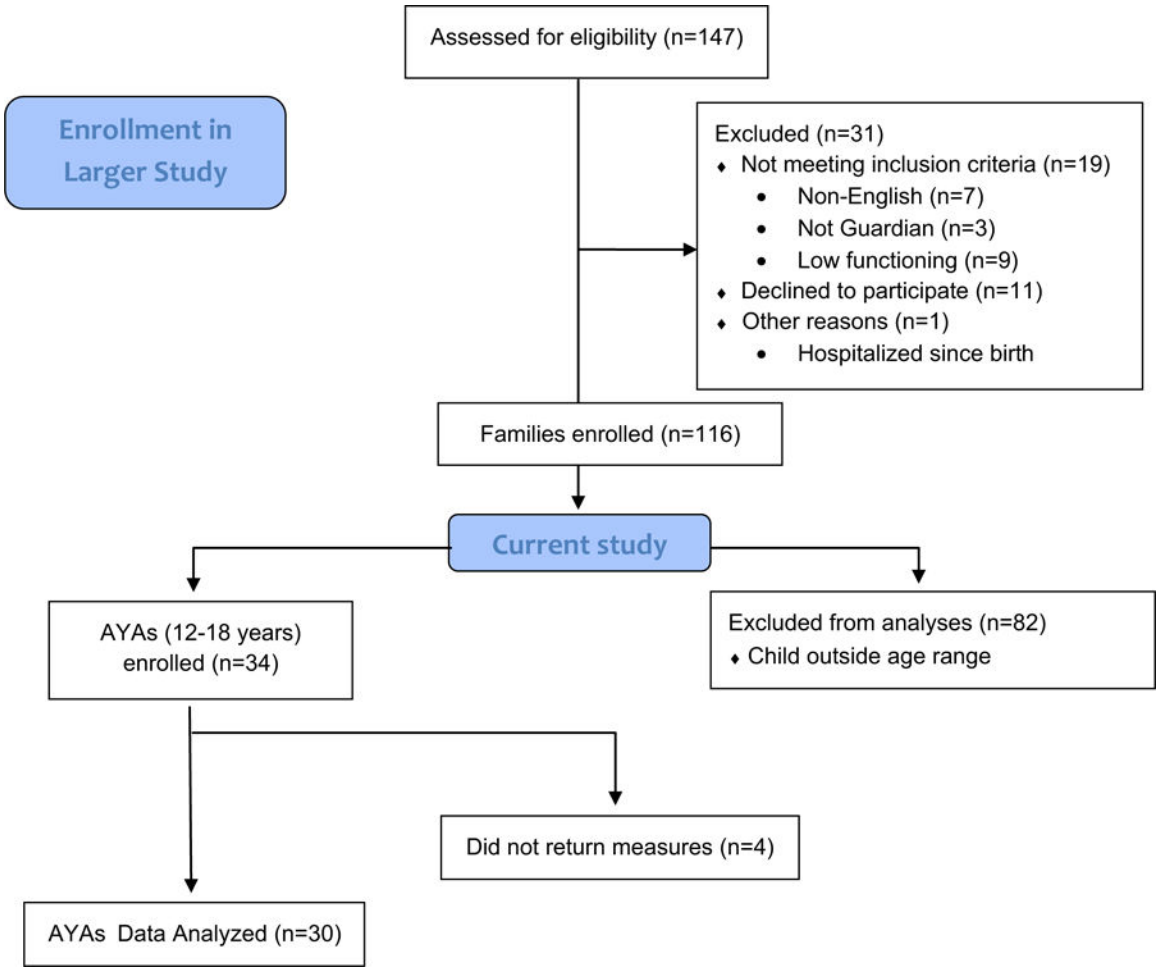

FIGURE 1.
Recruitment flow diagram

TABLE 1

Participant information

Variable	N = 30	
	M	**SD**
Age (y)	15.26	1.89
Years since diagnosis	9.31	5.93
	Frequency	**%**
Sex		
Male	9	30.00
Female	21	70.00
Race/ethnicity		
White	15	50.00
Black	12	40.00
Hispanic	2	6.70
Biracial	1	3.30
Family income		
<$10 000	2	7.10
$10 000–24 999	5	17.90
$25 000–49 999	3	10.70
$50 000–74 999	8	26.70
$75 000–99 999	4	13.30
$100 000+	6	20.00
Prefer not to disclose	2	6.70
Caregiver marital status		
Married	22	73.30
Single	2	6.70
Divorced	4	13.30
Other	2	6.70
Previous transplant	4	13.33
On dialysis	7	23.30
Organ group		
Kidney	16	53.30
Liver	8	26.70
Heart	6	20.00
Recruitment setting		
Inpatient	6	20.00
Outpatient	24	80.00

TABLE 2

Sleep quality in adolescents and young adults awaiting solid organ transplantation compared to a sample of healthy youth[a]

ASWS domain	Sample mean	Sample SD	Normative mean	Normative SD	Mean difference (95% CI)	*t*-score	*P*-value	Cohen's *d*[b]
Falling asleep	3.54	0.54	4.48	0.80	−0.94 (−1.13 to −0.73)	−9.48	0.001	1.38
Returning to Wakefulness	3.31	0.44	3.38	0.90	−0.065 (−0.23 to 0.10)	−0.81	0.426	0.10
Reinitiating sleep	2.93	0.70	5.15	0.60	−2.22 (−2.48 to −2.00)	−17.50	0.001	3.41
Total sleep quality	3.20	0.35	4.36	0.60	−1.16 (−1.29 to −1.03)	−18.31	0.001	2.36

[a]Healthy Normative group is a healthy sample collected by Murray et al.[16]

[b]Small effect size: $d = 0.20$, medium effect size: $d = 0.50$, large effect size: $d = 0.80$.