Published in final edited form as:

Pediatr Transplant. 2013 February ; 17(1): 48–54. doi:10.1111/petr.12011.

Adaptive functioning and its correlates after intestine and liver transplantation

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Abstract

In this cross-sectional study we compared levels of adaptive functioning and examined potential correlates of adaptive functioning in 18 pediatric intestine (ITX) and 22 liver (LTX) recipients transplanted between June, 2003 and March, 2009. Family caregivers completed the Adaptive Behavior Assessment System-II (ABAS-II) scale and provided sociodemographic information regarding recipients' age at transplantation, gender, ethnicity, time since transplantation, and caregivers' role, ethnicity, education, and family income. Overall adaptive functioning and all 3 adaptive functioning subdomain scores were significantly lower in ITX patients compared to LTX patients ($p = 0.04$) and compared to the general population normative mean ($p = 0.003$). Significant correlates of adaptive functioning after abdominal transplant included type of transplant procedure ($r = -0.4$, $p = 0.02$), gender ($r = 0.4$, $p = 0.01$), and educational level of caregiver ($r = 0.5$, $p = 0.003$) and together explained 45% of the variance in overall adaptive functioning. Findings provide new information regarding everyday functioning outcomes of ITX patients, add to existing data regarding non-medical outcomes for LTX patients, and highlight the need for ongoing monitoring and intervention following transplantation in order to enhance outcomes.

Keywords

adaptive functioning; pediatric transplantation; abdominal transplantation; intestine transplantation; small bowel transplantation; liver transplantation; multivisceral transplantation

Background

Since the inception of pediatric abdominal organ transplantation, evidence of improvements in medical and survival outcomes for intestine (small bowel and multi-visceral) transplantation (ITX) and liver transplantation (LTX) has accumulated, making abdominal transplantation an established treatment option for pediatric patients with end-stage diseases (1-3). The aims of transplantation also include improving daily life functioning which is of particular importance for pediatric transplant patients given that improvements in functioning are closely related to their ability to develop and mature. Calls for more research and growing interest in examining non-medical outcomes following transplantation have spurred research on the cognitive, school functioning, developmental functioning, and quality of life outcomes of pediatric transplant patients (1, 4-14). However, the number of studies in these areas remains modest and studies examining everyday life skills and/or comparing abdominal transplant groups are scarce (12, 15-17).

Studies that have examined non-medical outcomes after pediatric abdominal transplantation have found that a significant portion of LTX patients experience cognitive and psycho-educational delays as well as behavioral difficulties (5-10). A recent report examining a group of 144 pediatric LTX patients found a higher prevalence of cognitive and academic deficits in these patients than in the general population (7). In addition, a recent study of health related quality of life (HRQOL) in LTX patients found similar levels of HRQOL impairment among LTX recipients as among other chronic illness groups (e.g., renal transplant patients, cancer survivors) (18).

Relative to LTX, even fewer studies have examined ITX patients. The limited evidence suggests that cognitive and developmental functioning are significantly below the normal range (2, 8-10). A recent study examining HRQOL among ITX patients found significantly compromised HRQOL among ITX patients compared to normal controls across various areas including physical, social and school functioning (14). To our knowledge the only study that compared developmental outcomes between pediatric ITX and LTX recipients reported significantly greater delays after ITX as measured by the Bayley Scales of Infant Development (9).

Adaptive functioning per se has not been widely examined in pediatric transplantation. Adaptive functioning refers to “real life functioning,” i.e., how individuals perform and behave during daily living such as communicating with others, engaging in self-care, socializing, and managing everyday activities (19). Studies examining the relationship of adaptive functioning to cognitive and academic functioning have found significant correlations ranging from .39 to .67 suggesting that these concepts are related to the performance of everyday tasks, but different (19). Adaptive functioning is an important area to examine in transplantation because it provides a gauge of how well an individual functions in society at large (19, 20). Our group published one report examining adaptive functioning in a specific subgroup of pediatric LTX recipients, patients with Maple Syrup Urine Disease (17). However, because our findings were limited to a relatively rare underlying diagnosis, the findings may not be representative of other LTX recipients and therefore additional examination of outcomes would be beneficial.

The aims of our current study were to: a. describe and compare levels of adaptive functioning after abdominal transplantation among ITX and LTX patients, b. compare levels of adaptive functioning of ITX and LTX groups to levels within the general population, and c. identify correlates of adaptive functioning beyond type of transplant received. We chose to compare ITX and LTX patients because both groups can experience similar medical complications and comorbidities yet ITX patients have been previously shown to exhibit

greater developmental delays. Further, we could limit potential system level confounders by comparing transplant groups that are managed and followed by the same medical team. Lastly, previous research has highlighted the scarcity of studies comparing solid organ transplant groups and we believe the current comparison will be informative and useful for providers and families making decisions regarding transplantation (4, 14, 18). Given evidence suggesting significant cognitive and developmental deficits in ITX recipients we hypothesized that ITX recipients would have lower adaptive functioning levels than LTX patients as well as general population normative groups.

Patients and Methods

Sample

A cross-sectional sample of 18 ITX and 22 LTX patients between one to six years post-transplantation and their caregivers were recruited from the Hillman Center for Pediatric Transplantation at the Children's Hospital of Pittsburgh of UPMC (CHP). We chose patients in this range post-transplantation to capture non-medical outcomes for the period most commonly reported on by other researchers and tracked by registries. The study was approved by the University of Pittsburgh Internal Review Board. Participants were recruited during scheduled clinic visits to our transplant center. Caregivers provided written informed consent and completed study materials including the adaptive functioning measure and a socio-demographics form while they waited for their child's clinic appointment, or took the materials home to complete and return by mail or during a subsequent clinic visit. Medical information such as underlying medical condition, type of transplant, and years since transplantation were extracted from the medical record.

Measures

Adaptive functioning was measured using the Adaptive Behavior Assessment System-Second Edition (ABAS-II), a validated instrument that assesses 10 areas of functioning (Communication, Community Use, Functional Academics, Home Living, Health and Safety, Leisure, Self-Care, Self-Direction, Social, and Work) which are used to compute 3 subdomain scores: conceptual (CON), social (SO), and practical (PR) and an overall General Adaptive Composite (GAC) score (19). The ABAS-II has been extensively used to assess adaptive functioning in various populations including children with mental retardation, autism, behavior disorders, neuropsychological disorders, and learning disabilities (19). Internal consistency reliability coefficients for the General Adaptive Composite of the ABAS-II range from .86 to .98 with an average of .98 (19). The ABAS-II has also been validated against other measures of adaptive functioning including the Vineland Adaptive Behavior Scale ($r = .75$ for the parent self-report and $.84$ for the Interview Edition) and the Scales of Independent Behavior ($r = .70$) (19). ABAS-II raw scores for each of the 10 adaptive functioning subscales are adjusted for age and expressed as scaled scores based on a population mean of 10 and a standard deviation of three. Subdomain (CON, SO, PR) scores and the overall GAC score are based on a population mean of 100 and a standard deviation of 15 (19).

Data were also collected to describe characteristics of the recipients (gender, ethnicity, type of transplant, length of transplant stay, age at transplant, time since transplant) and the family caregivers (gender, ethnicity, educational status, and annual family income).

Statistical Analyses

Differences in baseline demographic characteristics between ITX and LTX transplant groups were computed using Chi-square tests for categorical variables and independent samples t-tests for continuous variables. The ITX and LTX groups were compared on the

overall GAC scale for adaptive functioning using a t test. They were compared on the three ABAS-II subdomains (CON, SO, PR) using MANOVA, followed by individual t tests (given that the overall F test was statistically significant). One-sample t-tests were used to compare the adaptive functioning levels of ITX and LTX samples to the general population normative mean. Pearson correlations were computed to determine which demographic variables (age at transplantation, time since transplantation, gender, participant ethnicity, family caregiver educational level, family caregiver ethnicity, and family income) were significantly associated with adaptive functioning. Age at transplantation and time since transplantation were divided into categories (see Table 1) as the distribution of the sample was skewed and we wanted to limit statistical error. Linear regression was used to identify a model that would explain the variance in adaptive functioning after pediatric abdominal transplantation due to type of transplant (ITX vs. LTX) and other identified correlates. All statistical analyses were performed using Statistical Packages for the Social Sciences version 19 (IBM SPSS Inc., v. 19, Chicago). For the purposes of our analyses p -values less than .05 were considered significant.

Results

Baseline Characteristics

All patients had a functioning transplanted organ and were medically stable at the time of study participation. Table 1 provides clinical and demographic characteristics of both study groups. In addition, we note that of the 18 ITX participants, eight received isolated small bowel transplants and ten had small bowel plus liver, pancreas, and duodenum. Of the 18 ITX participants underlying diagnoses leading to transplantation included gastroschisis, volvulus, malrotation, Hirschsprung disease, jejunal atresia, and necrotizing enterocolitis. Of the 22 LTX participants only three had underlying metabolic diseases (Wilson's Disease, Maple Syrup Urine Disease, and Urea Cycle Defect) leading to transplantation, indications for transplant in remaining patients included biliary atresia, hepatoblastoma, rhabdoid tumor, fulminant liver failure, congenital hepatic fibrosis, histiocytosis, and autoimmune hepatitis. LTX participants had mean alanine aminotransferase (ALT) values of 38.6 (Range = 13-98, SD = 22.3) and mean aspartate aminotransferase (AST) values of 43.4 (Range = 21-126, SD = 22.8). Twenty-eight percent of ITX participants ($n = 5$) required TPN at the time of study participation, and 22% of ITX participants ($n = 4$) required replacement fluids. One LTX participant and two ITX participants required gastrostomy tube feeds. Overall, participants were representative of patients requiring ITX and LTX.

As shown in Table 1, ITX participants had statistically significant longer hospitalizations at the time of transplantation than LTX participants. No statistically significant differences were found for other baseline demographic characteristics between ITX and LTX participant groups (Table 1).

Comparison between Itx and Ltx Patients

A preliminary analysis examining differences in adaptive functioning between isolated small bowel transplant participants and participants who had received a small bowel plus liver, pancreas, and duodenum found no association between adaptive functioning and isolated versus multivisceral small bowel transplantation. The ITX group as a whole (GAC mean = 76) showed significantly lower adaptive functioning scores than the LTX group (GAC mean = 94) for overall adaptive functioning ($r = 0.26$; $p = 0.007$). Because MANOVA indicated that the groups differed on the subdomains of adaptive functioning ($F(3, 36) = 2.93$, $p = 0.047$), we proceeded to perform individual t tests comparing the groups on each subdomain, and they differed significantly on each (see Figure 1). ITX patients scored within the borderline range of functioning (composite scores = 70-79) and below the average range

(composite scores = 80-89) of functioning across all adaptive functioning scales, while LTX participants fell within the average range (scaled scores = 90-109) of functioning across all scales (19). Findings are presented in Figure 1.

Comparison of ITX and LTX Groups to Normative Levels of Adaptive Functioning

Adaptive functioning scores are presented in Table 2. The ITX group scored significantly lower than the general population normative mean (standardized at 100) across the conceptual, social, and practical adaptive functioning subdomains as well as the overall GAC composite ($p = 0.003$). The LTX group scored significantly below the normative mean on the practical subdomain of adaptive functioning ($p = 0.004$). However, the LTX group did not differ from normative mean levels on the conceptual or social adaptive functioning subdomains or the overall scale of adaptive functioning (GAC).

Correlates of Adaptive Functioning

Gender was found to be significantly associated with GAC ($r = 0.41$, $p = 0.009$), as well as CON, SO, and PR subdomains of adaptive functioning ($r = 0.32$ - 0.48 , $p = 0.04$). Female recipients performed better than males across all areas of adaptive functioning. Adaptive functioning scores for females were primarily in the average range while males scored in the borderline and below average ranges (Figure 2).

Family caregiver education was also significantly associated with GAC, CON and SO adaptive functioning scores ($r = 0.38$ - 0.51 , $p < 0.05$). Patients with family caregivers with higher educational levels (i.e., more than a high school education) scored within the normal range of adaptive functioning for GAC, CON, and SO, and in the below average range for the PR scale. In contrast, patients with family caregivers with lower educational levels (a high school degree or below) scored in the borderline range for GAC, CON, and PR, scales and below average for the SO adaptive functioning scale. No differences were found in adaptive functioning levels based on age at transplantation, length of hospitalization at the time of transplantation, time since transplantation, patient ethnicity, caregiver ethnicity, or family income.

Each of the subdomains of adaptive functioning (CON, SO, and PR) were highly correlated with GAC, the overall measure of adaptive functioning ($r = 0.90$ - 0.96 , $p < 0.001$). Hence, for the linear regression, we used GAC as the outcome to identify the factors that explained variation in global adaptive functioning. The variables that were significantly correlated with adaptive functioning included transplant type, patient gender, and caregiver educational level (dichotomized into High School Degree and Below and More than a High School Degree [i.e., some college/trade school or above]) were included in the model (Table 3). Type of transplant ($p = .003$) and patient gender ($p = .008$), and caregiver educational level ($p = .03$) significantly contributed to the overall model ($p = .00$) and explained 45% of the variance in overall adaptive functioning.

Discussion

In the current study we hypothesized that ITX patients would have lower adaptive functioning levels than LTX patients and general population normative groups. Because adaptive functioning has not been widely investigated in pediatric solid organ transplantation, we thought that providing insight into this area of functioning would offer a reliable gauge of functionality and reintegration into normal daily life for these patient groups.

Our findings supported our hypothesis. Our data, in combination with previous research showing significant delays in other areas of functioning in ITX patients (i.e., cognitive,

developmental, HRQOL)(8-10, 14), suggests that ITX patients have significant room for improvement in multiple domains of functioning and well-being.

In contrast, findings for LTX patients were quite positive; no significant deficits were noted for this transplant group when compared to published general population norms. Our findings suggest that LTX patients are keeping up with their same aged peers across adaptive functioning domains. Because our assessment focused on functional abilities and not cognitive or educational outcomes, which can be significantly disrupted by prolonged absences from the educational system, our findings present a different perspective on post-transplant outcomes.

Of interest, our findings also suggest that demographic factors play a role in adaptive functioning. For example, female patients achieved higher adaptive functioning scores than males, regardless of type of transplant. The ABAS-II is normed by age, not normed by gender and we are not aware of data to suggest that pediatric female patients have an easier and more favorable medical course following liver or intestine transplantation. In addition, there is no evidence from the broader adaptive functioning literature to suggest gender should impact this area of functioning. Perhaps biological, parental, and/or environmental factors may explain this finding. Certainly gender differences have been previously identified in the pediatric transplant literature in regards to other areas of interest such as risk of lymphoproliferative disease (PTLD) and medical adherence with male pediatric kidney transplant recipients exhibiting greater risk of PTLD and poorer adherence (21, 22).

Another interesting finding was that children with family caregivers who had a higher level of education (i.e., those with educations above a high school degree) achieved higher levels of adaptive functioning. A relationship between parental education and functional outcomes has not been previously reported in pediatric transplantation. However, higher levels of parental education have been previously linked to cognitive functioning, which is a related concept (23). It is possible that parents who have achieved a higher level of education are more aware of the developmental milestones that their children should achieve and hence are better poised to seek remedial services when needed.

At this stage it is difficult to pinpoint a culprit for the differences we observed in adaptive functioning. Further research is needed to examine whether level of adaptive functioning prior to transplant predicts post-transplant functional status regardless of transplant group, or whether the underlying medical condition is the driving factor. Previous research has found associations between pre-transplant medical factors such as growth retardation and IQ (5). It is possible that adaptive functioning is also affected by physical development and/or nutritional deficiencies. Additional research is also needed to determine whether adaptive functioning levels vary by solid organ transplant group. For example, it would be interesting to examine whether heart, lung, and/or renal pediatric transplant recipients evidence deficits in adaptive functioning. Further research is also needed to assess whether the differences we observed in relation to gender and caregiver education are unique to pediatric abdominal transplant patients. In addition, if these relationships can be substantiated beyond the current study, we can use the information to focus efforts on those patients that might be at greater risk of having poor outcomes.

It will also be important to assess how adaptive functioning might impact other areas of functioning such as adherence, HRQOL, self-management of medical care, and transition readiness. A recent article by Modi et al (24) provides a framework for pediatric self-management, and based on this framework adaptive functioning could be viewed as part of the “patient level traits” that can play a significant role in successful self-management. For example, one could argue that a patient who has mastered adaptive functioning skills may be

more adept and ready to assume responsibility for his/her own care.. Further investigation of the overall impact of adaptive functioning could enhance current knowledge and provide an avenue for intervention

Our work has several limitations. The small sample size from a single transplant center makes the generalization of our findings difficult. In addition, the cross-sectional design and the lack of pre-transplant data regarding adaptive functioning limit our ability to draw stronger conclusions as it does not allow for an examination of pre-transplant functioning. Moreover, given that participants were assessed, on average, approximately three years after transplantation, it is possible that we captured ITX recipients (whose treatment and recovery tends to be more complex) at a time when they were still in the process of “catching up” and therefore not yet exhibiting their full potential following transplantation. We did not obtain data on the medical course post-transplantation, return hospitalizations, nor participation in additional support services (e.g. physical therapy) for our study sample—factors that might have impacted the patients' ability to gain greater experience in the “real world” and therefore affect acquisition of adaptive functioning skills. Lastly, findings are based solely on family caregiver reports of adaptive functioning. Caregiver reports in other areas of functioning have been shown to differ from child and even teacher reports and could perhaps be linked to the parent's own adaptive functioning something which we did not examine (7, 18).

Despite these limitations, this study provides a fresh perspective on non-medical outcomes after abdominal transplantation and ITX in particular. This research extends previous work by examining the real life functioning of abdominal transplant patients and provides a new approach to assessing outcomes following surgical intervention.

Conclusions

We believe that a first step in improving outcomes for pediatric transplant populations and ITX recipients in particular is to routinely assess and monitor adaptive functioning. Systematic examination of adaptive functioning prior to and following transplantation would provide opportunities for health care providers to detect problem areas early and discuss with patients and families ways to improve functioning. Most solid organ pediatric transplant patients are monitored closely the first year after transplantation and subsequently at least once yearly. We suggest that monitoring of adaptive functioning skills begin prior to transplant at evaluation to provide baseline measures of functioning and then be re-assessed on an annual basis. Annual prospective assessment of adaptive functioning along with other variables of interest such as HRQOL could focus on the patient's progress following transplantation and pinpoint areas of need. Families would then have an opportunity to learn of available services (e.g., rehabilitation, early intervention, individualized educational plans within schools) to help offset potential deficits. Creating such a structure would allow providers to provide individualized support to patients.

Our findings add to the growing number of studies examining non-medical outcomes in ITX patients and expand current knowledge by providing an understanding of how patients perform in day to day life.

Acknowledgments

Funding sources: Starzl Young Investigator Grant, The Starzl Transplantation Institute (Shellmer, PI), NIH, NINR R01 NR010711-02S2 (DeVito Dabbs, PI), and NIH, NINR K01 NR013189-01 (Shellmer-PI).

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Figure 1. Adaptive Functioning Mean Scores by Transplant Type N = 40

All adaptive scores were significantly different by transplant type, liver transplant patients scored higher ($p < 0.05$).

Figure 2. Adaptive Functioning Mean Scores by Patient Gender N = 40

General Adaptive Composite (GAC), Conceptual (CON) and Practical (PR) adaptive scores were significantly different by gender, females patients scored higher ($p < 0.05$)

Figure 3. Adaptive Functioning Mean Scores by Family Caregiver Educational Level N = 40
 General Adaptive Composite (GAC), Conceptual, and Social adaptive scores were significantly different based on educational level of family caregiver $p < 0.05$. Patients with caregivers with higher educational levels (i.e., those with more than a high school education) scored higher in these areas.

Table 1
Sample and between-group comparison of baseline characteristics

Characteristic	Full Sample (N = 40)	Intestine (N = 18)	Liver (N = 22)	Test Statistic*
Age at Transplant [†] (Mean/SD & Range)	2.9/3.4 (0.6-14.7)	2.46/2.6 (0.6-10.8)	3.28/3.9 (0.7-14.7)	$\chi = 0.53$
Age at Study Participation (Mean/SD & Range)	6.1/4.5 (1.9-18.8)	5.0/3.6 (1.9-14.4)	6.2/4.4 (2.2-17.8)	$t = 1.4$
Time Since Transplant ^{††} (Mean/SD & Range)	2.8/1.7 (0.9-6.0)	2.58/1.8 (0.9-5.7)	3.02/1.6 (1.0-6.0)	$\chi = 0.16$
Length Transplant Stay-Days (Mean/SD & Range)	38.6/19.1 (13-93)	47.9/17.5 (22-93)	30.9/17.1 (13-62)	$t = -3.1$
Primary Diagnosis (N) ^{†††} % Most Common	—	33% Gastroschisis	36% Biliary Atresia	
Gender (N) % Male	48% (19)	44% (18)	50% (11)	$\chi = 0.12$
Patient Ethnicity (N) % Caucasian	73% (29)	61% (11)	82% (18)	$\chi = 2.13$
Caregiver Role (N) % Mothers	93% (37)	94% (17)	91% (20)	$\chi = 0.65$
Caregiver Ethnicity (N) % Caucasian	78% (31)	72% (13)	82% (18)	$\chi = 0.52$
Caregiver Education (N) % > High School	63% (25)	56% (10)	68% (15)	$\chi = 0.67$
Family Income (N) % Above Poverty	57% (21)	53% (9) ^{††††}	60% (12)	$\chi = 0.19$
# Household Members (Mean/SD & Range)	3.75/1.56 (2-8)	3.6/1.59 (2-7)	3.86/1.56 (2-8)	$t = 0.48$

* Only Length of Transplant Stay in days was significantly different between groups with ITX recipients having longer hospitalizations following transplantation than LTX recipients.

[†] Age at Transplant calculated based on categorizing below and above median age = 1.6 years.

^{††} Time Since Transplant calculated based on categorizing sample into <2 years since transplant, 2- 4 years since transplant, and > 4 years since transplant.

^{†††} ITX diagnoses included gastroschisis (33%), volvulus and/or malrotation (22%), Hirschsprung disease (17%), jejunal atresia (11%), and necrotizing enterocolitis (17%). LTX diagnoses included biliary atresia (36%), hepatoblastoma (18%), metabolic disorder (14%), and other medical conditions (32%).

^{††††} N = 17, one refusal to provide income information.

Table 2
Sample and between-group comparison of adaptive functioning scores

ABAS Scales (Mean & SD)	Full Sample (N = 40)	Intestine (N = 18)	Intestine vs. Normative Mean $t(df=17)$	Liver (N = 22)	Liver vs. Normative Mean $t(df=21)$	Intestine vs. Liver $t(df=38)$	Effect Size Intestine vs. Liver
General Adaptive Composite (GAC)	85.72 (20.8)	76.22 (22.3)	-4.5*	93.5 (16.1)	-1.9	2.8**	0.26
Conceptual (CON)	91.00 (20.7)	82.22 (21.7)	-3.9*	98.18 (17.1)	-1.2	2.6**	0.25
Social (SO)	89.50 (19.6)	82.6 (18.7)	-3.5*	95.14 (18.8)	-0.5	2.1**	0.23
Practical (PR)	82.55 (19.2)	73.39 (20.7)	-5.4*	90.05 (14.5)	-3.2*	3.0**	0.27

* Significant differences between transplant group and normative mean ($p = 0.004$) in favor of normative mean.

** Significant group differences ($p = 0.04$) for all adaptive functioning scales in favor of LTX group.

Table 3
Linear regression Type of Transplant, Patient Gender and Caregiver Educational Level
Predicting Overall Adaptive Functioning

	R	R²	F
Model	.67	.45	9.92 [*]
Independent Variables	Standardized Coefficients	p-values	
Type of Transplant (Liver vs. Intestine)	- 0.40	.003	
Patient gender	0.36	.008	
Caregiver educational level (High School vs. >High School)	0.29	.033	

^{*}
 $p = 0.000$