

Transition of pediatric liver transplant recipients to adult care: Patient and parent perspectives

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Abstract: The need to prepare pediatric transplant recipients for the transfer to adult-centered transplant care has received increased attention. This study aimed to determine adolescent and young adult LTR and parent perceptions and attitudes about the transition process. LTR and their parents completed a survey assessing level of prior thought and interest in learning about transferring care, knowledge of the transition process, perceived importance of self-management skills, concerns about moving to the adult clinic, and responsibility for health management tasks. Responses were analyzed by age, gender, and time since transplantation. Participants included 46 LTR (mean age = 16.6 yr; range 12–21), and 31 parents. Recipients and parents reported moderate concern about transition, with leaving pediatric providers being a primary worry. LTR ≥ 16 yr reported greater health care responsibility and increased thought, interest, and knowledge about transition. There were significant differences between parent and LTR perceptions of health care responsibility, indicating that LTR perceive having more independence than what their parents report. Overall, results suggest that adolescent and young adult LTR and their parents perceive the importance of transitional care, but demonstrate poor knowledge of the process. There remains a need for improved transition planning for both adolescents and parents.

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With an increasing number of pediatric transplant recipients reaching young adulthood (1, 2), emphasis has been placed on the need to transfer from pediatric to adult-centered health care. “Transition” is defined as an active process that addresses the medical, psychosocial, and educational/vocational needs of adolescents as they prepare to move from child- to adult-centered health care (3), while “transfer” is the physical change in the location where care is provided (4, 5).

It is recommended that prior to transferring to adult-centered care, the pediatric transplant

recipient should be able to describe the reason for their transplant; be aware of how transplantation impacts on their overall health; demonstrate a sense of responsibility and have the capacity to independently manage their health (6). Moreover, it has been recommended that prior to physically transferring to the adult-centered clinic, pediatric transplant recipients should be able to describe their medication regimen, refill prescriptions independently, recognize how and when to seek medical attention, and be able to communicate with their healthcare providers (6).

In adult care settings, patients are expected to demonstrate self-management skills including the ability to independently discuss medical care with the treatment team, schedule and attend appointments, and adhere to medications and treatment

Abbreviations: CCTC, certified clinical transplant coordinators; CCTN, certified clinical transplant nurses; ER, emergency room; LTR, liver transplant recipient.

recommendations (7). Unfortunately, young adults who underwent liver transplantation in childhood are at risk for delayed autonomy and medication non-adherence (8). This has significant implications for pediatric providers as it is recommended that adolescents acquire self-management skills prior to the transfer to adult-centered health care (6). Yet, to date, there is limited research investigating the transition process among adolescent solid organ transplant recipients (9–14).

Our pediatric liver transplant program has been focused on the assessment of transition readiness skills to develop interventions to improve outcomes following the transfer to adult care (11). As part of our ongoing efforts, we conducted a cross-sectional study to investigate adolescent and young adult LTRs' and their parents' perspectives on the transition process. We assessed the level of prior thought about transferring to an adult transplant program, interest in and knowledge of the transition process, perceived importance of self-management skills, concerns about the transfer, and allocation of responsibility for health management tasks.

Methods

Study population

Adolescent and young adult LTRs (ages 12–21) who were >6 months post-transplantation and their parents, when present, were approached prior to their Pediatric Liver Transplant clinic visit and recruited to complete an anonymous survey of transition perspectives. This assessment is part of our program's ongoing efforts to develop a program to improve the process of transitioning from pediatric to adult-centered care (11). Participants in the current study were an independently recruited sample from the Pediatric Liver Transplant clinic and were not enrolled in a formal transitional care program at the time of survey completion. Fifty eligible recipients presented in the clinic between August 2009 and May 2010. Thirty-one recipients between the ages of 12–17 participated along with their parent/guardian, and 15 recipients ≥ 18 yr of age participated without a parent/guardian for a total of 46 recipients and 31 parents. This represents a recruitment rate of 92%. Patients self-reported their gender, current age, and age at transplantation. The medical center's Institutional Review Board approved all aspects of this study.

Assessment of transition perceptions and attitudes

Our previous work in transition readiness (11) did not specifically assess the attitudes and perceptions of the transition process. To explore these areas, we adapted a questionnaire used in a sickle cell population (15) to assess perspectives related to transition across the following domains: (i) level of prior thought; (ii) level of interest in transition; (iii) knowledge of the transition process; (iv)

perceived importance of tasks related to transitioning to adult care; and (v) concerns about the transfer. Published literature and anecdotal evidence indicate the importance of assessing the allocation of responsibility for health-related tasks (11, 16), thus we included items from other psychometrically sound measures of allocation of responsibility in children with asthma (11, 17), and pediatric LTRs (11) in this current survey (Table 1).

Level of prior thought and interest were graded on a 3-point scale ranging from "not at all" to "a lot." Items assessing knowledge of the process, perceived importance, and concerns about the transfer were rated on a 4-point scale. Knowledge of the transition process was scaled 0–4 reflecting the number of steps known to the participant. Allocation of responsibility for healthcare tasks was scaled 1–5 (parents alone = 1, adolescent/young adults alone = 5). Recipients and parents ranked their preferred method for receiving information about the transition process and the transfer to adult-centered care. Finally, respondents answered two open-ended questions regarding potential concerns and strategies for improving the transition process.

Table 1. Survey items assessing patient and parent perspectives on transitioning from pediatric to adult liver transplant clinic

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1. Prior thought: how much have you thought about moving from the pediatric liver transplant clinic to an adult liver transplant clinic? (0 = not at all, 3 = a lot)
 2. Interest in learning about transition: how interested are you in learning about the transition process now? (0 = not at all, 3 = very interested)
 3. Knowledge of the transition process: what do you know about the transition process (please circle all that apply)
 - a. I know which hospital or doctor I will transfer to
 - b. I know what information needs to be sent to my new doctor
 - c. I know how to make an appointment with my new doctor
 - d. I know if my insurance will be accepted at the new hospital
 4. Concerns about the transfer of care: when thinking about transferring to an adult clinic, what are you most concerned about? (0 = not concerned; 4 = very concerned)
 - a. Leaving behind my previous physician
 - b. Having to meet new caregivers
 - c. Not receiving as good medical care
 - d. Adult caregivers not being as caring
 - e. Being admitted to the adult hospital or adult floor
 - f. Being able to take care of my health by myself
 5. Importance of steps in the transition process: what do you think is important to know and do so that you can manage or take care of your health on your own? (0 = not important, 4 = very important)
 - a. Knowing about your medicines
 - b. Knowing what your labs mean
 - c. Knowing about sex/having children
 - d. Knowing about insurance coverage
 - e. Knowing when to go to the ER
 6. Allocation of responsibility: who is usually responsible for the following? (1 = parent/caregiver alone; 5 = adolescent/young adult alone)
 - a. Calling for your prescription refills
 - b. Remembering to take medications
 - c. Remembering to get labs drawn
 - d. Scheduling medical appointments
 - e. Calling the doctor/nurse with questions
 7. What can we do to help prepare you and your family for the transition from the Pediatric Liver Transplant Clinic to the Adult Liver Transplant Clinic?
 8. What questions or concerns do you have about transitioning from your pediatric team to the adult team?
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Data analysis

Mean scores for the six domains were determined and reported as mean \pm standard deviation. With the exception of the domain measuring parents' perceived importance of transition readiness, data were normally distributed and Pearson's product moment correlation coefficients were calculated to determine associations between measured domains and age, gender and time since transplantation. Spearman's rank correlation coefficients were calculated to examine the associations between parents' perceived importance of transition readiness and adolescent demographic factors. The level of agreement between parent and patient reports were analyzed using paired correlations. Discrepancies between parent and patient reports were examined using paired sample *t*-tests. We further examined the level of agreement between patient and parent perceptions of allocation of responsibility for health-management tasks by examining patterns of agreement between respondents. Two patterns, "over allocation" and "under allocation" were identified. "Over allocation" of responsibility refers to a pattern in which the adolescent endorses that they are responsible for a given task, and the parent reports that the adolescent is not. "Under allocation" refers to a pattern in which the adolescent endorses minimal responsibility, but the parent reports that the adolescent is primarily responsible. All analyses were conducted using PASW Statistics 18 for Windows (Version 18.0; SPSS, Inc., 2009, Chicago, IL, USA).

Results

Participant characteristics

Participants included 46 pediatric LTRs. Mean adolescent age was 16.4 ± 2.5 yr (range 12–21 yr) with an average time since transplant of 10.0 ± 4.9 yr (range 3–19 yr). Mean age at the time of transplantation was 6.18 ± 4.9 yr (range 1–16 yr). Parent reports were available for 31 patients. Mean age for recipients with corresponding parent reports was 15.06 ± 1.6 (range 12–17 yr), compared to the mean age of 19.43 ± 1.03 (range 18–21 yr) for recipients without parent report ($N = 15$). The majority of participants were women (54%).

Prior thought about the transition process

Prior thought about transition ranked low among patients (mean score of 0.87 ± 0.94 ; maximum three points possible). Nineteen patients (42%) reported no prior thought about transition. Parents also reported little prior thought with mean scores of 0.94 ± 1.03 . Fifteen parents (48%) reported that they had not thought about transition at all.

Interest in the transition process

Adolescent/young adult recipients reported moderate levels of interest in learning about the transition process (1.6 ± 0.96 ; maximum three

points possible), with 54% of recipients reporting "some" or "a lot" of interest (scores 2–3). Parents reported similar levels of interest in learning about transition, with mean scores of 1.8 ± 1.06 . Nineteen parents (61%) reported "some" or "a lot" of interest (scores 2–3) in learning about the process.

Knowledge about the transition process

Adolescent/young adult recipient knowledge of the basic steps in the transition process ranked lowest among the six components of the survey (mean = 1.09 ± 0.14 ; maximum four points possible). Approximately one-third of recipients (32.6%) reported they knew what information needed to be transferred to their new provider. Ten (21.7%) reported knowing which hospital/doctor they would be transferring care to, 13 (28.3%) reported they knew how to make an appointment with their new clinic/doctor, and 12 (26.1%) reported knowing whether their insurance would be accepted by their new provider/clinic.

Parent knowledge of the basic steps in the transition process also ranked lowest across the domains assessed (mean score of 1.1 ± 1.4 ; maximum four points possible). Approximately one-third of parents reported having knowledge about what information needed to be sent to the new provider (nine parents, 29% each). Likewise, nine parents (29%) reported knowing if their adolescent's insurance would be accepted at the new hospital/clinic. Eight parents (17%) reported knowing which clinic/provider their adolescent would transfer to, and eight parents (17%) reported knowing how to make an appointment with the adult clinic.

Areas of concern

Adolescent/young adult recipients reported moderate levels of concern about the transfer, with a mean score of 2.0 ± 1.1 (0 = not concerned, 4 = very concerned). The most common area of concern for recipients was that the adult team will not be as caring (2.33 ± 1.46). Recipients also identified leaving pediatric providers behind (2.28 ± 1.39), potential decline in quality of medical care (2.14 ± 1.56), having to meet new caregivers (1.96 ± 1.3), being admitted to the adult hospital facilities (1.9 ± 1.52), and being able to independently manage health care needs (1.91 ± 1.58) as additional areas of concern.

Parents also reported moderate levels of concern about the transfer (2.5 ± 1.6), with leaving pediatric providers behind being the greatest worry (3.19 ± 1.4). Parents also reported

concern about their adolescents' ability to independently manage health care needs (3.03 ± 1.22); having their adolescent admitted to the adult hospital facilities (2.43 ± 1.52); having to meet new providers (2.42 ± 1.70); adult providers not being as caring (2.26 ± 1.61); and potential decline in quality of medical care for their adolescent (2.03 ± 1.64) as additional areas of concern.

Perceived importance of self-management tasks

Adolescent/young adult recipients perceive self-management tasks as an important component to the transition process with mean scores of 3.4 ± 0.74 of a possible four points (0 = not important, 4 = very important). Recipients reported that knowledge about medications (3.8 ± 0.5) is the most important step in transition. They also placed high importance on knowledge about reproductive health (3.16 ± 1.30), meaning of lab values (3.53 ± 0.79), insurance coverage (3.07 ± 1.39), and knowing when to go to the ER for medical attention (3.49 ± 0.9).

Parents also perceive self-management tasks as important in the transition process with mean scores of 3.5 ± 0.79 . Parents reported that knowledge about when to go to the ER (3.70 ± 0.84) is the most important skill. They also placed high importance on knowledge about medications (3.65 ± 0.75), the meaning of labs (3.61 ± 0.76), reproductive health (3.29 ± 1.24) and insurance coverage (3.26 ± 1.15).

Allocation of responsibility for health care tasks

Adolescent/young adult recipient scores on the allocation of responsibility scale ($M = 2.8 \pm 1.2$) indicate that recipients perceive that responsibility for health-related tasks is shared equally

with their parent/guardian (Table 2). Across items for all participants, responsibility for medication taking was most commonly allocated to the patient. Among parents, the allocation of responsibility scale ($M = 1.69 \pm 0.61$) suggests that overall parents perceive that most health-care tasks are the responsibility of the parent/caregiver alone. Similar to the patient self-reports, responsibility for medication taking was most commonly allocated to the adolescent/young adult alone ($M = 3.07 \pm 1.1$).

For the 31 patient-parent dyads, paired sample t-tests revealed significant differences between parent and adolescent reports on this domain ($t = 4.89$; $p = 0.0001$) indicating that adolescents perceive more shared responsibility for health-related tasks ($M = 2.36 \pm 0.97$) than what their parents report ($M = 1.68 \pm 0.61$). An analysis of response patterns across items revealed that with respect to responsibility for obtaining prescription refills and making appointments, patients and parents were in agreement that the parent shouldered most of the responsibility. Adolescents perceived they had more responsibility than their parents reported with respect to medication administration (37.9%), remembering lab draws (48%), and calling the healthcare team with questions (39%).

There were no other significant differences between patient and parent reports on the survey.

Transition perceptions and recipient demographics

The association between transition perceptions and patient age, time since transplantation and gender were examined (Table 3). Recipient age was significantly correlated with knowledge about transition ($r = 0.37$, $p = 0.013$), prior

Table 2. Allocation of responsibility for health-management tasks

Who is usually responsible for the following tasks? (parent alone = 1, A/YA alone = 5)	A/YA report (M ± s.d.)	Parent report (M ± s.d.)	Significance*	Response pattern
Calling for your prescription refills	2.00 ± 1.4	1.65 ± 1.22	$t = 1.9$ $p = 0.062$	19.4% A/YA over allocation 74.2% agree
Remembering to take medications	3.72 ± 1.28	3.07 ± 1.16	$t = 3.78$ $p = 0.001^*$	37.9% A/YA over allocation 58.6% agree
Remembering to get labs drawn	2.38 ± 1.08	1.34 ± 0.67	$t = 5.9$ $p = 0.0001^*$	48.3% A/YA over allocation 51.7% agree
Scheduling medical appointments	1.66 ± 1.11	1.21 ± 0.56	$t = 2.65$ $p = 0.013^*$	13.8% A/YA Over allocation 86.2% agree
Calling the doctor/nurse with questions	2.21 ± 1.40	1.29 ± 0.85	$t = 3.69$ $p = 0.001$	39.3% A/YA Over allocation 60.7% agree

A/YA, adolescent/young adult.

* $p < 0.05$.

Table 3. Transition perceptions of older adolescents/young adults compared to younger adolescents

		N	Mean	s.d.	p-value
Prior thought about transition (0 = no thought, 3 = a lot of thought)	12–15 yr	16	0.37	0.62	0.008*
	16–21 yr	29	1.14	0.99	
Interest in learning about transition/transfer (0 = no interest, 3 = very interested)	12–15 yr	16	1.12	0.96	0.021*
	16–21 yr	30	1.80	0.89	
Knowledge of transition steps (0 = no, yes=1)	12–15 yr	16	0.56	0.73	0.007*
	16–21 yr	30	1.37	0.99	
I know which hospital or doctor I will transfer to	12–15 yr	16	0.13	0.34	0.277
	16–21 yr	30	0.27	0.45	
I know what information needs to be sent to my new doctor	12–15 yr	16	0.19	0.40	0.150
	16–21 yr	30	0.4	0.50	
I know how to make an appointment with my new doctor	12–15 yr	16	0.06	0.25	0.015
	16–21 yr	30	0.40	0.50	
I know if my insurance will be accepted at the new hospital	12–15 yr	16	0.19	0.40	0.419
	16–21 yr	30	0.30	0.47	
Concerns about transferring care (0 = no concerns, 4 = a lot of concern)	12–15 yr	16	2.16	1.14	0.621
	16–21 yr	30	1.99	1.12	
Leaving behind previous physician when transferring to adult clinic	12–15 yr	16	2.38	1.36	0.747
	16–21 yr	30	2.23	1.43	
Having to meet new caregivers when transferring to adult clinic	12–15 yr	16	1.81	1.52	0.603
	16–21 yr	29	2.03	1.27	
Not receiving as good of medical care after transfer to adult clinic	12–15 yr	15	2.40	1.77	0.428
	16–21 yr	29	2.00	1.46	
Adult caregivers not being as caring	12–15 yr	16	2.38	1.54	0.889
	16–21 yr	29	2.31	1.44	
Being admitted to the adult hospital or adult floor after transfer to adult clinic	12–15 yr	16	1.88	1.67	0.912
	16–21 yr	28	1.93	1.46	
Being able to take care of my health by myself after transfer to adult clinic	12–15 yr	16	2.19	1.56	0.389
	16–21 yr	29	1.76	1.60	
Perceived importance of transition skills/tasks (0 = not important; 4 = very important)	12–15 yr	16	3.26	0.82	0.332
	16–21 yr	29	3.49	0.70	
Knowing about your medicines	12–15 yr	16	3.69	0.60	0.224
	16–21 yr	29	3.86	0.35	
Knowing what your labs mean	12–15 yr	16	3.25	1.00	0.072
	16–21 yr	29	3.69	0.60	
Knowing about sex/having children	12–15 yr	16	3.06	1.44	0.725
	16–21 yr	29	3.21	1.24	
Knowing about insurance coverage	12–15 yr	16	2.69	1.49	0.176
	16–21 yr	29	3.28	1.31	
Knowing when to go to the ER	12–15 yr	16	3.63	0.72	0.455
	16–21 yr	29	3.41	0.98	
Allocation of responsibility (1 = parent alone; 5 = adolescent alone)	12–15 yr	16	2.01	1.01	0.001*
	16–21 yr	30	3.21	1.09	
Who is usually responsible for calling for your prescription refills?	12–15 yr	16	1.75	1.18	0.007*
	16–21 yr	30	3.10	1.71	
Who is usually responsible for remembering to take medications?	12–15 yr	15	3.33	1.11	0.021*
	16–21 yr	30	4.23	1.22	
Who is usually responsible for scheduling medical appointments?	12–15 yr	15	1.53	1.13	0.035*
	16–21 yr	28	2.54	1.58	
Who is usually responsible for calling the doctor/nurse with questions?	12–15 yr	15	1.67	1.29	0.002*
	16–21 yr	28	3.11	1.44	
Who is usually responsible for remembering to get labs drawn?	12–15 yr	15	2.07	1.16	0.017*
	16–21 yr	28	3.07	1.30	

*p < 0.05.

thought about the process ($r = 0.63$, $p = 0.0001$), interest in learning about transition ($r = 0.37$, $p = 0.011$), and allocation of responsibility ($r = 0.66$, $p = 0.0001$).

Follow-up univariate analyses between older adolescents/young adults (≥ 16 yr) and younger adolescents (≤ 15 yr) revealed that the older

group had more knowledge about the steps in the transition process ($t = 2.84$; $p = 0.007$), gave more thought to transferring care ($t = 2.79$; $p = 0.008$), had greater interest in learning about the process ($t = 2.39$, $p = 0.02$), and were more independent in health-related tasks ($t = 3.65$; $p = 0.001$). There were no differences

in transition perceptions among recipients based on time since transplantation. There were no significant interactions between age and time since transplantation with respect to transition perceptions and attitudes.

With respect to gender differences, female recipients placed higher importance on medication knowledge during the transition process ($M = 3.92 \pm 0.28$) than males ($M = 3.65 \pm 0.58$; $t = 2.03$, $p = 0.048$). Female recipients also reported more independence in remembering to take medications as compared to males ($M = 4.28 \pm 0.98$ vs. $M = 3.5 \pm 1.4$; $t = 2.16$, $p = 0.036$). There were no gender differences on remaining survey items.

There were no differences in parental reports of transition perceptions based on patient age, time since transplantation, or gender.

Responses to open-ended questions related to suggestions and concerns about the transition process

Based on the two open-ended questions presented, the majority of adolescent/young adults did not offer suggestions for improving the transition process (Table 4). Those who did offer suggestions requested that general information regarding the transfer process, including the timing of transfer and insurance coverage be provided. For example, one patient said, "You could tell us when or what age I'll be, what I have to do and help me understand the changing process more." Recipients also expressed concerns related to the emotional aspects of transferring care, including meeting new providers and remaining in contact with pediatric providers. One patient indicated

Table 4. Responses to open-ended questions eliciting suggestions and concerns related to the transition process

	Number of adolescents/ young adults (%)	Number of parents (%)
Suggestions for improvement		
No additional suggestions given	29 (63)	15 (48)
Provision of general information regarding transfer process (e.g., timing, insurance coverage)	12 (26)	12 (39)
Meeting new providers prior to transfer	5 (11)	3 (13)
Concerns about transition process		
No additional concerns or worries	36 (75)	16 (51)
Meeting new providers	4 (9)	7 (23)
Leaving pediatric providers	2 (4)	7 (23)
Age of transfer	2 (4)	4 (13)
Location of adult clinic	2 (4)	1 (3)
Transferring a teen with developmental delay	–	1 (3)
"The basics" (e.g., timing, location, age)	–	1 (3)

readiness for transfer, stating, "Transfer me." Similarly, among parents, nearly half did not offer any suggestions for the improvement of the transition process. More than a third of parents made suggestions regarding the provision of general information including the timing of the transfer and the location of the new provider. As one parent stated, "I just need to know where and when." The remaining parents made recommendations related to opportunities to meet the new providers prior to the transfer of care. For example, one parent said, "I am hoping we're introduced to everyone and shown around the clinic area."

With respect to concerns about the transition process, the majority of recipients denied any concerns or worries beyond those endorsed on previous survey items (Table 4). Those that did express worry focused on concerns related to meeting new providers, leaving pediatric providers, logistics related to the timing of transfer and location of the new clinic, and insurance coverage. Approximately half of the parents denied worries or concerns about the transition process that were not included on the survey. Parents who endorsed worries were most concerned about leaving pediatric providers and meeting new providers. For example, one parent asked "how close will they monitor her?" while another asked if they could "just stay with her previous caregivers as long as possible."

Preferred method of receiving transition-related information

The most preferred method for receiving transition-related information among recipients and parents was face-to-face contact with someone from the pediatric or adult team. Other mechanisms identified included the internet/website, handouts/brochures, or a group format with other transitioning recipients/families (Table 5).

Table 5. Preferred method for receiving transition-related information

	Number of adolescents/ young adults* (%)	Number of parents* (%)
Face-to-face with someone from the pediatric team	13 (37)	19 (73)
Face-to-face with someone from the adult team	13 (37)	11 (44)
Internet/website	8 (24)	5 (22.7)
Handouts/brochure	6 (18.2)	9 (34.6)
Group format with other transitioning recipients/families	3 (9.7)	2 (9.5)

*Thirty-five adolescent/young adults and 26 parents answered this survey item.

Discussion

Transition planning is a key developmental process among adolescent/young adults with chronic health conditions, and should begin well in advance of the anticipated transfer from pediatric to adult-centered care. To develop patient-oriented transition programs, we sought to determine patients' and their parents' attitudes, concerns and perceptions about transferring care. Given emphasis placed on increasing patient readiness and independent health self-management skills prior to transferring care (6, 11, 18, 19), we also examined perceptions about the allocation of responsibility for health management tasks.

Attitudes and perceptions about transferring to adult care

The results of this current study revealed that adolescent and young adult LTRs perceive the importance of the transition process, but were not aware of the steps involved in preparing to transfer care to a new clinic. Less than half of the recipients and parents reported that they have given thought to transferring care, and just over half of those surveyed reported interest in learning about the transition process. As we hypothesized, older adolescent/young adults reported a greater level of interest and knowledge about transferring care to the adult clinic. This may relate to younger adolescents' difficulty envisioning a future which includes adult-centered services. Delays in abstract thinking observed in adolescence (20) may influence perspectives about the transition process. Indeed, for parents, recipient age was not related to the degree to which they thought about transition and transfer. Likewise, the level of interest or knowledge among the parents did not vary based on the recipient's age, or time since transplantation. It is noted, however, that patients older than 18 yr of age did not have corresponding parental reports. To address this limitation we are focusing efforts on assessing aspects of transition readiness among parents of our older adolescents/young adults.

Adolescent/young adult LTRs and parents in the current investigation reported some degree of concern and worry about the transfer to adult clinic, with concerns about meeting new providers and leaving pediatric providers behind being the most commonly cited concerns. These reports are similar to previous assessments of patient and parent views of transition. For example, among children with special health care needs, barriers and resistance were most commonly related to perceptions of inferior care within the adult-oriented

clinics as well as differences between pediatric and adult-centered care, and insurance coverage (21). In the absence of comparison groups or normative data on measures of transition readiness, we cannot conclusively determine what degree of knowledge or worry about transition is appropriate or expected.

Though patients and parents often report concerns and resistance to transferring care, little is known about how this impacts their adjustment to care once they present in the adult center. Boyle et al. examined patient and parent views of transition from pediatric to adult cystic fibrosis care prior to the transfer of care and again following the transfer of care (22). Prior to leaving pediatrics, patients and parents were concerned about risk of infection, leaving previous physicians, meeting a new care team, and a potential decrease in quality of medical care. Parents were most concerned about their child's ability to care for their health independently. Interestingly, post-transfer of care, there was a significant decrease in all areas of concern, except the risk for infection. The pediatric patients who met the adult team prior to transferring care had significantly less concern across all areas (22). Thus, perceptions of the transition process might be quite different if assessed following the transfer to adult-centered transplant care.

The patients and parents surveyed in this study expressed interest in learning more about the transition process, particularly with respect to the logistics of the transfer to the adult clinic. These comments were made in spite of ongoing, dedicated transition efforts in our clinic (11). Adolescent/young adults reported that they would prefer to receive information from either the pediatric or adult health care team, or via the internet/website. In contrast, the majority of parents stated that they would prefer to receive information directly from the pediatric health care providers. This underscores the importance of collaborating with the adolescent/young adult recipient and parent to determine how to best provide them with information related to the transition process. The fact that parents overwhelmingly wish to have information from the pediatric team may reflect their own attachment to the pediatric care providers. The relationship between the parent and the pediatric team is an important one to consider in transition planning (23–26). Overall, the prospective assessment of predictors of successful transition and transfer to adult-care is warranted to develop and implement effective transition programs.

Responsibility for health self-management

The transition literature focuses on increasing adolescent readiness and independent health self-management skills (6, 11, 18, 19). Our results indicate that responsibility for health management tasks is shared between adolescents and parents. In general, adolescent/young adult recipients are primarily responsible for remembering to take medications, while parents have primarily responsibility for tasks such as scheduling appointments, calling the office with questions and filling prescriptions. Yet, there was discordance between perceptions of responsibility between parents and adolescent/young adult recipients, suggesting that both the recipient and the parent perceive that they are individually more responsible than the other for the health-related task. Adolescents over allocated responsibility for health-related tasks to themselves, suggesting that adolescents perceive they have more responsibility for these tasks than what the parents perceive. The impact of perceptions of responsibility on self-management, including medication adherence, and health outcomes remains an empiric question worthy of further investigation.

As expected, compared to younger adolescents, the older teens and young adults endorsed more independence with healthcare tasks. Indeed, the promotion of independence with health management tasks is an integral component to transition planning. However, encouraging adolescent/young adult recipients to have more independence with their medication regimen may have unintended, negative consequences. Lack of parental monitoring is associated with increased non-adherence among LTRs (11), adolescents diagnosed with type 1 diabetes (27) and HIV (16). Yet, parental over-involvement in health-related tasks has been cited as a barrier in the successful transition and transfer to adult-centered care (28). This presents a potential challenge in clinical care. Therefore, in addition to fostering independence and self-management in adolescents, attention must also be given to helping the parents gradually move from being the primary manager of health-related tasks toward being a supportive supervisor and consultant to their adolescent/young adult (11, 29, 30). This gradual shift should be based on the adolescent's acquisition of self-management skills, rather than one based on chronological age alone.

Limitations

The current study sought to examine the attitudes and perceptions regarding the transition

process among adolescent/young adult LTRs within a single center. To reduce response bias, we collected this information anonymously. Thus, we were unable to link responses with variables measuring medical stability or adherence. It is possible that medical issues, including history of rejection, re-transplantation, and/or medication non-adherence, may also impact perceptions and expectations about transferring to adult-centered care. To further examine the influence of these variables, we are collaborating with our adult liver transplant colleagues to examine the associations between transition readiness skills and perceptions, medical stability, adherence, and health status to refine our transition programming (11).

Another limitation of the current study relates to the lack of parental reports for the majority of respondents over the age of 18 yr, as most of these patients present independently in our clinic, precluding us from obtaining corresponding parental reports. This limits the generalizations we can make about the allocation of responsibility for health-related tasks among these young adults. This also limits the conclusions we can draw about the associations between recipient age and parent perceptions and attitudes about the transition process. In our continued quality improvement efforts, we are specifically targeting parents of adolescents/young adults between the ages of 18–25 yr to assist with program development.

This study was conducted in a single pediatric liver transplant center, which limited the sample size and the ability to generalize these findings to other pediatric transplant centers. For example, our program generally transfers pediatric patients to the adult transplant program within our University health system. This may influence perspectives about the transition process for our recipients and their parents. Specifically, because patients transfer care within the health system, they may not perceive that they are “leaving” as the facility is familiar, and the pediatric providers remain accessible. Likewise, patients may be reassured that there does not need to be a transfer of medical information as their new providers will have access to their complete electronic medical records. Additional studies of transition readiness and expectations among recipients and parents across pediatric transplant centers are warranted to develop consistent, and systematic interventions.

Lastly, this survey was not a comprehensive assessment of transition readiness or perspectives regarding transition to adulthood or adult-centered medical care. For example, aside from

knowledge of reproductive health, we did not include an assessment of knowledge of general adolescent health issues. Indeed, many aspects of transition preparation can be encompassed by developmentally appropriate health care (5). Unfortunately, many adolescents and young adults do not receive recommended preventive counseling and screening on core topics including alcohol, tobacco, and substance use, sexual activity, depression, physical activity, and diet (31). Among pediatric transplant recipients, primary care concerns may be overlooked given the attention to transplant-specific issues, and transplant physicians may not have expertise in areas key to promoting overall health in adolescents and young adults (32). Yet, further work is needed to determine components of transition readiness, including general health promotion, that lead to optimal long-term health outcomes.

Clinical implications and practice

Despite methodological limitations, the present study has important clinical implications. There remains a need for empirically-driven transition programs in pediatric transplantation (6, 33). Transition programs in other pediatric populations, such as rheumatology (34) and cystic fibrosis (35) can serve as examples for pediatric solid organ transplant clinics. Yet, to date, there are few published reports describing transition programs in pediatric transplantation (36, 37). Information obtained through this study is presently being used to develop a transitional care program within our pediatric liver transplant clinic.

The existing transition literature recommends that transplant clinics have a designated health-care transition coordinator to facilitate the transition process (6, 38, 39). The transition coordinator role may be fulfilled by nurse practitioners, CCTN, and CCTC, pediatric psychologists and/or social workers (36, 38, 39). A designated transition coordinator can assist with patient and family education, communication, and working toward meeting transition-related goals and milestones. Transition coordinators can also assist with preparing parents by educating them on strategies to increase the adolescent/young adult recipient's responsibility for healthcare tasks in a developmentally appropriate manner.

Our program has attempted to integrate recommendations from the literature as well as preliminary research from our center to develop a standard for transitional care. Within our pediatric liver transplant clinic, the transition process is facilitated primarily by the CCTN (VS)

and pediatric psychologist (EMF). The CCTN serves as the primary transitional care coordinator and takes the lead in planning for the transfer of care by facilitating communication with the adult care providers, assisting with the development of medical summaries, and providing support and education to patients and their parents. The pediatric psychologist's efforts are primarily directed at the transition of health-care responsibility from parent to patient, and the acquisition of self-management skills. We take a team approach to transitional care, which involves consultation with the transplant clinic hepatologist, surgeons, dietician, nurses, and social workers in developing individual transition plans. For example, the physicians determine appropriateness of transfer by considering medical stability of the patient while the transplant team social worker facilitates issues related to logistics of transferring care, including transportation needs, and insurance coverage.

Based on results from this and previous work (11), as well as recommendations from the literature (6), we have incorporated standard assessment of transition readiness skills and allocation of responsibility for health-related tasks for all patients 11 yr and older, and their parent/guardian. Assessment results are used to tailor intervention to the individual patient and family. Most often, clinic-based interventions target shifting responsibility for health-related tasks from parents to adolescents, appropriate parental monitoring and supervision, medication adherence, regimen knowledge, symptom recognition, and communication with healthcare providers. Given the high levels of concern among parents with respect to the transition process, we include adolescents/young adults and their parents, when present, in setting self-management and transition-related goals. This typically involves assisting parents in delegating responsibility for health-related tasks to their adolescent in a gradual and developmentally appropriate manner.

Additional aspects of our transition program development goals include developing mentoring programs to allow adolescents/young adults and their parents to connect with individuals who have successfully transferred from pediatric to adult-centered care (9), as well as "meet the team" events to allow an opportunity for patients and parents to meet and interact with the adult care team prior to the transfer of care.

Conclusions

In summary, transition is a continuous process and should incorporate routine assessment and

interventions to promote self-management skills as pediatric patients prepare to move from child-centered care to adult-centered care. Adolescent/young adults and parents perceive the importance of transition planning, and reported interest in learning about the transition process. Deficits appear to be related to knowledge about the logistics related to the transfer of care, as well as perceived independence with self-management skills. Transition programs should have designated team members to lead efforts in coordinating the transition process in order to provide timely education, communication, and collaboration among patients, families, pediatric transplant teams, and adult transplant teams. Researchers and clinicians should continue to focus on identifying predictors of successful health care transitions to develop and implement transition programs to ensure that adolescents, young adults, and their parents are receiving the necessary resources and support necessary for independent self-management and the transfer to adult-centered care.

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