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Growing Up: Not an Easy Transition—Perspectives of Patients and Parents regarding Transfer from a Pediatric Liver Transplant Center to Adult Care

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1. Introduction

With improved outcomes of postliver transplantation, a large number of pediatric liver transplant recipients are reaching adulthood [1]. The posttransplantation five-year graft/survival rate for pediatric liver transplant recipients currently ranges from 67% to 82% [2, 3]. Therefore, the need to prepare pediatric liver transplant recipients for the transfer to adult-centered transplant care has increasingly become an important area of investigation.

According to the American Society for Adolescent Medicine, the transfer process should include a planned movement of adolescents with chronic medical conditions that addresses their medical as well as psychological needs as they shift from pediatric to adult-oriented healthcare systems [4, 5]. There are a number of barriers that a young adult transplant patient faces, with the most important one being the development of a sense of autonomy and independence [6]. The suggested level of autonomy before transferring to adult care includes the patient's adequate demonstration of knowledge of the disease and transplant as well as a thorough understanding of the impact on his or her overall health [2]. In addition, the patient should be able to complete his or her medication regimen, refill medications independently, make and attend appointments, and recognize how and when to seek medical attention [7]. Furthermore, avoiding risky behaviors such as poor diet, unsafe sexual activity, drug and alcohol abuse, and bad hygiene is essential to the success of a patient [8]. A fully independent, self-governing, and autonomous adult patient at the time of transfer is a common goal of pediatric healthcare providers.

Patients who have undergone liver transplantation in their childhood are more likely to display a delayed sense of
independence and are at risk for medication nonadherence
[2]. A recent study revealed that nonadherence ranged from
17% to 53% [9, 10]. Nonadherence can have severe conse-
quences including poor graft survival rates, increased need
for clinical visits, and rejection episodes [7].

As pediatric patients approach the age for the transfer to
adult care, it is increasingly important for healthcare profes-
sionals to effectively equip their adolescent patients with the
knowledge and support to cope with the transfer. This study
is aimed at assessing the patient/parent perspectives of the
transfer process 1–3 years after their transfer to adult care in
order to develop a more effective transition program. In addi-
tion, the survey asked for suggestions for the improvement
of facilities and the changes pediatric caregivers can make
to facilitate the above. This information can help caregivers
and healthcare providers shape their services to better target
patient needs and ultimately encourage independence and
autonomy amongst adult patients.

2. Materials and Methods

2.1. Patients and Methods. Transplant patients, who have
previously been transferred from pediatric care at Children's
Healthcare of Atlanta to adult care at various different facil-
ities, completed a survey designed to assess the issues they
faced during the transition and their suggestions regarding
the transfer process. This study was conducted prior to
the establishment of a formal transition program at Chil-
dren's Healthcare of Atlanta and was aimed at patients who
had undergone a “simple transfer” process from Children's
Healthcare of Atlanta to adult services in the past 3 years.
The study was performed as a quality improvement service
and data were analyzed retrospectively. It was reviewed and
approved for an exemption by the Institutional Review Board
of Emory University. All patients who were between 1 and 3
years after transfer to the adult facility were contacted for a
survey over the phone. If the patients were unavailable, the
survey was conducted with the parents, only if the parents
were involved with the care of the child and accompanied
them to clinic visits at the Children's hospital. Patients who
had been diagnosed with chronic liver disease but had not
undergone a transplant were included in this study because
they were followed by the same medical team hence facing
a similar “transfer” process. Additionally, the challenges
faced during the transfer to adult care were very similar to
the challenges faced by transplant patients [11]. A nurse
navigator who was familiar with the patients and had been
closely involved with their care while in the pediatric facility
conducted the survey.

2.2. Survey. The survey was designed to assess the effective-
ness of each patient's transfer via certain key markers of health
outcome such as (i) ER visits; (ii) time until the patient's first
labs are drawn in the adult care; (iii) liver function tests;
(iv) number of rejection episodes; and (v) the evaluation
for a new transplant. In addition, the survey asked for any
suggestions these patients or parents may have had regarding
the transition process such as (vi) additional education on the
part of healthcare professionals, (vii) parent involvement and
management of their children, and (viii) changes that could
be implemented to evolve the current transition process.

Phone survey respondents were primarily given ques-
tions with multiple choice answers assessing the basics of
their transfer process including, for example, how much
medication they were given at the time of transfer as well
as the number of emergency room episodes that occurred
in the interim period. The respondent additionally had the
option of submitting an alternate, “free-form” answer that
was not listed for each question. There were three questions
which assessed the patient's transfer experience and any
suggestions that respondents may have regarding the transfer
process (Tables 1–3). The suggestion part of the survey gave
several different options for each question so that each person
surveyed was able to choose the answer(s) that best reflected
their perspective on the transition. The patient or parent
surveyed additionally had the option of inputting their own
suggestion if it was not listed.

The survey included questions about the patient's med-
ication access and availability for refill because they are
important indications of the effectiveness of the transfer.
Adherence to immunosuppressant medications is a critical
factor in the transfer process as poor medication adherence
is associated with an increased risk of poor long-term health
outcomes, including increased graft loss and rejection [10, 12].

3. Results

3.1. Patient Demographics. All patients were within the range
of 18–23 years (median age: 20). Majority of them were
Caucasians (57%), with 33% being African American and
10% being Hispanic. Females were predominant in this group
(70%). Of the 31 survey respondents, 39% were patients,
and the remaining 61% were parents of patients. There
were 4 patients (or parents) who did not have a working
phone number and were unable to be contacted. Hence, our
response rate was 31/35 (88.5%).

3.2. Patient Diagnosis and Transplant Information. The pri-
mary diagnosis for liver transplant and chronic liver disease
was reported by the patients and parents and is detailed in
Figure I(a). The largest percentage of surveyed patients had
autoimmune hepatitis with the second largest group being
biliary atresia. The majority of the patients surveyed had
received a liver transplant (67%) with two (6%) receiving
both a liver and kidney transplant. The rest of the patients
had chronic liver disease of varying etiology (27%) and had
not been evaluated for a transplant at the time of transfer
(Figure I(b)).

3.3. Time Lag between the Last Visit with the Children's
Hospital and First Visit with the Adult Facility. The time
eled between the last visit at the Children's hospital and
the first visit at the adult facility is an important predictor
of nonadherence with clinic visits and the possibility of
being lost to follow-up [10, 12]. At the time of the survey, it
was our center's practice to recommend follow-up with the
adult practice within 3 months of transfer from Children's
Healthcare of Atlanta. A small number of young adults (17%)
Table 1: What can be done to make the transition to adult care easier?

<table>
<thead>
<tr>
<th>Suggestion</th>
<th>Parents</th>
<th>Patients</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Educate about their disease</td>
<td>14</td>
<td>4</td>
<td>18</td>
</tr>
<tr>
<td>Educate about insurance</td>
<td>13</td>
<td>4</td>
<td>17</td>
</tr>
<tr>
<td>Educate about college with transplant</td>
<td>13</td>
<td>3</td>
<td>16</td>
</tr>
<tr>
<td>Educate about drugs/alcohol/sex</td>
<td>13</td>
<td>4</td>
<td>17</td>
</tr>
<tr>
<td>Educate about medication</td>
<td>14</td>
<td>4</td>
<td>18</td>
</tr>
<tr>
<td>Educate about nutrition after transplant</td>
<td>12</td>
<td>3</td>
<td>15</td>
</tr>
<tr>
<td>Educate about total body care (hygiene, yearly exams, etc.)</td>
<td>13</td>
<td>7</td>
<td>20</td>
</tr>
<tr>
<td>Educate about support system</td>
<td>13</td>
<td>4</td>
<td>17</td>
</tr>
<tr>
<td>Make the kids listen</td>
<td>1</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Give specific instructions about new place</td>
<td>0</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Meet other transitioned teens</td>
<td>1</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Teen clinic</td>
<td>1</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Nothing</td>
<td>4</td>
<td>3</td>
<td>7</td>
</tr>
</tbody>
</table>

Table 2: How can parents be prepared and help prepare patients for the transition?

<table>
<thead>
<tr>
<th>Suggestion</th>
<th>Parents</th>
<th>Patients</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parent support Groups</td>
<td>16</td>
<td>3</td>
<td>19</td>
</tr>
<tr>
<td>Parents setting boundaries with children with chronic illness</td>
<td>2</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>Parents/caregivers letting kids grow and do self-care</td>
<td>8</td>
<td>5</td>
<td>13</td>
</tr>
<tr>
<td>Parents should not be involved in care</td>
<td>0</td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td>Review how adult care center works</td>
<td>1</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Parents need to be more involved</td>
<td>2</td>
<td>2</td>
<td>4</td>
</tr>
</tbody>
</table>

Table 3: What should be changed to help with transition of care?

<table>
<thead>
<tr>
<th>Suggestion</th>
<th>Parents</th>
<th>Patients</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Earlier education about facility</td>
<td>10</td>
<td>4</td>
<td>14</td>
</tr>
<tr>
<td>Let kids learn and not remind them so often</td>
<td>4</td>
<td>6</td>
<td>10</td>
</tr>
<tr>
<td>Educate about insurance and what to do if you lose it</td>
<td>1</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Educate about how to deal with pregnancy</td>
<td>1</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Nothing</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>

were seen within one month of leaving the Children's hospital facilities. The majority of patients (47%) were seen at the new facility 2–6 months after their last scheduled appointment with the Children's hospital. Furthermore, about 20% of the young adults were not seen until between 6 and 12 months and 13% were not seen until after a year (Figure 2(a)). This was regardless of the adult facility they were transferred to.

We also assessed the time until the new facility was first contacted to make/confirm an initial appointment after transfer because this is reflective of the efficiency of the transfer, with 26% of patients contacting between 2 and 4 weeks, 13% between 2 and 3 months, 22% of patients between 4 and 6 months, and 25% not contacting until after six months. Some patients (13%) did not contact the adult facility to make an appointment.

3.4. Medication Supply at the Time of Transfer. Through our survey, we wanted to gain insight regarding the patients’ adherence to their prescribed medication regimen. In order to accomplish this, we asked direct questions relating to the amount of medication they had at the time of transfer (Figure 3(a)). Interestingly, most patients (68%) had more than 4 months’ supply of medication at the time of transfer, with 6.4% having just under 4 months’ worth and 9.7% having 2-3 months’ supply of medications (Figure 3(a)). This, however, could possibly be a reflection of the pediatric transplant center’s prescribing practices rather than the patients themselves. Prior to seeing the adult caregivers, 68% of patients did not run out of medications. Some of the surveyed patients (19%) did run out of medication. The remaining 13% were unable to answer questions or were unsure of the amount of medication in their possession at the time of transfer (Figure 3(b)).

A patient’s ability to refill their medication as needed is highly indicative of their autonomy. A majority of the patients (81%) reported that they did not need to refill their medication (Figure 3(c)). The majority of the patients did not run out of their medications (Figure 3(d)). Of the patients who did run out of medication, 67% were able to refill their prescription at some location (50% at the Children’s hospital pharmacy, 25% at ER, and 25% other) within 1–7 days. The remaining 33%, representing 6% of the total patients, were not taking their medication.

3.5. First Contact with the Adult Facility. Having assessed the medication supply of the patients at the time of transfer and the time lag before they were seen at the adult facility, we wanted to evaluate the health status during the transition prior to first contact with the adult care providers. Interestingly, we found that 23% of the patients had a visit to the emergency room prior to seeing the adult care providers in the outpatient setting. Out of these, the majority (5/7; 71%) had 1-2 visits and 2/7 (29%) had 3-5 visits to the emergency room (Figure 4(a)). After leaving the Children's hospital, almost half of the patients (47%) did not get labs done until more than 3 months after transfer. Only a quarter of the patients reported labs being done within 1–4 weeks after transfer. The remaining 28% had their labs done between 2 and 3 months (Figure 4(b)).

3.6. Status of Liver Function. While the timing of getting labs drawn was an important indicator of patient compliance or responsibility, it was also critical to assess the actual status of the disease or disease severity. At the time of the survey,
more than one-third of the patients (39%) reported having abnormal liver function tests (Figure 5(a)), with 10% being diagnosed with acute rejection soon after being transferred from the pediatric facility. Most however had normal liver function and had not had a rejection episode (Figures 5(a) and 5(b)). About 19% of the patients were being evaluated for a new transplant. None of the patients with chronic liver disease were undergoing a transplant evaluation at the time of transfer (Figure 5(c)).

### 3.7 Patient and Parent Suggestions for Transition Clinics

At the time of this survey, the liver transplant service did...
not have a formal transition process. In order to establish
an effective transition clinic, we wanted to assess patient
needs and perspectives. We asked the patients who had
transferred from the Children's Hospital to the adult services
what they felt were the important components to make the
transition to adult services smoother and of higher utility.
More than half of the survey respondents were the parents.
The difference between the suggestions and perceptions
of patients and parents was striking. Education about the
disease, transition process, insurance, and medications were
all deemed extremely important by the parents but by only
about quarter of the patients. About half of the patients did
feel they needed to be educated about their disease with
emphasis on the total body care (Table 1).
When asked about how parents and patients could be
better prepared to ensure a smooth transition, a majority of
the patients and the parents agreed on one thing: patients
needed to be "let go" and empowered in order to assume self-
care and independence. 25% of the patients felt that parents
needed to be "less" involved in the care of the patients and
very few of the parents and patients (10% and 16%, resp.)
felt that there needed to be more involvement of the parents.
About 50% of the patients felt that they should receive fewer
reminders about their healthcare regimen and that the parent
should trust them to be capable of self-care (Table 2).
Most parents felt that a parent support group would help
them in learning how to empower their children and let them
assume independent care, which can be incredibly difficult
after several years of taking care of a child with a chronic
illness (Table 2). The parents also reported that they would
have preferred earlier education about the adult facilities,
rather than information at the time of transfer.

It was interesting to note that one-third of the
patients/parents felt that repeated reminders should not
be given and were actually counterproductive to a good
outcome. Of concern was the fact that there was a lack of
interest reported from both the patients and parents with
regard to education about insurance and what to do in the
face of loss of insurance (Table 3).

4. Discussion
Liver transplantation is now an accepted treatment for sev-
eral end stage liver diseases. The survival rate of patients
with pediatric transplantation is at an all-time high as the
posttransplantation five-year graft/survival rate for pediatric
liver transplant recipients currently ranges from 67% to 82%
[2, 3, 13, 14]. However, it is also clear by UNOS data that graft
loss increases dramatically from ages of 16–30 years [15–17].
Since most pediatric and adult centers operate in their own
freestanding hospitals, the process of transfer from pediatric
to adult services has been deemed as one of the primary
reasons for this graft loss [9, 10, 17]. Adolescents have not
been prepared for or are unable to maneuver the demands of
the adult healthcare system and hence find themselves lost in
the maze leading to increased noncompliance, nonadherence,
and eventual graft loss [18].
Our study set out to evaluate patient and parent per-
spectives of the transfer process in order to determine the
key factors, which were critical to the establishment of a
successful transition program. We wanted to assess this
process from the patients' and parents' viewpoint, instead
of exclusively basing it on what was deemed important by
caregivers. This study provided us with some interesting

![Figure 2: Time lag between the last visit with the Children's hospital and first visit with the adult facility. (a) Time between the last visit at the Children's hospital and the first visit with the adult care facility. (b) Time until first contact with Emory University to make/confirm a clinic appointment.](image)
Most care providers worldwide attempt to provide enough medication refills to the patients prior to transfer [19]. In this study, we found that there was still a significant number who ran out of their medications and did not attempt to refill their prescription, which can be detrimental to the overall health outcomes. Similarly, since graft loss is high during this stressful time of transition, it was best to conduct more frequent labs, with the first labs and clinic visit being within one month of transfer, at the adult center [1]. Most of our patients did not make the first contact with the adult services until after 3 months of transfer, with a quarter of patients waiting more than 6–12 months, during which they had emergency room visits. This resulted in a “limbo period” in which the patients were technically “not owned” by any service and were not under the care of any provider, as is evident by the rejection episodes and graft dysfunction. This is a critical period and underlines the importance of instituting measures to bridge this gap.

**Figure 3**: Medication supply at the time of transfer. (a) Amount of medication obtained at the time of transfer. (b) Patients who ran out of medications prior to being seen by the adult care facility. (c) Number of patients who refilled their medication prior to being seen by the adult care facility. (d) Time lag between refills.
In addition, clinic appointments for the adult care facility are best scheduled prior to transfer since a percentage of patients are likely to show up in the emergency room in critical condition. However, this does not always solve the problem, as it has been reported that patients do not show up for appointments even if they are scheduled beforehand [6, 9, 10, 20]. In order to alleviate some of the anxiety associated with the first visit, we have instituted joint clinics with the adult care providers with the goal that this will alleviate anxiety associated with the first visit and hence encourage the patient to be compliant and work towards building a relationship new care team.

Changes in medication prescription and scheduling of appointments and joint clinics with the adult care providers are structural issues that can be resolved by the medical providers. More difficult are the conceptual and ideological issues associated with pediatric medical teams, who have not only provided care to the children from sometimes as early as infancy and neonatal period, but have also bonded with them to the extent of being part of the “enabling team” along with their parents. The parents and patients both felt that there should be earlier teaching towards independent care and ownership. Neither the parents nor the providers followed the philosophy of “letting go.” One example of that was the repeated phone calls and reminders made by the pediatric care team for missed clinic and laboratory appointments.

Based on these recommendations, we changed the structure of a visit within our transition clinics to have a greater focus on self-empowerment and education about adult facilities. Instead of an entire care team seeing the patients during clinic, after the patient is 18 years old, the physician and the nurse saw patients exclusively, as occurs in adult clinics, without the parents being present. They were given the opportunity to voice their concerns and ask for any other care provider who they felt was necessary for them to see, such as the nutritionist, pharmacist, psychologist, and social worker. Updated “the parents” separately. For patients 14–16 years of age, the parents were asked to step out of the room for personal questions only. Between the ages of 16 and 18 years, the physician first saw the patients individually, and the appointment was concluded with the parent in the room. All patients were expected to make their own future appointments and given training to call in their own refills. The transition program was renamed Adolescent Program, “I own It” (AP101), which emphasized self-care, empowerment, education, and independence.

We also instituted parent support groups, which included sessions on insurance, college courses, and jobs with benefits. This education was also provided to the patients, since it was concerning to see that very few felt education about their insurance was an important issue in the United States, where healthcare is not government provided [21].

As with any retrospective data collection, there were some limitations to this study. Markers of health outcomes (LFTs, rejection episodes, new transplant evaluation, etc.) as well as indicators of adherence, such as medication supply at the time of transfer and the first visit at the adult facility, were based on the responses of patients or parents. This method of data collection is subject to such limitations as lapses in memory or recall bias, which may have resulted in relatively inaccurate responses. While ideally a patient’s health outcomes could be drawn from medical records, in this case it was extremely difficult to obtain access to those records considering that this study included patients who had been transferred to a number of different healthcare facilities both within and outside of the state of Georgia. As a result, we chose to rely
on the responses given by the patient or parent. Furthermore, there could be a difference in the accuracy of information provided by a parent or a patient. However, we felt that this gave us a different perspective which also added valuable information.

The study group we chose was limited by its size of 31 survey subjects composed of 12 patients and 18 parents of patients, none of which were patient/parent dyads. We chose a cut-off of 1–3 years since the time of transfer in order to limit the amount of recall bias in the responses. Furthermore, we limited the study to liver transplant recipients and chronic liver disease patients since the same care team managed both, and the education provided to each patient was similar. We could have increased our sample size by introducing kidney and heart transplant patients but chose not to do so to avoid introduction of individual provider and care team practice styles, which may have skewed the data. Additionally, since the outcomes and longevity of the grafts between the solid organs are different [22], we wanted to ensure a uniform study group. Hence, though the study group is small, its strength is that it is homogenous in terms of the disease process and the medical team practices and hence provides valuable

![Liver function test (LFT) results](image1)

(a) Liver function test (LFT) results

![Number of rejection episodes](image2)

(b) Number of rejection episodes

![Number of patients evaluated for a new transplant](image3)

(c) Number of patients evaluated for a new transplant

**Figure 5:** Status of liver function. (a) Status of the liver function tests. (b) Number of rejection episodes. (c) Number of patients evaluated for a new transplant.
information, which was utilized in the organization of the transition services.

5. Conclusion

This study provided us with valuable input from the patients who had experienced both the pediatric and adult care in the recent past and were in a unique position to provide genuine and workable solutions towards the establishment of a successful transition process. Implementation of these simple strategies has a global application for children with chronic disease transitioning to the adult services and will go a long way in ensuring safety and good outcomes for young adults.

Conflict of Interests

The authors declare that there is no conflict of interests regarding the publication of this paper.

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References