Clinician perceptions of transition of patients with pediatric-onset chronic disease to adult medical care: Comparing a pediatric facility integrated within an adult institution with a free-standing pediatric hospital

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Abstract

We sought to determine if the delivery of transitioning education/assessment and barriers to transfer to adult centered care differed across two types of pediatric institutions. Design: A web-based, multiple-choice, cross-sectional survey was distributed to 195 outpatient clinicians at a pediatric facility integrated within an adult institution. Results were then compared to previously reported data from a free-standing children’s hospital. Results: Overall, the response rate was 56% (109/195) with 81/109 (74%) respondents providing outpatient care to patients >11 years of age. The majority of clinicians (67%) stated that their patients receive transitioning education/assessment, usually informally (90%), between the age of 11 and 16 years (44%). Older age (74%) and the presence of adult co-morbidities (70%) were the most common triggers to transfer.

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The patient’s (95%) and parent’s (91%) emotional attachment to the pediatric provider was perceived to be the most common barriers to transfer. In comparison with previous data from a free-standing children’s hospital, there were no significant differences in the report of delivery of transitioning education/assessment, triggers to transfer and barriers to care and desire for departmental and hospital support for transitioning programs.

Conclusion: Delivery of transitioning education/assessment for patients with pediatric onset chronic disease is often inconsistent and informal regardless of the type of pediatric institution. Age and adult co-morbidities appear to be the most common triggers to transfer while emotional attachment remains the most common perceived barrier to transfer. Clinicians overwhelmingly favor hospital based resources for the development of transitioning programs and resources to streamline the transfer process.

**Introduction**

Medical and surgical innovation for the treatment of complex pediatric diseases has increased survival into adulthood for diverse patient populations, including those with cystic fibrosis, congenital heart disease, diabetes, sickle cell disease, inflammatory bowel disease, childhood cancers and organ transplantation (1-7). As these patients enter adolescence and young adulthood they will require skills to become independent adults capable of managing their own healthcare needs. Despite this, transitioning programs have not become universally accepted, with the majority of such existing programs being condition-specific and informal (5, 7-11).

In the United States many adults with pediatric origin chronic disease continue to receive care at pediatric facilities (12). The lack of a standard approach to transitioning education/assessment may inhibit the successful transfer of these patients to an adult-oriented health care system.

In a recent study, we found that at one of the largest free-standing children’s hospitals, patients are not routinely provided with this transition related education and assessment. Attachment of the patient and parent to the pediatric provider and facility emerged as significant barriers to adult-oriented care (13).

The objective of this study was to determine if the delivery of transitioning education/assessment and barriers to transfer to adult-centered care differ at a pediatric facility that is integrated within an adult institution compared to a free-standing children’s hospital. We hypothesized that many of the barriers to adult-centered care in free-standing children’s hospitals would not exist in a pediatric facility intimately aligned with an adult healthcare institution.

**Methods**

We conducted a cross-sectional web-based survey of health care clinicians at a pediatric facility that is integrated within an adult institution (IPF) and a free-standing children’s hospital (FSCH), as previously reported (13). In the IPF, we identified 195 clinicians, including physicians, nurses and social workers who were likely to provide care to patients over the age of 11 years in outpatient settings. Clinicians not actively seeing patients over the
age of 11 in outpatient settings were excluded from further questioning. The survey was approved by the local institutional review board and administered in July of 2010.

Survey design

The survey tool has been previously described in detail (13). It was developed over a 12-month time frame, through a working group of 10 clinicians and researchers with an interest in health care transition. The working group included physician, nursing, physician assistant and social worker representation. The clinicians had a wide range of outpatient clinical expertise including cardiology, pulmonology, gastroenterology, adolescent medicine, general surgery and hematology/oncology.

Questions were developed based on a review of the health care transition literature and guided by a survey methodologist. The final survey included a total of 25 questions within the following six categories: 1) inclusion criteria; 2) transitioning education/assessment; 3) transfer to an adult-oriented health care system; 4) demographics; 5) age appropriate care; and 6) resources.

Transitioning was defined as the “tools required by patients to become independent adults capable of managing and self-directing their healthcare” and encompassed disease knowledge, understanding of medication use and side effects, symptoms requiring urgent care, congenital/genetic anomalies in offspring, impact of high risk behaviors and disease impact on education and insurability. Transfer was defined as the “movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-oriented health-care systems” (14).

Statistical analysis

Descriptive analyses of provider demographics were summarized using means and standard deviations for continuous variables and proportions for categorical variables. Demographic differences across the four provider sub groups were analyzed using Pearson’s chi-square or Fisher’s Exact test for categorical variables and one way analysis of variance (ANOVA) for continuous variables.

Barriers to and impetus for the transitioning of patients into adult care were ranked and differences in clinician beliefs were assessed using chi square analysis. In order to evaluate differences between clinicians that care for adult patients, we dichotomized age into over 25 years versus all other age groups. Chi square analysis was used to assess differences in clinician characteristics between these two groups. Survey results were reported in aggregate so that clinician confidentiality was ensured.

Comparisons between responses at the two institutions (i.e., FSCH versus IPF) were performed using independent sample t-tests for continuous variables and Fisher’s Exact tests for categorical variables. All analyses were performed using SAS software version 9.2 (SAS, Cary, NC), and a 2-sided p value <0.05 was considered to indicated statistical significance.
Results

A total of 195 outpatient clinicians (135 physicians, 52 nurses, 8 social workers) at an IPF were invited to participate in the web-based survey. The response rate was 56% (109/195). Overall, 81/109 (74%) provided outpatient care to patients >11 years of age and were, therefore, eligible for analysis: 55 physicians, 19 nurses and 7 social workers. Clinician characteristics are presented in table 1.

Table 1. Clinician Characteristics

<table>
<thead>
<tr>
<th>Clinician Role</th>
<th>Overall</th>
<th>MD</th>
<th>RN</th>
<th>SW</th>
<th>p value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total Responses</td>
<td>N= 81</td>
<td>N=55</td>
<td>N=19</td>
<td>N=7</td>
<td></td>
</tr>
<tr>
<td>Number of Years in Practice</td>
<td>0.535</td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Mean ± SD</td>
<td>19.0 + 11.6</td>
<td>17.7 + 12.0</td>
<td>13.9 + 10.6</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Number of Years at Facility</td>
<td>0.021</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean ± SD</td>
<td>15.5 + 10.4</td>
<td>14.2 + 11.9</td>
<td>3.7 + 3.3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Female</td>
<td>60.5%</td>
<td>44.3%</td>
<td>94.1%</td>
<td>100.0%</td>
<td></td>
</tr>
<tr>
<td>Hispanic Ethnicity</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>0.258</td>
</tr>
<tr>
<td>Yes</td>
<td>3.9%</td>
<td>3.8%</td>
<td>0.0%</td>
<td>14.3%</td>
<td></td>
</tr>
<tr>
<td>Race</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>94.5%</td>
<td>91.8%</td>
<td>100.0%</td>
<td>100.0%</td>
<td>0.355</td>
</tr>
<tr>
<td>Black</td>
<td>0.0%</td>
<td>0.0%</td>
<td>0.0%</td>
<td>0.0%</td>
<td></td>
</tr>
<tr>
<td>Asian</td>
<td>16.7%</td>
<td>23.3%</td>
<td>0.0%</td>
<td>0.0%</td>
<td>0.187</td>
</tr>
<tr>
<td>Age Group Currently Caring For</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Providing care for patients ≥25 years</td>
<td>23.0%</td>
<td>26.4%</td>
<td>12.5%</td>
<td>20.0%</td>
<td>0.504</td>
</tr>
<tr>
<td>Department</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Medicine</td>
<td>54.3%</td>
<td>69.1%</td>
<td>21.1%</td>
<td>28.6%</td>
<td></td>
</tr>
<tr>
<td>Cardiology</td>
<td>21.0%</td>
<td>14.6%</td>
<td>47.4%</td>
<td>0.0%</td>
<td></td>
</tr>
<tr>
<td>Surgery</td>
<td>9.9%</td>
<td>9.1%</td>
<td>15.8%</td>
<td>0.0%</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>6.2%</td>
<td>0.0%</td>
<td>0.0%</td>
<td>71.4%</td>
<td></td>
</tr>
<tr>
<td>Not Specified</td>
<td>8.6%</td>
<td>7.3%</td>
<td>15.8%</td>
<td>0.0%</td>
<td></td>
</tr>
</tbody>
</table>

Transitioning education/assessment

The majority of clinicians (67%) at the IPF stated their patients receive transitioning education/assessment (65% physicians, 74% nurses and 57% social workers, p= 0.690).

A substantial number of clinicians (33%) stated their patients did not receive this type of assessment/education or were unsure if they were receiving it. The overwhelming majority of clinicians (90%) indicated that transitioning education/assessment was usually provided informally between the ages of 11 and 16 years (44%).
Reasons for transfer to an adult-oriented health care system

The most common patient characteristics cited by clinicians as reasons to transfer a patient to an adult-oriented health care system included age (74%), presence of adult co-morbidities (70%), and graduation from college (69%). Marriage (64%) and pregnancy (47%) were also common reasons to prompt transfer.

The use of alcohol or illicit drugs (19%) and graduation from high school (14%) were less likely to prompt transfer. Physicians at the IPF were more likely to consider adult co-morbidities (81%) as a reason to transfer compared to nurses and social workers (p=0.017). Nurses (61%) were more likely to indicate pregnancy as a reason for transfer compared to physicians and social workers (p=0.038).

Barriers to transfer to an adult oriented health care system

Clinicians at the IPF tended to agree on barriers to transfer. They listed the patient’s (95%) and parent’s (91%) emotional attachment to the pediatric provider as the most common barriers to transfer. Patient’s emotional/cognitive delay (87%) was a common perceived barrier as well as the pediatric provider’s attachment to the family (81%).

The lack of qualified adult clinicians in specialty (73%), patient non-compliance with transfer (68%), and unstable medical conditions (57%) were also identified as barriers by more than half the clinicians. Only 17% indicated that insurance issues were a barrier to adult-oriented health care.

Adult-oriented healthcare within a pediatric setting

Most of the clinicians at the IPF felt that they (97%) and their department (94%) could provide age appropriate care to patients under the age of 18, with decreasing percentages as patient age increased. Only 43% thought that they could provide age appropriate care to patients >25 years and only 33% felt their department could provide age appropriate care for patients >25 years. However, 26% of clinicians stated they could provide age-appropriate care for patients >40 years and 25% for patients >50 years, while only 19% thought their department could provide age appropriate care for patients >40 years of age.

Resources for transitioning and transfer

Clinicians at the IPF were in agreement regarding the need for departmental and hospital resources for the development of transitioning programs and resources to streamline the transfer process (p= 0.682, p=0.340, p=0.569 respectively). Many clinicians (68%) felt there should be a specific program within their department to provide transitioning education/assessment and 83% of clinicians thought their institution should provide this resource. The majority of clinicians (88%) felt that their institution should provide resources to streamline the transfer process.
Free-standing pediatric hospital versus pediatric institution integrated within an adult hospital

Survey results from the FSCH have been previously reported (13). The response rate was higher at the FSCH compared to the IPF (368/479, 77% versus 109/195, 56%, p=<0.001). Demographics of the respondents were similar, except that physicians constituted a greater proportion of respondents at the IPF (68% versus 37%, p= <0.001) and more women participated in the survey at the FSCH (75.2% versus 60.5%, p=0.011). Comparisons of clinician characteristics are summarized in Table 2.

A similar proportion of clinicians at the FSCH (72%) and IPF (67%) stated that their patients receive transitioning education/assessment (p= 0.281). Both centers overwhelmingly indicated that these services were provided informally (92% versus 90%, p=0.910) and both centers indicated that this assessment/education typically begins between the ages of 11 and 16 years (48% versus 44%, p=0.509). A comparison of the two institutions with regard to the most common patient characteristics that prompted transfer of a patient to an adult-oriented health care system are presented in Table 3. There were no significant differences. The top five most important characteristics were common to both.

<table>
<thead>
<tr>
<th>Table 2. Comparison of Clinician Characteristics</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pediatric facility integrated within an adult institution</td>
</tr>
<tr>
<td>Total Responses</td>
</tr>
<tr>
<td>Response Rate</td>
</tr>
<tr>
<td>Provide outpatient care for patients ≥11 years</td>
</tr>
<tr>
<td>Clinical Role</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>Number of Years in Practice</td>
</tr>
<tr>
<td>Number of Years at Institution</td>
</tr>
<tr>
<td>Gender</td>
</tr>
<tr>
<td>Hispanic Ethnicity</td>
</tr>
<tr>
<td>Race</td>
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<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>Age Group Currently Caring For</td>
</tr>
</tbody>
</table>
Transition

Table 3. Characteristics requiring transfer to an adult oriented healthcare system

<table>
<thead>
<tr>
<th>Requirements for Transfer</th>
<th>Pediatric facility integrated within an adult institution</th>
<th>Free-standing children’s hospital</th>
<th>p value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>74.4%</td>
<td>78.7%</td>
<td>0.412</td>
</tr>
<tr>
<td>Adult co-morbidities</td>
<td>69.7%</td>
<td>78.5%</td>
<td>0.105</td>
</tr>
<tr>
<td>College graduation</td>
<td>68.8%</td>
<td>67.1%</td>
<td>0.773</td>
</tr>
<tr>
<td>Marriage</td>
<td>63.6%</td>
<td>56.3%</td>
<td>0.241</td>
</tr>
<tr>
<td>Pregnancy</td>
<td>46.8%</td>
<td>58.0%</td>
<td>0.075</td>
</tr>
<tr>
<td>Alcohol/Illicit drug use</td>
<td>18.7%</td>
<td>29.2%</td>
<td>0.067</td>
</tr>
<tr>
<td>High school graduation</td>
<td>14.5%</td>
<td>15.9%</td>
<td>0.755</td>
</tr>
</tbody>
</table>

Clinicians at both institutions tended to agree regarding the most common barriers to adult-oriented health care, as presented in Table 4. More than 90% of clinicians at both institutions identified the patient’s and parent’s emotional attachment to the pediatric provider as a significant barrier to adult-oriented health care (p=0.987 and p=0.140 respectively). Clinicians at the FSCH were more likely to state that insurance issues were a barrier to adult-oriented health care than clinicians at the IPF (p=0.001). The regular provision of care of patients over the age of 25 years was not uncommon in both institutions (33% versus 23% in the FSCH and IPF, respectively, p=0.112). Clinicians at both institutions often continued to provide care for patients over the age of 40 years (23% versus 26%, p=0.583) and a similar percentage of clinicians continued to care for patients over the age of 50 years (21% versus 25%, p=0.574). The overwhelming majority of clinicians at both institutions favored departmental or hospital based programs to improve the delivery of transitioning education/assessment, with no significant differences between the two institutions (p=0.527 and p=0.127, respectively). Clinicians at the FSCH felt more strongly about the need for resources to streamline the transfer process (95% versus 88%, p=0.038).

Discussion

The care of adolescent and adult survivors with pediatric onset chronic disease poses a significant challenge for the healthcare system. Successful transition to independent self-care and transfer to an adult-oriented health care system are dependent on numerous factors that may be impacted by the type of health care setting. In this study, we evaluated clinicians’ perceptions for transition education/assessment at an IPF, assessed perceived characteristics that prompt transfer to an adult-oriented health care system, and explored perceived barriers of transfer. Comparisons were made to our previously conducted survey in a FSCH.

Our key findings include: 1) while the majority of clinicians at both institutions perceive that their patients receive transitioning education/assessment, it is most often reported as informal; 2) age and adult co-morbidities are the most frequently quoted triggers for transfer in both types of institutions; 3) the overwhelming majority of clinicians perceive the patients’ and parents’ attachment to the provider to be the most common barriers to transfer; 4) clinicians at both institutions favor institutional support for the development of transitioning programs, but clinicians at the FSCH were more likely to indicate the additional need for resources to streamline the transfer process.
Transitioning programs have been recommended by numerous organizations (15-17). Reasons for the lack of institutional commitment to such programs is unclear but is likely multi-factorial, including costs, lack of reimbursement for such programs and a lack of evidence demonstrating improved outcomes as a result of such programs. The timing of transfer is likely determined by a clinician’s perceived ability to provide age appropriate care to a particular patient, as well as patient and family readiness for transfer and departmental and institutional policies regarding adult care (18). Of interest, the majority of clinicians at both institutions felt that they and their department could provide age appropriate care to patients 25 years of age and younger, with support for this statement decreasing beyond 25 years of age. There is some evidence that transfer is more successful at older ages (19) after the late adolescent years therefore it may be reasonable for pediatric providers to be involved in their care until a patient’s early 20s. Patients, parents and clinicians appear more likely to support care transfer to an adult-oriented health care system at an older age cut-off.

The presence of adult co-morbidities was a commonly perceived trigger to transfer by clinicians at both institutions. The ability to manage adult co-morbidities may place the pediatric trained clinician beyond their level of comfort in care provision. If transfer is prompted by the onset of an adult co-morbidity, that transfer may then occur during clinical instability. The relationship between patient and family and the new adult provider may be strained in this acute setting, which may put adult providers and institutions at risk for litigation (20). Formal processes of transitioning education/assessment, partnered care between pediatric and adult clinicians, and elective transfer (4) when clinically stable should mitigate these risks.

Many clinicians believe that the patients and parents’ emotional attachment to the provider and institution leads to resistance to transfer. This has been previously observed by Clarizia and colleges in Canada, although at a lower prevalence, 69% versus 95%, likely secondary to cultural and healthcare system differences (21). This perception may be biased by the clinician’s own admission that their own attachment to patient and family is a barrier to transfer (22). Departments and institutions, therefore, may choose to address the emotional needs not only of their patients and families but also of their affected clinicians. Implementation of transitioning programs may help provide the necessary skills and confidence for patients and parents to overcome this emotional hurdle while educational programs for clinicians may provide support and guidance on successful transition and termination of direct care relationships.

The lack of qualified adult clinicians in specialty was considered a common barrier to adult centered care for patients with pediatric onset chronic disease by a large number of clinicians. A collaborative effort towards patient care, training of providers to care for this adult population, establishment of quality outcomes and reporting of such may contribute to overcoming of this barrier. Caring for the needs of the growing number of patients with pediatric onset chronic disease likely to reach adulthood over the next decade is likely to exhaust resources in pediatric facilities (7). Collaborative efforts between pediatric and adult facilities so as to accomplish these stated goals are to be encouraged.

The practitioners in this study stated the overwhelming desire for departmental and hospital-based programs to improve the delivery of transitioning education/assessment, although more clinicians favor hospital-based rather than departmental based programs. This sentiment is in accord with the success that has been seen at the institutional level in other forms of transition programming, where such has been shown to reduce hospital admissions.
and increase patients’ ability to reach self-identified personal goals in the geriatric population (23). Adolescent and young adults with complex childhood onset disease face many of the same challenges, as do elder patients with chronic conditions. Healthcare institutions may therefore benefit from hospital-wide programs that encourage self-care management for all persons, including adolescents and young adults, with chronic disease. Such institutional based transition programs have the potential to result in improved patient satisfaction and decreased overall health care costs and resources. Establishment of quality measures regarding transition outcomes will assist in the validation of reimbursement strategies for these services.

Clinicians at the FSCH were more likely to indicate the need for resources to streamline the transfer process. If patients stay within an IPF, rather than shift to an entirely new healthcare system, the facility, hospital culture and medical record system may not change. Regardless of whether patients transfer within an institution to a new set of providers or to an entirely new system, care transfers places patients at increased risk for medical errors, duplicate testing, inappropriate testing and loss to care (24). Healthcare institutions are encouraged to develop strategies to mitigate this risk; such may be assisted by ensuring that the patient who is transferring care has the necessary transitioning skills to improve the direction and implementation of their health care.

Our study has several limitations. The characteristics and geographic location of the two institutions within this study may not allow for generalizability to other institutions. In addition, results reflect self-reporting. Social desirability response bias may have overestimated the actual percentage of clinicians who perform transitioning education/assessment and the lack of open-ended survey questions may result in leading question bias.

Contrary to our hypothesis, few differences in the perception regarding delivery of transitioning education/assessment, triggers to adult-oriented care, or barriers to transition were identified between clinicians in IPF and FSCH. We recognize the complexities of testing perceptions, which may not reflect actual practice. Given this, further study examining actual practices and exploration of the impact of care organization and clinician demographics on transition and transfer practices is indicated. An assessment of the patients’ and their parents’ perceptions in comparison to the clinicians’ perception/practice is also indicated.

In conclusion, as individuals with pediatric onset chronic disease mature to adult age, the preparation of these individuals to manage and participate in their health care appears to have components that lie with parents, patients and providers.

Regardless of the type of pediatric institution, the delivery of transitioning education/assessment often appears as inconsistent and informal. Older age and new onset adult co-morbidities are stated as the most common triggers to transfer, and may lead to risk to patient-caregiver relationship formation at an extremely vulnerable phase of development. In the clinician’s perspective, parental and patient emotional attachment to the provider and institution is a major barrier to transfer, in addition to their own attachment to the patient and family.

Transitioning programs should, therefore, address patient and family-related and clinician-related barriers. Clinicians overwhelmingly favor hospital-based resources for the development of transitioning programs and resources to streamline the transfer to adult oriented health care.
Acknowledgments

The authors would like to acknowledge the efforts of Handan Titiz, Ed. M. and Meera Midha. Research funded by the Dunlevie Foundation. There are no relationships with industry.

References


