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Chapter 5

Current practices for the transition and transfer of patients with a wide spectrum of pediatric-onset chronic diseases: Results of a clinician survey at a free-standing pediatric hospital

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Abstract

Health care transition is a process in which adolescents with chronic disease develop disease self-management skills allowing for successful transfer to adult-centered health systems. In this chapter we wanted to determine current clinician practices and perceived barriers to transition of care at a large academic free-standing children's hospital. A web-based, multiple choice, cross-sectional survey was randomly distributed to 479 outpatient clinicians. Results: Overall, the response rate was 77% (368/479), with 329 (89%) providing outpatient care to patients >11 years of age. Most respondents stated that transitioning skills assessment/education was provided to their patients (72%), usually informally (92%) between the ages of 11-16 years (48%). Clinicians felt that transfer to an adult oriented health care system should be based on age (79%), adult co-morbidities (79%) and graduation from college (67%). The parents' emotional attachment to the institution and the parents' /patients' emotional attachment to the provider were felt to be the most common barrier to transfer (96% and 95% respectively). Most respondents

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agreed that the institution should provide resources for the development of transitioning programs (90%) and to streamline the transfer process (95%). Conclusion: The majority of clinicians at our free-standing pediatric hospital report providing transitioning skills assessment/education, but most state that they do so informally without a structured program.

Providers identify parents' and patients' emotional attachment to both the provider and institution as a major barrier. Clinicians desire departmental and institutional resources for transitioning skills education and assessment, as well as streamlining the transfer of patients to an adult oriented healthcare system.

Introduction

The impetus for health care transition programs for adolescents with chronic illnesses is a tribute to the advancement of medical and surgical technology. Today, a large number of patients with such varied conditions as congenital heart disease, cystic fibrosis, inflammatory bowel disease, diabetes, childhood cancers, organ transplantation, and sickle cell disease are expected to live well into adulthood (1-6).

Health care transition has been defined as "the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-oriented health-care systems" (7). It has since been further defined to mean preparation of patient for self-care to distinguish from transfer, as there are disease states for which an adult healthcare system is not available (8). Recognizing the importance of empowering patients to become independent adults capable of disease self-management, many pediatric institutions have implemented disease-specific transition assessment and education programs, with or without the ability to transfer to an adult oriented healthcare system (9,10).

However, the most programs are informal and function independently in a specific disease domain, resulting in duplication of effort and resource utilization (11). In addition, many adolescents with special health care needs report not receiving appropriate transition services (12).

Finally, the transition literature has focused predominantly on disease or condition-specific issues and has not addressed attitudes and perceptions of clinicians from different medical specialties. We assembled a multi-disciplinary team to critically examine the spectrum of transition and transfer practices across a broad spectrum of disorders, beginning with provider perception.

Our study

We conducted a cross-sectional web-based survey of health care clinicians at Children's Hospital Boston (CHB), a 396-bed tertiary care pediatric hospital. We identified 1,068 clinicians, including physicians (MD), nurses (RN), advanced practice nurses, physician assistants (PA) and social workers (SW) who were likely to provide care to patients over the age of 11 years in the outpatient setting.

A randomized sample of physicians, nurse practitioners, and nurses from this initial group were selected to receive the survey. All social workers and physician assistants were sent the survey, given that they are fewer in number. Selection criteria were verified at the point of survey entry. Clinicians not actively seeing patients over the age of 11 in the outpatient setting were excluded from further questioning. The survey was approved by our local institutional review board and administered in December of 2009.

The survey tool 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, primary care, general surgery and hematology/oncology.

Questions were developed based on a review of the health care transition literature, including a recent national survey (11) and guided by a survey methodologist. The final survey included a total of 25 questions within the following six categories: 1) inclusion criteria; 2) self-management (transitioning) skills assessment and education; 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 planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-oriented healthcare systems (12).”

Section 1 on self-management (transitioning) skills assessment and education included questions to determine if the clinician and or another member of the team provided these skills to their patients and the age of initiation. Clinicians were also asked how skills assessment and education were provided, with the following response categories: informally, by questionnaire or checklist, or other with a description. For section 3 clinicians were asked two questions regarding characteristics that prompt transfer to an adult-oriented healthcare system and barriers to transfer. For each characteristic prompting transfer and for each barrier listed, the clinicians had the opportunity to indicate: “yes, no, don’t know”.

For section 5, three questions were listed. Clinicians were asked if they felt that they were able to provide age-appropriate care to patients 11-14, 15-16, 17-18, 19-21, 22-24, 25-30, 31-40, 41-50 and >50 years of age and were given the option to indicated “yes, no or don’t know” to each age group.

They were also asked if they felt their department and institution was able to provide age-appropriate care. Section 6 included three questions that sought to assess whether the clinician believed that their department should have and support a specific program to provide education and assessment of self-management (transitioning) skills and if the institution should provide resources to streamline the transfer of patients to an adult oriented healthcare system.

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 subgroups (physicians, nurses/nurse

practitioners, social workers and physician assistants) were analyzed using Pearson's chi-square or Fisher's Exact test for categorical variables and 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 in their practice and those that do not, age group of patients cared for was dichotomized as predominantly under 25 years of age versus all 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. All analyses were performed using SAS software version 9.2 (SAS, Cary, NC), and a 2-sided p value <0.05 was considered to indicate statistical significance.

What we found

A total of 479 outpatient clinicians (200 physicians, 200 nurses/nurse practitioners, 53 social workers and 26 physician assistants) were invited to participate in the web-based survey via email.

The overall response rate was 76.8% (368/479), subdivided as follows: physicians 72% (143/200), nurses/nurse practitioners 79% (157/200), social workers 75% (40/53) and physician assistants 100% (26/26). Overall, 329 (89.4%) provided outpatient care to patients >11 years of age and were, therefore, retained for analysis: 123 physicians, 141 nurses/nurse practitioners, 40 social workers and 25 physician assistants. Clinician characteristics are summarized in table 1.

Transitioning (self-management) skills education/assessment

The majority of clinicians (73%) stated that their patients receive transitioning (self management) skills assessment/education (71% MDs, 75% RN/NPs, 80% PAs, 60% social workers $p=0.486$). Only 7% of respondents indicated that these services were provided by one individual clinician. A majority of respondents (58%) indicated that such skills assessment is conducted by the clinician and other members of their team. A substantial number of clinicians (27%) stated that their patients did not receive this type of assessment/education or were unsure if their patients were receiving it. A large majority of the respondents (92%) indicated that transitioning (self-management) skills assessment and education were usually provided in an informal fashion. A small number (12%) stated that they utilize a combination of informal assessment/education in addition to a questionnaire, checklist or survey.

Table 1. Clinician Characteristics

	Overall	Clinician Role				p value
		MD	PA	RN/NP	SW	
Total Responses	N= 329	N=123	N=25	N=141	N=40	
Number of Years in Practice						<0.001
Mean \pm SD	17.5 \pm 11.7	15.7 \pm 11.0	7.0 \pm 8.3	22.1 \pm 11.3	15.0 \pm 10.6	
Number of Years at Institution						<0.001
Mean \pm SD	12.5 \pm 10.2	13.1 \pm 9.9	3.6 \pm 3.8	15.1 \pm 10.6	8.1 \pm 8.2	
Gender						<0.001
Female	75%	43%	100%	97%	95%	
Hispanic						0.716
Yes	5%	5%	0%	6%	5%	
Race						
White	96%	94%	100%	96%	100%	0.268
Black	2%	2%	0%	3%	0%	0.888
Asian	15%	27%	13%	3%	14%	0.004
Age Group of Patient Population						0.002
Providing care for patients 25 years and older	33%	23%	50%	42%	23%	
Department						<0.001
Pediatric-Medical Specialty	31%	76%	16%	30%	37%	
Surgical Specialty	22%	15%	48%	15%	18%	
Not Specified / Unknown	36%	9%	36%	55%	55%	

The vast majority of providers stated that they begin their transitioning assessment starting in mid adolescence. Only 13% reported starting such assessment before age 11 years, while 48% reported initiation between ages 11-16, 24% between 17 and 21 years of age, and only 4% after 21 years of age. Relatively few (11%) did not know at what age this assessment began. Further analysis revealed that female clinicians responded that they began transitioning (self-management) assessment and education at a younger age than their male colleagues (17 versus 19 years, $p=0.042$). Clinicians that reported not providing this assessment and education had also been in practice for fewer years (14 ± 11.2 years versus 19 ± 11.6 years, $p=0.001$). Clinician ethnicity and race were not associated with clinician response regarding the provision or timing of transitioning (self-management) skills assessment and education.

Reasons for and barriers to transfer to an adult oriented health care system

The most common patient characteristics endorsed by clinicians as reasons to transfer a patient to an adult-oriented healthcare system are presented in table 2 and include age (79%), presence of adult co-morbidities (78%) and graduation from college (67%). Pregnancy (58%) and marriage (56%) were also common characteristics to prompt transfer. The use of alcohol

or illicit drugs (29%) and graduation from high school (16%) were less likely to prompt transfer. Different criteria were, however, observed among the clinician categories. Physicians were less likely to consider graduation from college (55%, $p=0.002$) or high school (5%, $p<0.001$) as reasons to transfer compared with other clinicians. Social workers were less likely to cite marriage (36%, $p=0.013$) as a reason to transfer and nurses were more likely to include alcohol/illicit drug use (39%, $p=0.036$). Clinicians tended to agree on barriers to transfer. They listed the parent's emotional attachment to the institution (96%), patient and parent emotional attachment to the provider (each 95%), and patient's emotional attachment to the institution (93%) as common barriers to transfer. Patient's emotional/cognitive delay (86%) was also sensed as a common barrier. The provider's attachment to the family was noted as a barrier by 79% of clinicians surveyed.

Table 2. Patient characteristics that should require transfer to an adult oriented healthcare system as reported by clinicians

Perceived Requirement for Transfer	Overall Rank	Combined	MD	PA	RN/NP	SW	p value
Age	1	79%	73%	74%	82%	89%	0.106
Adult co-morbidities	1	79%	80%	74%	80%	71%	0.477
College graduation	2	67%	55%	74%	74%	78%	0.002
Pregnancy	3	58%	53%	70%	64%	49%	0.382
Marriage	4	56%	53%	61%	65%	36%	0.013
Alcohol/Illicit drug use	5	29%	21%	35%	39%	20%	0.036
High school graduation	6	16%	5%	48%	19%	20%	<0.001

Table 3. Reported barriers to transfer that witnessed or experienced by clinicians

Barriers to Transfer	Overall Rank	Combined	MD	PA	RN/NP	SW	p value
Parent's Emotional attachment to institution	1	96%	98%	91%	96%	92%	0.328
Parent's Emotional attachment to Pediatric Provider	2	95%	95%	100%	95%	92%	0.617
Patient's Emotional attachment to Pediatric Provider	2	95%	94%	96%	95%	97%	0.894
Patient's Emotional attachment to institution	3	93%	94%	86%	93%	92%	0.626
Patient's Emotional/Cognitive Delay	4	86%	86%	86%	85%	84%	0.986
Provider's attachment to family/patient	5	79%	78%	57%	78%	92%	0.018
Patient's Non-Compliance with Transfer	6	78%	72%	71%	83%	84%	0.144
Patient's Unstable Medical Condition	7	68%	68%	77%	61%	87%	0.015
Lack of qualified adult providers in specialty	8	66%	75%	29%	63%	67%	0.006
Insurance Issues	9	37%	32%	24%	42%	42%	0.209

However, social workers were more likely to identify provider's attachment to family/patient and patient's unstable medical condition as barriers to transfer compared to other clinicians ($p < 0.05$). Additional reported barriers and their overall ranking by clinical role can be found in table 3.

Adult-oriented healthcare within a pediatric setting

Most of the clinicians (98%) reported that they could provide age-appropriate care to patients under the age of 18 but these percentages decreased as the age of the patient increased.

Table 4. Clinician Perceptions of Institutional Role in Transition Differs Based on Patient Population Served

	Age Group of Current Patients		p value
	Includes Patients < 25 yrs old only	Includes Patients ≥ 25 yrs old	
	N=193	N=93	
Clinician Type			0.002
MD	46%	28%	
PA	56%	12%	
RN	34%	52%	
SW	14%	9%	
Have patients undergone transitioning skills education/assessment			0.749
Yes	72%	74%	
Feels individually able to provide adequate care to established patients			<0.001
18 years and under <i>only</i>	10%	2%	
24 years and under	61%	33%	
<i>All ages</i> , including 25 years and older	29%	65%	
Feels department is able to provide adequate care to established patients			<0.001
18 years and under <i>only</i>	6%	3%	
24 years and under	56%	30%	
<i>All ages</i> , including 25 years and older	38%	66%	
Feels institution should provide adequate care to established patients			<0.001
18 years and under <i>only</i>	3%	2%	
24 years and under	69%	41%	
<i>All ages</i> , including 25 years and older	28%	57%	

Only 43% reported that they could provide age-appropriate care to patients >25 years. However, 23% still responded that they could provide age-appropriate care for patients >40 years and 21% >50 years. Among the subset of physicians who reported no adult medicine

training (n=98), 20% reported that they could provide age-appropriate care to patients >30 years and 12% reported they could provide this care to patients >40 years. Table 4 provides a comparison of clinicians who stated they predominately take care of patients <25 years and those who reported also caring for patients over age 25 years. No significant difference was noted in the percent who reported providing transitioning skills assessment/education to their patients (72% versus 74%, p=NS). There was, however, a significant difference in the clinician's belief that their department (38% versus 66%, p<0.001) and their institution (28% versus 56%, p<0.001) could provide age-appropriate care for patients over the age of 25 years.

Resources for transition and transfer

Many clinicians (64%) felt there should be a specific program within their department to provide education and assessment of transitioning (self-management) skills, although a greater proportion of nurses/nurse practitioners (80%) and social workers (80%) supported this claim than physicians (58%) and physician assistants (29%), p=0.002. The majority of clinicians (90%) thought their institution should provide resources for the development of such programs, again with greater support among nurses/nurse practitioners (95%) and social workers (97%) than physician assistants (83%) and physicians (83%), p=0.004. The overwhelming majority of clinicians (95%), were in agreement (p=0.276) that there should be a process to streamline the transfer of patients to an adult-oriented healthcare system.

Discussion

Transitioning adolescents to become independent adults capable of caring for themselves is a societal goal, and is life-altering for all involved. The patient with pediatric onset chronic disease offers a far greater challenge during this tumultuous time. In this study, we evaluated, across multiple pediatric subspecialties and disciplines, the current practices for transition (self-management) assessment and education at a large freestanding pediatric hospital. We also assessed characteristics that prompt transfer from a pediatric to adult-oriented healthcare system and perceived barriers of transfer. The key findings of our study were: 1) The majority of clinicians felt that their patients receive transitioning (self-management) assessment and education usually during early to mid-adolescence, but this is often done informally; 2) Age and adult co-morbidities are perceived as the most frequent trigger for transfer from a pediatric to and adult-centered health care system; 3) Patients' and parents' attachment to the provider and the institution are the most common barriers to transfer; 4) Across the board, clinicians favor institutional support for the development of transitioning programs and resources to streamline the transfer process.

Based on this survey, it appears that transitioning (self-management) assessment and education occurs frequently within our institution, usually during mid to late adolescence, and is usually provided by multiple types of clinicians. However, most of this assessment and education is seemingly provided informally without structured transition programs. This appears to mirror the literature in multiple disease-specific studies (11,14-16). Despite the fact

that numerous organizations, including the American Academy of Pediatrics and the Society for Adolescent Medicine have called for the development of formal transition programs for more than 15 years (12,17-18) and that there appears to be universal agreement among clinicians about the need for formal transition services these programs remain primitive and largely unimplemented. Cost, increased resource utilization, lack of institutional commitment and the lack of literature demonstrating improvements in morbidity, long-term survival and quality of life with structured transition programs are likely hampering the development of such programs. Many models have been suggested for disease-specific transitioning programs. These included the use of a transition coordinator/liaison, joint visits with a pediatric and adult providers when circumstances allow (2,10,19) and/or less hospital-based, cross-specialty program. The majority of these programs have not quantified measurable outcomes to persuade administrative decision making. Given this, it is imperative that transition programs develop in such a way as to critically assess their impact on institutions, clinicians, patients and their families can be demonstrated.

Surveyed clinicians were in agreement that age and adult co-morbidities were the most likely patient characteristics to prompt transfer to an adult-oriented healthcare system, which is similar to what has been previously reported (13,20,21). There appears to be recognition and understanding that with increasing age patients are much more likely to develop additional medical issues, including atherosclerosis, systemic hypertension, hyperlipidemia, diabetes, thyroid disease, psychiatric illness, and cancers, that are not routinely addressed in a pediatric setting. The ability to manage these additional issues is itself challenging, but is intensified in the patient with pediatric-onset chronic disease by the presence of underlying organ dysfunction. Surprisingly, only a little more than half of the clinicians surveyed thought pregnancy would prompt transfer to an adult-oriented healthcare system. The ability to accurately assess maternal and fetal risk of pregnancy as well as the genetic impact of chronic disease on offspring is often beyond the scope of the pediatric trained clinician. Similarly, the use of illicit drug use and alcohol was not a common reason for triggering transfer in this survey, but informal discussions with receiving adult providers suggest that non-compliant patients who participate in high risk behaviors are often transferred to an adult-oriented healthcare system regardless of readiness. Although we were unable to elicit reasons why clinicians chose particular characteristics as prompts for transfer, we are currently conducting focus groups in order to gain a clearer understanding of this and other barriers cited by our respondents. Further studies including adult providers are required to better understand their views on triggers for transfer.

The literature is ripe with studies describing barriers to transfer (22). In our study we found that the parents' and patients' emotional attachment to the institution and pediatric provider was the most commonly perceived barrier. The basis of these perceptions is unclear, but lack of institutional policy regarding transfer, lack of communication regarding transfer, fear of compromised care with transfer, and the lack of resources including adult health care providers with proper education and sub-specialization may all contribute. In addition, clinicians may be expressing a fear that the parents of their patients may be excluded from the care process. Our findings may be consistent with a study of transition for patients with cystic fibrosis in which clinicians' perceptions of patient concerns regarding transfer exceeded that reported by the patients themselves (21). A provider's attachment to the patient and family is also a potential barrier to transfer (23) and this was recognized by most clinicians in our survey as well. Of interest, in our survey, social workers felt that provider attachment was a

common reason for transfer not to take place. Further exploration with clinicians, patients and families are required to better understand the complexities that contribute to these perceived barriers. Despite the fact there may be a lack of qualified adult providers nationally (22), this was not seen as a barrier to transfer by a fair number of clinicians at our institution. This may be impacted by the presence of numerous adult subspecialty practices within our institution and a close collaborative relationship with an adjacent adult institution.

Our current study provides a unique perspective across a wide diversity of clinicians likely to be involved in the transition (self-management) assessment and education process at our institution, including multiple pediatric subspecialties and disciplines. These clinicians provide some type of informal transitioning (self-management) assessment and education to their patients and they often work in collaboration with their colleagues. There is a general consensus regarding the most common characteristics that should require transfer and the barriers that prevent transfer to an adult-orientated healthcare system. In addition, clinicians uniformly favor institutional support for the development of transitioning programs and resources to streamline the transfer process.

Although we had an excellent response rate and the randomized sample of physician and nurses may limit potential response bias, the single-center nature of the study may not allow for generalizability to other institutions.

In addition, results are self-reported, thus a social desirability bias may have overestimated the actual percentage of clinicians who perform transitioning (self-management) education and assessment.

We have recently assembled a working group on health care transition at our institution with the goal of more fully engaging individual programs in the transition process, as well as obtaining more objective evidence of current transition practices from the clinician and patient-family perspective.

Conclusion

In conclusion, the majority of clinicians at our free-standing pediatric hospital report providing transitioning (self-management) skills assessment and education in a collaborative effort during early to mid adolescence, but most do so informally without a structured program. Age and the presence of adult co-morbidities are the most common identified triggers for transfer to an adult-oriented healthcare system and clinicians identify parents' and patients' emotional attachment to both the provider and institution as a major barrier. Further study of patient and family perceptions around transitioning is needed. Clinicians express a strong need for institutional resources for transitioning (self-management) skills assessment and education, as well as resources to streamline the transfer of patients to an adult-oriented healthcare system.

Further development of transitioning assessment and education strategies, including outcomes evaluation, are needed to engage institutional commitment for the provision of these important services.

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