Transition of Pediatric Patients to Adult Care: An Analysis of Provider Perceptions Across Discipline and Role

Joanne O’Sullivan-Oliveira, Susan M. Fernandes, Lawrence F. Borges, and Laurie N. Fishman

Health care providers across disciplines increasingly recognize the importance of successfully transitioning our pediatric patients to adult care. A consensus article published jointly by the American Academy of Pediatrics, American Academy of Family Physicians, and the American College of Physicians, Transitions Clinical Report Authoring Group (2011) calls for transition planning to become a standardized part of care provided to all pediatric patients. This can be a daunting task for the generally healthy pediatric population, let alone for children coping with chronic disease. A position paper from the Society for Adolescent Medicine appropriately states that “many adolescents with chronic conditions are at higher risk than peers for unnecessary dependency, developmental difficulties, and psychosocial delay” (Rosen, Blum, Britto, Sawyer, & Siege, 2003, p. 309). However, the time of transition can also be seen as an opportunity.

The importance of successfully transitioning pediatric patients to adult care is increasingly recognized as more children with chronic diseases are living to adulthood. The aim of this study was to investigate the current state of provider perceptions across disciplines regarding transition of pediatric patients to adult care. Focus groups made up of providers of various roles and experience levels were conducted. A total of six major themes were identified. We conclude that pediatric providers share common concerns about transitioning pediatric patients to adult care. We reinforce many of the issues raised in the literature and also discuss a sense of professional ego that was identified as a barrier to successful transition, which is not widely reported in other studies.

The same paper goes on to suggest that a successful transition process can help to enhance autonomy, responsibility, and self-reliance.

The recognition of the importance of transition has prompted a growing body of literature that examines patient and provider experience through the transition process. The hope is that the information gathered from these studies will eventually guide the creation of objective criteria for transition programs. Much of the current literature is devoted to examining patients’ lived experiences or provider perceptions at the physician level. However, there are fewer studies that report the consensus opinion of the health care team as a whole.

In pediatrics in general, and particularly at our large tertiary care pediatric institution, we take a multi-disciplinary, family-centered approach to disease management. As a result, multiple providers are often involved in the care of our patients we are trying to transition to adult care; these include physicians, physician assistants, nurse practitioners, nurses, and social workers – the disciplines at our institution that are directly responsible for transitioning the patients from pediatric to adult care. We recognize the importance of each team member in the success of our patients, and thus, the importance of including all team members in the effort to improve transitional care. To this end, we expound on a previous survey study at our institution (Fernandes et al., 2011) by conducting descriptive focus group analysis to assess provider experience in transitional care across discipline and role.

Methods

A purposive sample was recruited from a population of English-speaking clinicians (i.e., physicians, physician assistants, nurse practitioners, nurses, and social workers) within a 396-bed, free-standing, urban, pediatric hospital in the northeastern United States. Participants were identified through a survey sent to health care providers regarding issues surrounding barriers to transitioning pediatric patients to adult health care settings. One question in this survey was used to identify interest in participation in a focus group to further discuss clinicians’ lived experiences and perceptions of transition and transfer in a pediatric population.

Four focus groups were conducted with multidisciplinary providers in each. Every attempt was made to have the members of each focus group be from different departments and divi-
Adequacy of the sample was determined by saturation or redundancy in the statements made by the clinicians regarding their perceptions about transition, self-care management, and transfer of pediatric/adolescent patients to adult care facilities. A total of 28 participants were included, with six to eight participants in each group. Participants ranged in years of experience from three to 35 years (M = 18.69, SD = 11.73) and also ranged in their current number of years of working at the current pediatric study site (M = 15.81, SD = 11.56). Additional demographic information is summarized in Table 1.

Focus group interviews allowed clinicians to share their experiences in a semi-structured, hermeneutic interview format. Participants were asked to reflect on and interpret their current perceptions and trends regarding transitioning and self-care management with their patients (Van Manen, 1990). Interviews lasted approximate-
ly 60 minutes and were digitally recorded. Questions asked and data collected were determined by the Transitioning Committee Working Group and centered on issues of the current transition and transfer practices at the institution, as well as the clinicians’ perceived barriers. A professional transcriptionist transcribed the data. The transcripts from the focus group interview constitute the data collected for analysis. The project was approved by the setting’s Institutional Review Board (IRB).

Data Analysis

Each transcription was reviewed by one of the co-investigators and corrected (if necessary) to improve trustworthiness (Morrow, 2005). The transcripts were then downloaded into NVIVO 7.0, a qualitative research software program used to assist in the overall data coding to prepare for thematic analysis. Each transcript was summarized in an attempt to define themes related to transitioning, self-care management, and transferring patients from pediatric to adult care facilities.

To ensure that conclusions drawn from the quality improvement (QI) project reflect the concerns expressed by participants during the interviews, a form of recursive comparative and thematic analysis was applied to the interview data. This is “a process by which the unfolding descriptive thetmes emerge from the data are constantly tested and refined to take account of all relevant data” (Cooper & McIntyre, 1996, p. 48). Interview data were then analyzed thematically using Van Manen’s (1990) phenomenological method, which calls for reflection and entails two approaches to the data; in the holistic approach, each text is considered a whole where investigators seek a phrase that captures the fundamental meaning of the text as a whole. Second, in the selective approach, texts were reviewed several times as the investigators searched for essential quotes describing the informant’s experiences. A line-by-line coding approach was used. The researcher considered what each line or sentence said about the experience being described and bucketed them into common categories (see Table 2). When the coding was completed, relationships between the codes were then organized into themes.

Table 2

Provider Theme Overview (N = 28)

<table>
<thead>
<tr>
<th>Major Themes</th>
<th>Examples</th>
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<tbody>
<tr>
<td>I. “Chronological Age Is Not the Answer” – Complex Patients</td>
<td>Cognitively impaired patients</td>
<td>12</td>
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<td>Medically complex patients</td>
<td>9</td>
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<td></td>
<td>Mental health concerns</td>
<td>9</td>
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<td></td>
<td>Developmental spectrum (e.g., college)</td>
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<td>II. “We’re Not Going to Let You Go” – Provider Barriers to Successful Transitions</td>
<td>Fear of letting go</td>
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<td></td>
<td>Ego’s (i.e., “we are the best”)</td>
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<td></td>
<td>Attachment to patients/grief</td>
<td>13</td>
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<td></td>
<td>Negative view of adult providers</td>
<td>12</td>
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<td></td>
<td>Poor structural support (e.g., insurance)</td>
<td>12</td>
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<td></td>
<td>Lack of adult specialists</td>
<td>12</td>
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<tr>
<td>III. “Please Don’t Abandon Us” – Patient and Parents’ Resistance to Transitions</td>
<td>Fear of moving on/letting go</td>
<td>12</td>
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<td></td>
<td>Feeling rejected/abandoned</td>
<td>4</td>
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<td></td>
<td>Conflicting messages from providers</td>
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<td></td>
<td>Negative experiences with adult providers</td>
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<td>IV. “Help! We Need to Transition this Patient!” – Provider Recognition of Importance</td>
<td>Burnout from adult patients</td>
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<td></td>
<td>Lack of specialty/comfort with adult issues</td>
<td>5</td>
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<td></td>
<td>Adults using up pediatric resources/time</td>
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<tr>
<td>V. “Let’s Get on the Same Page” – Institutional Support and Multi-Disciplinary Approaches</td>
<td>Transition guidelines</td>
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<td></td>
<td>Starting conversations earlier</td>
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<td>Assessment tools for transition readiness</td>
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<tr>
<td>VI. “If This Were an Ideal World” – Resources for Successful Transitions</td>
<td>Transition clinic and staff</td>
<td>12</td>
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<td></td>
<td>Referral network</td>
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<td></td>
<td>Training adult providers</td>
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<td></td>
<td>Facilitating transfer with patient</td>
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Rigor and Protection Of Human Subjects

Within the interpretive paradigm, rigor in qualitative inquiry methods ensures trustworthiness. In this QI study, trustworthiness and rigor were guided by the generally accepted criteria for the evaluation of qualitative research, which relates to the process, rather than to the specific findings (Sandelowski, 1993). According to Lincoln and Guba (1985), trustworthiness of a naturalistic endeavor can be judged by its credibility, transferability, dependability, and confirmability. Several procedures, such as prolonged engagement and peer debriefing, were also employed to analyze data and enhance credibility of the interpretation. Interviews were conducted over a period of six months (prolonged engagement), and after each focus group, investigators met (peer debriefing) to discuss findings and determine if data were representative of the questions asked.

Results

All four focus groups were examined for commonalities, and a total of six major themes emerged:

- “Chronological Age Is Not the Answer” – Complex Patients.
- “We’re Not Going to Let You Go” – Provider Barriers to Successful Transitions.
- “Please Don’t Abandon Us” – Patient and Parents’ Resistance to Transitions.
- “Help! We Need to Transition this Patient!” – Provider Recognition of Importance.
Theme 1: “Chronological Age Is Not the Answer” – Complex Patients

The issue of when is the appropriate age or time to transition a patient is one of major concern. Providers suggested that age may vary depending on social support, education, and learning capabilities. A senior-level physician (J) stated:

Age to me, 25 years, I think is approximately what I think. But what is much more important is their developmental attainment, and where the young adult is in his or her life with respect to education, entering the adult world with job, benefits, and so and so, with living arrangements.

There is not a simple answer to this, and almost every focus group member stated that chronological age was not the answer because of the complexity of patients in a specialized facility. There is a general consensus that a vast majority of the patients who do not transition to adult care centers are those with developmental disabilities and/or with severe chronic illness. An early career nurse practitioner (NP) (A) stated: “Adult providers say, ‘Oh I don’t want that big autistic kid in my practice,’ and so that is a tremendous challenge.” Another stated:

These are very often children/young adults with much higher rates of developmental concerns and may not have the capacity for self-care and/or may never have the capacity for self-care, so really, that’s almost off the table for them. (R, mid-level physician)

It is equally and maybe more difficult to transition children with chronic mental health issues to the adult system because of system issues (e.g., health insurance). Social workers voiced issues surrounding health insurance “that sometimes make it difficult to keep treating patients and/or transition them...and they can have years of treatment that just goes completely down the tubes” (H, senior level NP). There was also frustration expressed surrounding the aging out of services.

Theme II: “We’re Not Going to Let You Go” – Provider Barriers To Successful Transition

Participants voiced issues related to fear of letting go, ego, attachment/grief, negative views of adult providers, poor structural support, and lack of adult providers. The fear of letting go was a genuine concern regarding the continuity of care. There were concerns regarding the lack of self-care management resulting in adverse health outcomes. One physician (R) stated:

I think if I were ever in a situation needing to be hospitalized, and there was adult care here [at this pediatric facility], I would choose here – we are very – all in all a friendly, caring environment – that isn’t a model that you definitely see outside uniformed in an adult setting.

In this specialized pediatric facility, providers had great pride regarding the care they provide. One senior-level physician (S) stated:

The patients are seen in one place by several different disciplines usually on the same day. There is just no type of facility like that in the adult world, and it is very difficult to get the adult providers to come together to provide this kind of service that we provide here.

There is also a strong sense of professional ego, as expressed by a mid-level social worker (J):

In my division, my experience has been that those are the physicians and the team are more likely to say we just know them so well. We know how to handle them when they are here, and we know how to deal with the fact that they are combative. We know when he hasn’t taken his bipolar meds and how to handle him, and so those are the patients that the physicians tend to just feel like it’s easier for everyone to just keep them longer.

There is a fair amount of ambivalence regarding transitioning patients. Providers admitted to being attached to the patients and their families, and being sad at seeing them move on. One social worker (J) stated: “It is actually openly communicated in a good faith effort to the family by the physicians that it is going to be really hard to let you go.” Another senior-level nurse practitioner (N) stated: “I always find that sometimes it is hard for providers like me to let go. Some patients have known me their whole lives, and they don’t want to go, and quite frankly I don’t want them to go.”

Perceptions are that the adult world medical model is very diagnosis-driven. Pediatric providers seem to have a somewhat negative view of the adult health care system. There is a stereotypical model of adult primary care – that it operates to conserve cost and look for ways to make things operate smoothly and is for the betterment of groups rather than individuals. One senior-level female NP (H) stated:

Adult settings don’t think like we do in pediatrics, which is why patients get too attached to the care they get here – because they get the support, and they get the coaching and the mentoring and the connections and the relationships, and in an adult world, you are on your own.

Some providers seem to think there is a lack of adult providers. However, one mid-level social worker (J) stated: “There is not a lack of adult providers; it is more of a trust. Do we trust them? Does the patient trust them/the family?”

Overwhelmingly, there was a concern with the ability and structural support of a pediatric institution to care for adult patients. A mid-level NP (S) said: “We do take care of adult patients here, but then told that we can’t get our imaging done here anymore, and can’t take them into the operating room, so I’m never really sure where we stand.”

Providers seemed confused about hospital-wide policies regarding the care of adult patients. They stated there are no facilities to support some surgical procedures, and there are no adolescent or adult units. Patients would be housed on pediatric units with pediatric patients. A senior-level NP (M) said: “Depending upon the disease, depending upon the day of the week, the hospital seems to have
different opinions on when they can be seen and where.”

One provider stated:

So you really have to look at what is the hospital’s role in that in caring for those really complex care patients who are multi-system failures, and is that something to transition to in an adult world vs. the pulmonary patients or the renal patient that most assuredly go to another institution because I don’t think we have done our homework in that regard. (M, senior-level NP)

Every participant in the focus groups agreed there was a lack of adult providers to transition patients to, even if there were a transitioning program in place. Providers agree they need to think about the community at large and how to come up with plausible solutions for the less complex patients. They all agreed there needs to be a process to outreach to community providers “because not everybody can continue to come here forever” (H, senior-level NP). One provider, an early career NP (A) expressed:

There might be an adult specialist who can care about this specific issue that the child has. But when an adult developmentally is a child or even an infant, it can become hard to find providers who feel comfortable taking that on and being in a position where they are interacting with the family, where they, unlike us in pediatrics, are used to interacting only with the patient themselves.

Theme III: “Please Don’t Abandon Us” – Patient And Parents’ Resistance To Transition

Participants in the focus groups stated that patients and parents exhibited a real fear of moving on/letting go. The key issue is fear of the unknown and the perception that the care may be less than ideal at another site. It was also stated that it is very hard for parents to give up their level of involvement in their children’s care when they have been in the midst of it for their child’s entire life. The fear is that in an adult setting, parents will not be as involved as they are in a pediatric setting. They also stated that there was a major issue related to trust. A senior level NP (V) stated:

The whole key really in transition is trust, and they trust you, and they don’t trust that person, so if they come back and then you are saying that you don’t agree with what that person plans for them, then what?

It was also stated that there was an issue with the older patients feeling rejected and abandoned. Providers stated that some adult age patients reflected that transition feels like a punishment, and it is usually around non-compliant behavioral issues (e.g., not taking their medications or hydrations – whatever they need to do or not do that leads them to frequent hospitalizations). Patients have expressed concern because they are constantly in and out of the hospital and feel that staff get burned out, and they are being punished. They then become resistant to conversations surrounding transitioning. Other providers stated that hospital staff become family or parents to them. One senior-level NP (V) stated: “A lot of them don’t have mothers that do care…or even have mothers…we become the mothers.”

Some participants felt that patients and families receive conflicting information from providers. It is important to support the plan provided by the “new/adult” provider and try to help patients/families understand why things may be recommended and also what some other options might be, or in other words, to present multiple options. However, not all providers believe this, as noted by one senior-level RN (L) who stated: “In our department, some providers are saying, if you leave, you will die. No one can take care of you like I take care of you.”

In pediatric medicine, there have been many improvements in chronic disease management. When some programs were first developed, some patients were not expected to live to adulthood. One senior level NP (N) stated: “I think that for our older young adults, we did not necessarily do a good job of empowering them to be ready to move on.” It was also stated that some pediatric providers treat patients more like children than adults. This causes a problem when it is time to transition. One social worker (E) stated: “Even as we tell them they need to move on, and we will help them find a provider, they are resistant to do so, and they continue to schedule appointments.”

There were then those comments that addressed negative experiences with adult providers. It seems that the older pediatric patients were not prepared for the adult health care system and would bounce back to their pediatric providers. An advanced-level RN (L) stated:

We have a lot of kids that bounce back and forth that we try to send out, and they end up coming back and saying – no one knows my child like you know my child, no one treats our child like you do – and so, it’s an ongoing issue.

There are also those incidences when a patient transitions to an adult facility and is then told they cannot handle their care, and they are advised to go back to the pediatric facility.

Theme IV: “Help! We Need To Transition this Patient!” – Provider Recognition of the Importance of Transition

Participants expressed a sense of burnout working with the young adult patient population. There was a feeling of frustration with providers. They should be able to save the world and care for all the patients, but there was a feeling that boundaries need to be set with patients. One advanced-level NP (P) stated: “It gets difficult to be a savior and also a limit-setter at the same time.” There is a range within the providers. There are those who enjoy challenges and working with complex chronic disease. They bond with their patients and their families, and do not know how or when to transition, and there are others who are eager to prepare patients/families at the earliest possible age for anticipated transition.

Another issue is the lack comfort and experience with the needs of young adult issues. Many of the younger providers who have gone from medical school directly into pediatric internships and training programs have not had much adult care experience. Therefore, once a patient reaches 18 years of age, he or she is looking to transition into adult care facilities/practices. One advanced-level physician (P) expressed:

I think we have to acknowledge that there are things which we can no longer do as well as the other providers…the problems are so different when there are co-morbidi-
ies…It’s just frustrating to think I cannot give them the full services that they need at an adult level when we are taking care of young adults.

Another issue was raised regarding adult patients continuing to be treated at a pediatric facility causing the use of important and limited pediatric resources. A mid-level NP said (T):

> What we are starting to see in our practices is that we are trying to still maintain this level of care for adults, and it is squelching our ability to see our true pediatric patients, so our practices are so big now because nobody is leaving that we actually have less and less time to prepare the adult patients for that transition.

The issues of resources being used and the lack of appropriate equipment and personnel to care of patients are also being affected by the lack of transitioning. Another advanced-level social worker (J) stated:

> “Some providers have been here a long time and think they can be all things to patients, but those patients become inpatients, and the equipment is not big enough for them because of the co-morbidities.”

Theme V: “Let’s Get on the Same Page” – Institutional Support and Multi-Disciplinary Approaches

A major concern among multi-disciplinary providers is that there are no institutional policies or standardization surrounding the transitioning of a patient. One advanced-level NP (P) stated:

> The one advantage that I would see of having an age maximum is that it would be a message that we can provide services up to that age. It would not necessarily be in the best interest of the individual, and certainly a person could choose to leave sooner, but it would give a clear message that we have some sense of vision of what our mission to young adults is.

If there were a standardized policy, communication and transition education would be incorporated into the patient’s plan of care. The experiences of patients who have successfully transitioned have been very positive. It was stated that patients who were contacted a few years after transition reported to have had a good transition experience and have confidence in their current providers.

A help for providers would be the development of transition assessment tools to evaluate the readiness of a patient to transition. These tools would evaluate the self-care management and independence skills of youth at various developmental stages during adolescence.

Theme VI: “If This Were an Ideal World” – Resources for Successful Transitions

An interesting finding surfaced in all four focus groups. It was stated that the responsibility of transitioning should not lie only with the actual provider, but should be deemed to another entity or team. It was stated that if there were a wish list, resources would be allocated for a team to work with the patients, providers, and adult health care centers facilitating the process to a healthy transition. In situations where there may be specialty/chronic health issues, the medical home might reside with an adult provider, but when issues regarding the chronic disease arose, there may be a shared team effort with the patient followed by their pediatric/specialty provider for those concerns. The role of a medical/pediatric provider, family nurse practitioner, and/or physician’s assistant trained to care for both pediatric and adult patients should be considered to lead these transition teams and/or clinics. One senior-level physician (J) stated:

> “If we had within our staff individuals who enjoy taking care of these patients and that it was an expectation they would see the older patients, then that would be a workable solution.”

It is important to include adult providers in the transitioning team, which may involve some training to these providers in regard to specific health needs. One provider stated they have had the opportunity to have people within their system work closely with adult specialists to help them gain the expertise that they might need in primary care. When adult providers have been identified and become part of the transition team there has been great success. One advanced-level social worker (J) stated:

> We have identified at least two providers who our kids transition to, and that has been enormously successful. I mean, she has come over here, we’ve gone over there, she meets the patients before they leave, and it has made the transition much easier.

Once an adult provider has been identified, families need education regarding the cultural differences between pediatric and adult care centers to avoid unrealistic expectations. It is also important to provide closure with patients and work on termination issues with them. Patients need to know that eventually within a certain time frame, they will be moving from a pediatric center to an adult center for care. The provider can facilitate patient separation by having the patient explore and visit new adult facilities before the actual transitioning occurs. One senior-level RN (V) stated:

> I try to when they make an appointment…say this is going to be your last one, and then you will need to go on, but let’s make a last appointment where we can set some things up, and then we will formally say goodbye.

Discussion

A review of the existing literature reveals common themes in transition between specialties. In cystic fibrosis, Tuchman, Schwartz, Sawicki, and Britto (2010) recently published a comprehensive review on the progress of transitional care. Several issues they discuss include the difficulty in determining the appropriate age and time to transition, the availability of willing adult-oriented physicians to accept patients, lapses in insurance coverage, and benefits that come with adulthood. Studies have also noted that despite a high number of transition programs available for patients with cystic fibrosis, there is a lack of standardized approach to promoting patient maturity and self-management (McLaughlin et al., 2008; Tuchman et al., 2010).

A review of current practices in the care of adolescent patients with inflammatory bowel disease by Leung, Heyman, and Mahadevan (2011) reveals a similar degree of variability within existing transition programs for pediatric patients with inflammatory bowel disease (IBD). Their review also suggests that parents who remain too heavily involved in care past the
appropriate time and the patients’ lack of understanding and trust of the adult health care system both pose significant barriers to transition. Interestingly, a survey study of adult gastroenterologists in The Netherlands found that adult providers most commonly reported patients were unable to discuss how IBD affects daily life, patients’ lack of knowledge of their medications, and patients’ lack of awareness of how substance abuse can have an impact on their health (Barendse et al., 2011). “Pediatric providers can use this information to guide how they orchestrate transition skill building and how they initiate transfer.” (Barendse et al., 2011, p. 615).

This same study also reports that while adult gastroenterologists identify accurate transfer of medical information during the transition as highly important, they rarely report it as problematic.

Pediatric providers report more difficulty than adult providers in the transfer of medical information. A focus group study of patient and provider experience in the transition of youth with intellectual disability in Colorado found that pediatric providers do not feel they have adequate time to prepare their patients’ records for transition, particularly because the time spent gathering and preparing records is not reimbursed. In addition, insurance coverage issues were a problem for both pediatric and adult providers (Pickler, Kellar-Guenther, & Goldson, 2011).

In the case of sickle-cell disease, one qualitative study looking retrospectively at the experience of patients after transitioning to adult care identified four themes that defined the adjustment process for these patients. These themes were reluctance toward transition, concerns over leaving well-known pediatric providers and meeting new adult providers, a feeling of being pushed out of pediatric care, and eventual acceptance that transition was inevitable (Bryant, Young, Cesario, & Binder, 2011). One conclusion was that the topic of transition should be approached early in patients with sickle-cell disease well before they turned 18 years of age because many patients reported feeling stunned when they were told they could not return to pediatric care. Similar results were reported in a study giving questionnaires to patients with sickle-cell disease and caregivers at a separate pediatric clinic, transitional clinic, and adult hematology clinic at the same institution (Latzman et al., 2011). Pediatric clinic patients were most concerned with meeting new adult providers, and caregivers were most concerned with leaving the pediatric team. Interestingly, the authors also found that the transitional clinic patients reported higher levels of positive effect than the adult patients who had not previously passed through a transitional clinic. This suggests a positive impact of the transitional clinic model.

Pediatric patients with chronic neurologic disease pose a significant problem because they often have comorbid intellectual handicap and behavioral issues. Camfield, Gibson, and Douglass (2011) examined this problem in relation to pediatric patients with Lennox-Gastaut syndrome and related epilepsy disorders. Their survey of providers finds a wide variability in methods of transitioning patients, and they suggest that transition clinics organized jointly with pediatric and adult providers may be needed to facilitate this process.

Fredericks et al. (2011) explored the experience of pediatric liver transplant recipients and their parents through a survey study designed to determine their perspectives on the transition process. The study reports that while patients and parents in this cohort perceived the importance of preparing for transfer to adult care, they lacked knowledge of the logistics related to transfer of care, and there is a difference in the perception of patients and their parents with regard to self-management skills.

Several common concerns are identified from the above discussion. These include uncertainty about the best time for transition, apprehension of patients and families about meeting new providers, and a lack of consensus guidelines for how transition should be structured. The themes identified from our focus group analysis serve to reinforce that these concerns are shared across discipline and provider role within a large, tertiary care institution. All providers agreed that chronicologic age alone is not the answer as to when a patient should transition (Theme 1). Psychosocial and developmental needs must also be accounted for if transition is going to be successful. All providers agreed that the transition process in its current form is a daunting adjustment for patients and families (Theme 3). Fear of the unknown can be a significant barrier, both with regard to meeting new adult providers and for parents to decrease their level of involvement in their child’s care in favor of promoting self-care management skills. To address these issues, it was widely agreed that successful transition was needed before a patient grew too old (Theme 4) and that a more structured approach is needed to guide the transition process (Themes 5 and 6). The need for objective evidence to help create transition guidelines is often pointed out in the literature, and our participants echoed this need to help structure their approach to patients on a daily basis.

Further, our analysis identifies a sense of professional ego that many providers view as a barrier to successful transition (Theme 2), which is not widely cited in the current literature. As discussed earlier, existing studies report provider reluctance toward the transition process. Participants in our study alluded specifically to a sense of ego by stating providers knew patients better than anyone else and were the only ones who could care for them. There was a general perception that adult providers would not be qualified enough to accept their patients, and many participants reported mistrust of the adult health care system in general. We believe our analysis highlights an equally important and less-often acknowledged aspect of team-oriented care. Although concerns expressed may be grounded in experience, patients and families perceive these feelings as provider ambivalence toward them making the transition. As stated in a review of physician barriers to transition, “Casual asides by the pediatrician that imply this lack of confidence to patient or family can easily undermine the whole transition process” (Fox, 2002, p. 4). Our findings suggest that this power extends beyond the pediatrician to other members of the care team as well. Similar concerns are reported in a focus group study by Reiss, Gibson, and Walker (2005), which included a wide range of pediatric providers. Perhaps more alarming was the perception of pediatric provider ambivalence also reported in a survey study of interns on the receiving end of the transition process (Peter, Forke, Ginsburg, & Schwarz, 2009).
Conclusions

Several common themes in provider perceptions about transition have been reported in the literature. Our comprehensive focus group analysis reinforces the existing literature and further supports the commonality of these concerns across disciplines and between providers of varying roles. In addition, we identified a strong sense of professional ego among pediatric care teams that is not widely discussed. We worry that the negative impact of this perception is under-estimated, and this underscores the importance of including the entire care team when assessing provider perspectives.

This study has several limitations. The characteristics and geographic location of the institution where the study was conducted may not allow for generalizability to other institutions. In addition, results reflect self-reporting. Social desirability responses may bias statements made by some participants. However, few differences in the perception regarding delivery of transitioning education/assessment, triggers to adult-oriented care, or barriers to transition were identified between clinicians. Given this, further studies examining actual practices and exploration of the impact of care organization and clinician demographics on transition and transfer practices are indicated. An assessment of patients’ and their parents’ perceptions in comparison to the clinicians’ perception/practice is also indicated.

It is important we recognize the power we have in preparing patients and families for successful transition in the objective transfer of information regarding termination and/or transfer of care. It is also important we reinforce patient self-care management and endorse/partner with adult care systems. Transitioning programs should, therefore, address patient and family-related and clinician-related barriers. The development of transition assessment tools may be introduced at early ages and revisited at developmental stages. Hospital-based transitioning programs may be the venue to streamline the transfer of pediatric patients with chronic disease to the very least adult-oriented primary health care.

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Goal

The purpose of this article is to provide an overview of transitioning pediatric patients to adult care.

Objectives

1. Explain the current state of provider perceptions regarding transition of pediatric patients to adult care.

2. Discuss common concerns regarding the transition of pediatric patients to adult care.

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