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Transition to adult care: Systematic assessment of adolescents with a chronic illness and their medical teams

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Abstract

Objective—To examine the process of transition from pediatric to adult healthcare services from the perspectives of young adults with chronic disease and pediatric and adult healthcare providers.

Study design—A qualitative approach using focus group interviews was performed to investigate transition experiences. Novel innovation games were also utilized to generate data. Content and narrative analyses of interview transcripts were performed.

Results—Six focus groups were conducted with 10 young adults with chronic disease and 24 healthcare providers. Content analysis yielded 3 content domains: transition experiences in the context of relationships between patients, parents, and healthcare providers; differences between pediatric and adult-oriented medicine and how these differences inhibit or facilitate transition; and identifying transition services that should be provided to young patients with chronic disease.

Conclusion—This study demonstrates the need for gradual transfer of disease management from parent to child and better communication between adult and pediatric services during the transition process. Pediatric medicine and adult medicine represent different subcultures; acknowledging these differences may improve cooperation during transition from pediatric to adult providers. Young adult patients with chronic disease embrace the use of technology for specific interventions to improve the transition experience.

Various national healthcare agencies have identified successful transition from pediatric to adult healthcare services as a process crucial to healthcare outcomes in children with chronic disease [1-3]. Although position statements on the issue of transition have been published by relevant societies [1, 4-8], there remains a notable and demonstrable deficiency in services provided to patients to ensure a smooth transition [2, 9]. Data to date suggest that the healthcare transition can be traumatic with adverse morbidity and even mortality outcomes [2, 10-12]. However, interventions to improve outcomes are lacking, and the characteristics

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of successful transitions and the qualities of medical practices that promote successful transitions have yet to be fully identified. Similarly, how current technologies may be used to promote successful transitions have yet to be fully explored or utilized.

In this qualitative study, we sought to characterize the recent transition experiences of young adults with chronic disease in order to identify facilitators and detractors from successful transitions and to identify how web-based technologies might be used to help this vulnerable population as they transition from pediatric to adult healthcare services.

METHODS

Investigators recruited young adult patients with chronic disease through pediatric and adult healthcare providers and healthcare providers at a pediatric tertiary care hospital. Inclusion criteria for young adult patients included diagnosis with inflammatory bowel disease(IBD), cystic fibrosis, or type I diabetes and transition to adult healthcare services within the past 3 years [2006-2009]. We recruited both pediatric and adult healthcare providers representing the typical variety of services provided (i.e., nutrition, social work, health education) at care visits. Separate, disease-specific focus groups were held for young adult patients and for healthcare providers. The research was approved by the Institutional Review Board of the University of California at San Diego.

Focus Groups and Protocol

Trained focus group leaders conducted focus groups using a standard protocol. Focus group meetings began with open-ended questions (Table I) regarding personal experiences with and the process of transition. These topics were followed by a series of Innovation Games[13] to identify topics to be addressed when preparing patients for transition and to develop their ideal intervention addressing transition issues. We used the following games: (1)*Buy a Feature*(performed at both patient and practitioner focus groups) in which participants collaboratively bid,using distributed money, on predetermined topic options for a transition program; (2)*Buy a Feature* (performed at patient focus groups only) in which participants collaboratively bid on predetermined technology-based (web, internet or mobile phone) elements of a personalized transition program; and (3) *Product Box* (performed at patient focus groups only) in which participants were asked to sell their ideal transition technology-based intervention at a tradeshow and to perform a sales pitch to a skeptical customer in front of other focus group members.

Analysis

Focus group discussions were transcribed verbatim, and 2 focus group leaders reviewed transcripts for accuracy. All transcripts were reviewed and coded by 2 members of the research team. Discrepancies were discussed with co-authors for clarification and finalization. Themes were organized into 3 broad content domains: transition narratives, healthcare systems, and intervention strategies. For further identification of subthemes within content domains, we used open, axial and selective coding for analyzing the narratives and constructing a conceptual framework of the transition process[14]. We used open coding, a word by word analysis, to identify, name, and categorize barriers and facilitators of the transition process reality of participants [14-16] followed by axial coding, the relating of themes and categories with their subcategories, to identify causal relationships in the data. Finally, with selective coding we integrated the emerging relationships and classified emergent categories as enacted and perceived barriers and facilitators of the transition process.

RESULTS

Ten individuals (3 with inflammatory bowel disease [IBD], 4 with diabetes, and 3 with cystic fibrosis; 6 females and 4 males; 8 attending college and 2 currently employed; mean (range) age of 20 (18-25) years; 8 participants had been patients of the pediatric center) participated in patient focus groups, and 24 individuals participated in healthcare provider focus groups. Healthcare providers consisted of 4 nurse practitioners (1 adult), 9 physicians (6 pediatric, 3 adult), 1 physician assistant, 3 health educators, 3 nurses, 3 social workers, and 1 dietitian. Actual participant comments from performed focus groups are provided in the Appendix (available at www.jpeds.com).

Patients' experiences

In most cases, the transition process occurred at the time of graduation from high school. Most reported cessation of pediatric healthcare services and subsequent initiation of adult services. Main themes identified as influencing the transition process included parental involvement, communications between pediatric and adult services, and differences between care models at pediatric v. adult centers.

Subthemes regarding parental involvement in patient healthcare interactions included: hampering of patient involvement, abrupt withdrawal of parental support at initiation of adult services, and subsequent forced assumption of responsibility by patients. The more involved parents were while patients were being cared for in the pediatric healthcare system, the less control and interest patients had in disease self-management. Parents often abruptly reduced their involvement once patients attended adult healthcare visits (within the first two clinical visits for 9 of 10 patients), providing little to no preparation time to learn how to conduct a clinical appointment. Nevertheless, removal of parental involvement often served as the impetus for patients to begin to take control of their disease issues.

In regards to healthcare communications, young adults identified the need for better communication between pediatric and adult healthcare providers. Lack of referral to vetted adult providers was a common barrier to a smooth transition, particularly among patients who relocated outside of the local area. Patients with adult and pediatric healthcare providers who communicated well and/or had an overlap period of concomitant adult and pediatric care reported an easier transition than category counterparts. Insurance also was a common barrier to ease of transition.

Patients perceived differences in care provisions between pediatric and adult healthcare systems. In particular, patients described more coddling and services provided by pediatric providers whereas adult providers “expected more” in regards to disease self-management. Patients with minor disease issues who were relatively independent in managing their disease welcomed the efficiency of and ”being treated like an adult” by the adult system. However, for patients with active disease issues who relied heavily on their parents for disease management, the adult healthcare system did not offer sufficient opportunities for patients to express their concerns.

Healthcare providers' opinions

Pediatric healthcare providers uniformly recognized the importance of parents in the transition process. In particular, practitioners identified high “overbearing” parents as a barrier to transition. Provider recommendations to help patients transition focused on reducing the role of the parent and enabling the adolescent/young adult to take ownership of his/her own disease issues. Common motifs were to direct conversations at the adolescent/ young adult (with the parent out of the room ideally) and to include the patient in decisions regarding his/her own management. All practitioners recognized the need to identify patientdesired goals and endpoints and to provide repeated, positive reinforcement for performed disease management behaviors. Acknowledged limitations to performing these recommendations included the patient's neurocognitive developmental stage and maturity level.

Practitioners also identified the lack of a systematic transition protocol as a major barrier. Although transition recommendations from national societies were followed by some of the clinics, there were no protocols in place to ensure compliance with suggested guidelines. Transition of services was described as scattered and not standardized, resulting in poor communication between adult and pediatric services, and poor timing of transition (transition of services was best performed during periods of wellness rather than during period of illness). In addition, healthcare providers identified insurance issues as a significant barrier to a successful patient transition experience.

Healthcare professionals acknowledged the need to address transition issues in a more direct and systematic fashion. Suggestions to improve the transition process included promoting an overlap period between adult and pediatric services. Specific recommendations included: having patients meet adult providers prior to physical site transition, transferring medical records to adult providers prior to patients' first visits, and distributing brochures about adult care programs to patients at the pediatric site.

Intervention strategies

Transition topics “bought” by patients and practitioners during the *Buy a Feature* game are summarized in Table II. Patients were most interested in receiving relevant news regarding their respective diseases, input from actual patients, reports of their health status over time, and opportunities to network with other patients like themselves. When asked to “sell” their proposed ideal intervention for chronic disease management to colleagues during the *Product Box* game, many patients promoted connectivity as the main attractive element of their ideal intervention. Patients also welcomed the use of technology to deliver a chronic disease management intervention. In particular, they appreciated the ready accessibility of technology at any time of day and that technology interventions would be delivered without judgment.

DISCUSSION

We report results from focus groups on the topic of transition among recently transitioned young adults with chronic disease and their healthcare providers. Although some of our findings regarding transition experiences are similar to prior studies[17, 18], we add to the body of literature by highlighting the role of parents in the transition process and the need for adult and pediatric healthcare services to communicate effectively with each other for transfer of care. We used novel methods to explore how technology might serve patients with chronic disease as they begin to manage their own disease.

Our findings highlight the importance of parental involvement in the transition process. Both patients and healthcare providers indicated that greater parental involvement inhibits a successful transition[18]. In particular, parental over-involvement in the pediatric setting delayed the necessary transfer of disease management control from parent to child. Interestingly, there was often an abrupt, ill-prepared release from parental oversight once patients moved from the pediatric to the adult healthcare setting. Current recommendations advocate that the transition process begin by age 14 years depending upon the cognitive maturity of a given patient[1]. Our findings reinforce this and other recommendations that patients meet with their pediatric provider without their parent and/or that providers specifically direct questions to the adolescent so that he/she learns to answer health-related questions and discuss health-related issues[1, 5-7, 17]. *"Put the decision making into the teen's hands."*

As has been reported in other studies[17], differences between the pediatric and adult healthcare settings often required patients to adjust their expectations of, and their interactions with, their new healthcare team. Patients generally reported an emotional bond with their pediatric healthcare team that was difficult to replicate with their adult provider. There also was the common perception that pediatric healthcare settings provided more services than adult care settings. Conversely, some patients felt liberated from being treated like a child when they transitioned from pediatric to adult healthcare.

Systems barriers have long been identified in evaluations of the transition process [17, 19-21]. In our study, the main health systems barrier to a smooth transition was lack of information transfer and/or poor communication between pediatric and adult providers. Even though pediatric healthcare practitioners provided referrals to local adult practitioners, no formal systematic transfer of information took place. Transfer of care appeared to be the best tolerated where patients had open lines of communications with both pediatric and adult practitioners over the transition period, as has been advocated for young adults with HIV disease [20].

Concerns regarding the availability of qualified adult providers to accept transitioning young adult patients have been well-documented in the literature [17, 21]. Similarly, in our cohort, when patients relocated to a different geographic location (as is common in this age group), vetted referrals were often not available. Potential solutions to these issues include improved networking among adult and pediatric subspecialists both locally and nationally (e.g., via email list servers or similar professional discussion boards), regional website listings of adult subspecialists who are familiar with and willing to work through the issues of pediatric patients who are ready to transition, and/or clinician education campaigns by national organizations interested in facilitating the process of transition among youth with chronic disease.

Financing and insurance prove to be additional systems barriers to a smooth transition. Until recently, transition from pediatric to adult healthcare often occurred during a time of financial instability where parental insurance coverage is scheduled to terminate without an adequate replacement. However, current healthcare reform may extend parental insurance coverage to provide a period of overlap. Whether this overlap period is sufficient for young adults to obtain adequate replacement insurance coverage remains to be determined.

Transition intervention targets identified in this study include having parents gradually relinquish disease management control to their child, fostering independence and disease self-management activities, and improving communication between adult and pediatric health services. Similar targets have been identified in previous studies and guideline statements regarding successful transition[1, 3, 5-8].

We report the use of "Innovation games" to improve participation by all members of a focus group. Prescribed games allowed us to obtain the viewpoints of all participants in a non-intimidating format. In the *Buy a Feature* game, which identified topics for a transition intervention, topics related to lifestyle management in the setting of disease were of greatest importance to patients, and practitioners identified consequences of disease as issues of interest. These findings suggest a need to refocus transition efforts to address patient-valued priorities in order to better engage patients in disease self-management. Encouraging patient involvement in self-care and physician-patient collaboration have been linked to increased satisfaction with care [22, 23], improved health outcomes [24], and improved adherence to treatment regimens [25].

Importantly, patients reported a high degree of interest in intervention delivery over private web-based and mobile technologies. These technologies offer several advantages for behavioral interventions, including: quick and ready access, messages tailored to the participant, and anonymity that may be attractive for sensitive health issues [26]. Interactive technology is well-received and beneficial in self-management[27, 28].

Lastly, our patients expressed strong interest in meeting and obtaining transition experiences and information from other patients like themselves. This desire may reflect generational longing to connect with people as evidenced by almost ubiquitous (72% of online 18-29 year olds [29]) adoption of social media and networking technologies. It may also have arisen from loneliness, as reported in other patient groups with chronic disease [30-32]. This may be particularly important in young adults with cystic fibrosis, where concerns regarding transmission of respiratory pathogens severely limit interaction between patients.

Generalizability of our findings is hampered by the study's small sample size and recruitment from one pediatric healthcare center and a small sample of adult providers. Nevertheless, many of our findings overlap those reported in the small number of transition-focused studies [17, 18]. Further research is needed to assess whether identified concerns translate to widespread issues as compared with regional problems.

In conclusion, we report a qualitative assessment from young adult patient and practitioner discussions on the process of transition. The need for parental withdrawal for appropriate shift of locus of control of disease management was acknowledged by both patients and health practitioners. Similarly, improvement of the transfer of health information between pediatric and adult healthcare systems was identified as an important intervention goal. In regards to personal intervention, young adult patients welcomed technology-based activities to address their disease management issues.

PATIENT QUOTATIONS

1 Quotations from young adult patients related to parental involvement during pediatric clinical visits:

“I think it was helpful that my mom stopped coming with me (to doctors’ visits) because when I was at the children's clinic she'd...answer all the questions for me and I didn't really know what to say once I got to the adult clinic.”

“When I was younger ... it was more like my mom's disease. It was mine but I didn't really care.”

“She (my mother) pretty much did everything. She paid, and drove here (the children's clinic), asked questions that (I) couldn't think of.”

2 Quotations from young adult patients related to parental withdrawal at the time of initiation of adult clinical visits:

“(I would have appreciated) maybe not her (my mother) leaving, but just maybe like backing down a little bit and like letting me like (answer my own questions a little more)...”

3 Quotations from young adult patients related to abrupt assumption of responsibility by young adults during the transition process:

“I preferred going on my own ...It forced me to take more of an active role in caring for myself.”

"If I can stay here (the pediatric healthcare site) I would. I (now) have to get out and ask the questions. I actually make the doctor stay now and whereas before my mom knew all the questions and everything."

"When you transition out of that, it's now it's you... what do you want out of it...what are you wanting to know. And ... I know that's my own disease."

4 Quotations from young adult patients related to lack of pediatric provider referral to vetted adult health service providers:

"(My pediatric doctor) gave us a few recommendations of people locally, but then when we were trying to look for people up at school, it was difficult."

5 Quotations from young adult patients related to their transition experience when there was contemporaneous overlap between pediatric and adult care visits or when their pediatric and adult care providers communicated with each other:

"That transition year they allowed us to still come back here. That was really nice ... It wasn't like 'ok, bye' (and) kick you out the door."

"It was (a) very easy (and) simple transition. The two doctors- the pediatrician-spoke and the adult practitioner (then) was well aware of my history."

"I think it's really important that the two physicians speak with each other on a lengthy basis and I think it'd be even great if even the family or the patient could be there with the two physicians. Whether it's on the phone or what not."

6 Quotations from young adult patients related insurance issues and their transition experience:

"Between parent insurance and university insurance it's always sort of a game to see who will actually pay for ...supplies. That's been one of the bigger hassles to be perfectly honest."

7 Quotations from young adult patients related to their experience at adult clinical care facilities:

"I kind of liked the transition 'cause I felt like I was still kind of being treated like a child but with the transition to the adult clinic I just liked it much more because they were all honest and I just liked going to the adult clinic more."

"I've gone to (adult doctor) for a second time now and ...she just asked me questions.Here (pediatric site) they are more thorough - there (adult site) you have to tell them what you want."

"If you have questions (at the adult site), you didn't get really get to ask them and I was used to being able to ask all my questions right then and there."

"Here (pediatric site), you are kind of sheltered and... everything is at your fingertips. ... But those resources aren't really there (at the adult site)... you have to go out of your way to get them."

"I built a history for 6 years with my pediatrician and I went through a lot of bad times. And because of that I had...an emotional connection with him ... I had the impression that when I went to an adult physician -- it's less connection to patients. I connect fine with my (adult) doctor, but I remember when I first went over (I felt pressure to) show this doctor - how bad can I make my past look so that he can want to help me... he needs to know the toll that it's taken on me and how important this is in my life. ...That connection that you have with the doctor is more important than a lot of things.”

8 Quotations from young adult patients related to their ideal technology-based intervention helping them feel connected and not alone:

“There's a really important social aspect to this ...the ability to talk to other (patients) actually has a lot of appeal.”

“I know this kid who's diabetic and he thinks it's the coolest thing that I’m also diabetic and he can relate to me.”

9 Quotations from young adult patients related to technology-based interventionsfor the process of transition:

“No matter what time of day, day of week, you can get help.”

“With technology, it's not that invasive (and) you’re not going to feel like ... feel stupid or embarrassed for ask(ing) anything and you know you won't be reprimanded for it..”

CLINICIAN QUOTATIONS

1 Quotations from clinicians related to parental involvement during pediatric clinical visits:

“Transition needs to start with the parent”.

“There is a normal power struggle between parent & teen.”

“There are different priorities and agendas (in transition) .... The parent has a priority, and the patient/teen has a priority and they are different.”

“Parents, they just can't let go... (they think that their child) can't do that...and the parents keep (the child) in the sick role.”

2 Quotations from clinicians related to recommendations regarding how to deal with parents during pediatric clinical visits:

“Separate the child from the parent. Ask the hard questions without the parents there (or don't allow the parent to talk) and make sure they understand the issues.”

“Direct the conversation at the teen and not the parent even if the parent is in the room. Put the decision making into the teen's hands.”

3 Quotations from adult clinicians related to communications with pediatric providers during the transition process:

“(I – an adult provider) rarely get any personal communication from the pediatric physician. My wish list at the first visit (where the adult provider sees the patient) would be to have a summary form from the pediatric provider detailing pertinent medical information, such as whether the patient has had surgery or not, what medications they are on, etc.”

4 Additional quotations fromclinicians related to the transition process:

“Proactive patients can make the transition smooth, but some patients wait until they are sick to make the transition and that is hard.”

“Get patients to come when they are healthy.”

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TABLE 1

Schedule of Focus Group Meeting

Written Consent Process

Greeting and Review of Meeting Proceedings

Introductions

Open-ended Questions

1. Please think back to when you transitioned from the pediatric to adult medical service and tell us about your transition experience...
    - a) How did it go well? How did it not go well?
    - b) What help did your pediatric provider provide? Was this useful or not?
2. - When you think back to your transition again – how involved were your parents? How involved did you think they should have or should NOT have been?

Buy a Feature Game

Product Box Game

Conclusion/Closing Remarks and Review

TABLE 2

Selected topics for a transition intervention program (from *Buy a Feature*) by group.

TOPIC	IBD Patients	CF Patients	DM Patients	IBD-HP	CF-HP	DM-HP
Food & Diet	X		X	X		
Career/Education and Chronic Disease	X	X	X			
Having Babies and Chronic Disease	X	X				
Physical Activity	X	X				
Anxiety and Stress	X	X	X	X	X	X
Fatigue and Depression			X	X	X	X
Managing Relationships	X	X	X	X		X
Alcohol, Drugs, Sex	X	X	X	X	X	X
Dealing with Pain	X					
How to interpret medical records	X					
Figuring out insurance	X	X	X			X
Complementary Medicine		X		X		
General healthy lifestyle		X	X			
Getting your prescription filled			X	X	X	

IBD = Inflammatory bowel disease

CF = Cystic Fibrosis

DM = Type I Diabetes

HP = Healthcare Practitioners