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# Health Care Transition: Youth, Family, and Provider Perspectives

John G. Reiss, PhD\*; Robert W. Gibson, MSOTR/L\*; and Leslie R. Walker, MD†

**ABSTRACT.** *Objective.* This study examined the process of health care transition (HCT) posing the following questions: What are the transition experiences of youths and young adults with disabilities and special health care needs, family members, and health care providers? What are promising practices that facilitate successful HCT? What are obstacles that inhibit HCT?

*Methods.* A qualitative approach was used to investigate these questions. Focus group interviews were conducted. Content and narrative analyses of interview transcripts were completed using ATLAS.ti.

*Results.* Thirty-four focus groups and interviews were conducted with 143 young adults with disabilities and special health care needs, family members, and health care providers. Content analysis yielded 3 content domains: transition services, which presents a chronological understanding of the transition process; health care systems, which presents differences between pediatric and adult-oriented medicine and how these differences inhibit transition; and transition narratives, which discusses transition experience in the broader context of relationships between patients and health care providers.

*Conclusion.* This study demonstrated the presence of important reciprocal relationships that are based on mutual trust between providers and families and are developed as part of the care of chronically ill children. Evidence supports the need for appropriate termination of pediatric relationships as part of the transition process. Evidence further supports the idea that pediatric and adult-oriented medicines represent 2 different medical subcultures. Young adults' and family members' lack of preparation for successful participation in the adult health care system contributes to problems with HCT. *Pediatrics* 2005;115:112–120; *adolescent, young adult, physician patient relationships.*

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ABBREVIATIONS. HCT, health care transition; SHCN, special health care need; A-OM, adult-oriented medicine; A-OP, adult-oriented provider; SSI, Supplemental Security Income; CF, cystic fibrosis; SCD, sickle cell disease; HMO, health maintenance organization.

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**A**s young people mature and their medical and personal needs change, it is important that they receive age-appropriate medical care. The process of moving from pediatric to adult-oriented

medicine, health care transition (HCT), is an important and necessary process in the lives of all adolescents and young adults, especially those with disabilities and special health care needs (SHCNs),<sup>1,2</sup> yet despite many years of discussion, HCT remains an unfulfilled promise for many young adults with disabilities and SHCNs.<sup>3</sup> Although it is widely known that HCT is often unsuccessful, few empirical data have been collected to help understand and explain the difficulties. This study examines the process of HCT posing the following questions: What are the transition experiences of youths and young adults with disabilities and SHCNs, family members, and health care providers? What are promising practices that facilitate successful HCT? What are obstacles that inhibit HCT? In light of the limited data regarding HCT, a qualitative approach was used to answer these questions. In the absence of a term that describes adult medical practice similar to the term "pediatric," we use the phrases "adult-oriented medicine" (A-OM) and "adult-oriented provider" (A-OP) to denote the variety of medical services and providers for individuals who are older than 18 years.

The current literature on HCT is primarily in the form of policy and position statements,<sup>2,4,5</sup> program descriptions,<sup>6</sup> and suggested transition practices.<sup>7</sup> The majority of research has been conducted through surveys of small samples and focused on service provision, needs assessments, and patient satisfaction in condition-specific clinics or hospital-based programs in the United States<sup>8–10</sup> and other countries.<sup>11,12</sup> A few qualitative research studies have also been reported.<sup>13,14</sup> Details of these studies can be found in Table 1.

A number of barriers to successful HCT have been identified. HCT was found to be abrupt with little or no preparation before transfer from pediatric to A-OM. In many instances, age rather than indicators of maturity or independence was used as the trigger for transition.<sup>10,15,16</sup> Delay in reestablishing medical care with A-OPs after discharge from pediatric services was also noted.<sup>11</sup> Other barriers included a lack of insurance coverage for adult-oriented medical care,<sup>8,9,13</sup> few A-OPs with knowledge of and expertise with pediatric-onset chronic conditions,<sup>8,9</sup> a general lack of communication between pediatric providers and A-OPs,<sup>13</sup> and differences between adult and pediatric care<sup>11,13,14</sup> such as pediatrics' supportive and family-centered approach versus A-OMs' expectation of independence. Young adults and their families were also reluctant to leave familiar and trusted health care providers and settings.<sup>13,14</sup> The supportive nature of pediatrics was observed to fos-

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**TABLE 1.** Summary of Transition Research

Author	Site	Sample	Diagnosis/Participants	Design	Result
Anderson et al <sup>16</sup>	US, Europe, Australia	334, 25.9% response rate	CF/members of International Association of Cystic Fibrosis Adults	Mailed survey	Age was predominate factor for transfer to adult-centers. Result demonstrated a lack of transition program for most adults with CF. Young adults voiced less concerns about transfer than their parents and directors of pediatric CF centers.
Flume et al <sup>15</sup>	US	110 pediatric program directors, 65.5% response rate; 44 adult program directors, 72.7% response rate	CF/program directors of CF centers	Mailed survey	Age was used as a primary factor in transferring to adult care. Transfer was not introduced until quite late, and many families did not meet adult provider until first adult visit. Pediatric directors perceived more difficulty with transition than adult directors.
Hauser and Dom <sup>13</sup>	US	Purposive sampling A = 12 PC = 12 P = 8 YA = 135, 36% response rate	Adolescents with SCD aged 13–21, parents and practitioners	9 focus groups/interviews	Concerns about leaving familiar settings, going to providers who may not be familiar with SCD, and establishing new family roles.
Pacaud et al <sup>11</sup>	Canada	YA = 135, 36% response rate	Diabetes/patients transferred to adult care from 2 pediatric hospitals	Mailed survey	50% had difficulty with transition, differences noted between pediatric and adult care
Patterson and Lanier <sup>14</sup>	US	Nominated sample total 7	Adolescents and young adults with disability	3 focus groups	3 themes: barriers, supports, and strategies
Scal et al <sup>9</sup>	US	Nominated sample of transition programs, 155 programs with a response rate of 46%	All/nominated sample of programs that provide HCT services to youths and adolescents	Mailed survey	Observed 2 models of organization: adolescent and condition focus.
Telfair et al <sup>8</sup>	US	A = 36 YA = 60 C = 25	SCD/patients in a comprehensive sickle cell program	Cross-sectional survey/interview and mailed survey	Barriers to transition: funding, access to adult providers. Family and adolescent resistance rarely reported.
Westwood et al <sup>12</sup>	South Africa	A = 13 PC = 21 YA = 8 PA = 5 77% response rate	CF/patients in a pediatric program and their parents and patients in an adult program and their parents	Cross-sectional mailed survey	Consensus from all groups regarding concerns about leaving pediatric care and need for transition programs 80% of the respondents unsure of transition, and 90% believed that a transition clinic would be helpful.
Wojciechowski et al <sup>10</sup>	US	Convenience sample of 18	SCD/18- to 24-year-olds transferred to adult SCD care within the past 3 y of study's initiation	Structured interview, face to face or telephone	Young adults with SCD receive little preparation for transition, follow-up care in adulthood diminishes, and transition often based on age

A indicates adolescent; PC, parents of children; P, practitioner; YA, young adult; C, caregiver; PA, parents of adults.

ter dependence in the young adult, which made transition to A-OPs difficult.<sup>13</sup>

The literature included a number of suggestions for making HCT more successful: beginning transition early, having pediatric providers share medical histories with the A-OP, using nurses to oversee transition,<sup>14</sup> and the use of transition clinics.<sup>12</sup> Other suggestions involved helping the young person become an expert in his or her own medical condition, improving his or her understanding of the difference between pediatric medicine and A-OM, providing young adults with opportunities to practice independent disease management and navigating the adult health care systems,<sup>13</sup> and promoting peer-to-peer information sharing.<sup>14</sup> Providing training to A-OPs about the adult sequelae of pediatric-onset chronic conditions was also suggested.<sup>13</sup>

Although the literature provides some information about barriers and identifies promising practices, a full understanding of the transition experience and the variables that contribute to its success or failure remains illusive. We hypothesized that by examining the lived HCT experience of youths and young adults with a broad range of SHCNs and disabilities and their families and health care providers, we could gain a more in-depth understanding of the process and identify practices and factors that make transition more or less successful.

## METHODS

A qualitative approach<sup>17–21</sup> was used in this study to address the need for exploratory research on HCT and to document the transition experience from the perspective of those involved in the process of HCT. This approach allowed for the identification of variables that have an impact on HCT and systematically document and analyze the lived HCT experience of young adults and their family members and health care providers.

## Design

Participants who represented 3 groups (youths and young adults with disabilities and SHCNs, family members, and health care providers) were recruited at children's hospitals, outpatient clinics and treatment programs, community medical centers, and professional meetings. In keeping with the exploratory nature of the study, participants were not expected to constitute a representative sample. However, individuals with a variety of diagnoses, medical conditions, racial and ethnic backgrounds, geographic origins, and medical practice experience were recruited. Most participants were identified through nominations by health care providers. Inclusion criteria for adolescents/young adults were age (13–35 years), a chronic disability or SHCN, and initiation of treatment occurring before age 18. Family members consisted of the parents, guardians, grandparents, siblings, and spouses of adolescents and young adults with chronic disabilities and SHCNs. Participation of family members was not dependent on their child's participation in the research and vice versa. All focus groups were held in accessible spaces, and adapted communication options were available. Adolescents/young adults and family members were provided with a \$25.00 incentive. Health care providers with experience or knowledge of HCT were recruited through professional contacts and nominations with the goal to represent a range of medical training and experience.

Focus groups and interviews (occasions when there was only 1 participant) were 60 to 90 minutes in length (see Table 2). Separate focus groups were held for youths and young adults, families, and providers. Focus groups were conducted using a standard protocol (see Question Protocol), and focus group leaders ( $n = 3$ ) received training to ensure uniformity in the implementation of the protocol. The research was approved by Institutional Review Board of the University of Florida.

## Analysis

After all focus groups, leaders participated in a structured, self-administered debriefing session and completed field notes. All focus groups were transcribed verbatim, and transcripts were reviewed by 2 members of the research team for accuracy. Transcripts and field notes were analyzed with the assistance of ATLAS.ti,<sup>22</sup> a qualitative data management program. Debriefing discussions and field notes served as the basis for initial content analysis<sup>20,23,24</sup> of transcripts. All transcripts were reviewed and coded by 1 member of the research team. Codes and emerging themes were discussed continually among the principal investi-

TABLE 2. Participant Demographics

	Total	Youth/Young Adult	Family	Provider
No. of groups	30	10	10	10
No. of interviews	4	1	0	3
Average $n$ /group	4	5	4	4
Range	1–11	1–9	2–7	1–11
No. of participants	143	49	44	50
Male/female		24/25	8/36	9/41
Age range		13–37	15–65	39–69
Age distribution				
13–19		25	1	0
20–29		19	1	1
30–39		5	7	17
40–49		0	15	10
50–59		0	16	18
60–69		0	3	3
Ethnicity				
White	81	19	23	39
Black	56	26	20	10
Mixed/biracial	1	1	0	0
Other	5	3	1	1
Title				
MD				7
RN				25
Psychology				1
Social work				9
Administration				4
Other				4

gators and agreed on or revised through a process of consensus. Themes then were organized into 3 broad content domains: stages of transition, health care systems, and transition narratives. Narrative analysis<sup>17</sup> was conducted on transition stories that were presented during the focus groups. Narrative analysis was used to understand the meanings that HCT had for participants and the beliefs that they held about the process. An outside consultant with expertise in qualitative analysis reviewed selected transcripts and coding strategies. This external review concurred with the coding strategy, theme development, and narrative analysis.

## RESULTS

### Participants

A total of 143 individuals participated in 34 focus groups and were almost evenly divided across the participant groups: youths and young adults (49), family members (44), and health care providers (50; see Tables 2 and 3 for participants' demographics). Focus groups were held in 9 cities in the Southeastern and Midwestern United States. Participants were drawn from >20 states. Health care providers practiced predominately in the area of pediatrics, although some had experience in A-OM. To protect the identity of participants, pseudonyms are used and quotes are attributed to the participant's group, youth/young adult and age (YA-age), family member (Fam), and health care provider and discipline (HCP-discipline).

### Factors That Affect Transition

Two factors that had a significant effect on the process and outcomes of HCT were identified: cognitive ability of the young adult and the progressive nature of the SHCN or disability. Although cognitive ability does not seem to be the sole arbiter for success or failure of HCT, it emerged as an important concern for families and providers. Young adults with impaired cognitive ability but sufficient skills for independent living could transition successfully, provided that they received additional supports to address cognitive deficits. The problems of transition were markedly increased for young adults with severely impaired cognitive ability; it was very difficult to find A-OPs who would both provide care for the young adult and work collaboratively with the family.

Participants also believed that youths whose condition was progressive in nature and likely to shorten significantly their life span should not be transferred to new A-OPs for end-of-life care if the change was not desired by the young adult or the

family. Participants also noted that it was important to recognize the changing developmental needs of these young adults when providing medical care.

### Stages of Transition

Participants viewed transition as a developmental process composed of 3 stages that we have labeled "envisioning a future," "age of responsibility," and "age of transition." The first 2 stages involved general developmental tasks that laid the foundation for addressing transition-specific activities that occurred during the "age of transition."

"Envisioning a future" was described as beginning as soon as a disability or SHCN was identified. Envisioning the child growing up to be an adult helped to promote future planning. Participants acknowledged that plans were subject to extensive revisions as the child's abilities emerged over time. However, it was asking questions about the future rather than the details of the plans that was important. Asking questions about future education, employment options, independent community living, and needed health care prompted families and providers to initiate activities that promoted the child's future independence. As one parent stated, "He [the child's pediatrician] looked at the kids developmentally. So when Bobby was 3 or 4 months old, he said to me, 'Where do you want Bobby to be in 20 years?' And because of that, I began to think about where it was that I wanted him to be in 20 years" (Fam).

In conjunction with envisioning and planning for a future, participants recommended starting the transition process early. Practitioners and parents alike talked about the importance of "starting early." One parent stated, "I think a lot has to do with instilling an attitude of self-confidence with the kids early on and just expecting them to do things for themselves" (Fam). "He [pediatric specialist] was a very firm believer in the children taking responsibility for their own health care. And so when Bobby was 2½ years old, he started answering his own questions when we came to clinic, and as a family we started rehearsing those questions and answers on the way to clinic" (Fam).

"Age of responsibility" was the second stage delineated by participants. It was during this stage that family members laid the foundation of future independence by teaching and giving responsibility to the child to carry out tasks of daily living and medical self-care. Examples included talking with health

**TABLE 3.** Disabilities, SHCNs, and Providers' Practice Areas Represented in the Study

Attention-deficit/hyperactivity disorder/ learning disabilities	Endocrine	Muscular dystrophy
Arthrogryposis	Gastroenterology, gastrointestinal problems	Neurologic problems
Asthma	Head injury	Orthopedics
Autism/developmental disability	Hearing impairment	Osteogenesis imperfecta
Cancer	Hematology/oncology	Pierre Robin syndrome
Cardiology	Hemophilia	Renal disease
Cognitive impairment	HIV/AIDS	Rheumatic diseases
Congenital heart defect	Juvenile rheumatoid arthritis	Seizure disorder
Cerebral palsy	Juvenile diabetes-type 1	Sickle cell anemia
Craniofacial/cleft palate	Lupus	Spina bifida
CF, pulmonary	Mental illness (bipolar, depression)	Transplant
Down syndrome	Mental retardation	Trauma

care providers, ordering and taking medications, and developing positive medical habits and routines. Several participants suggested that this transfer of responsibility occur before the onset of adolescence.

The “age of transition” was divided into 2 periods: adolescence (ages 12–17) and young adulthood (ages 18–23). The dividing point for these periods was flexible but centered around the legal age of emancipation, which begins in the United States at 18 and generally is completed by age 21. With some allowance for developmental delays, these age markers were in agreement with the typical expectations for independence in healthy young adults. Examples include, “Since he’s been 16 or 17 years old, he’s gone to a lot of his [doctor’s] visits by himself” (Fam); “So around 14 is when we usually say and it varies if we have problems with appointments, we have the child make the appointment or the adolescent” (HCP-Nurse).

Maturity and experience were also seen as necessary to carry out successfully medical responsibilities associated with transition. The following statement from a pediatric cardiologist draws the distinction between maturity and chronological age and its importance in transition: “If someone is on coumadin because they have an artificial valve which will clot if they stop taking it, our practice is fairly aggressive about ensuring that they do the appropriate monitoring for that and track them down. I think that’s an uncommon trait in a practice that only follows adults, and it isn’t uncommon that someone is 28 [years old] before they are responsible for that, and it makes us hesitant to transition into practices that don’t have that degree of follow through.”

In addition to strategies for facilitating the HCT developmental process, most of the participants reported obstacles that impeded transition. These are discussed below in Health Care Systems and Transition Narratives.

### Health Care Systems

Participants noted differences in the operation of pediatric and adult-oriented medical systems that created a number of barriers to transition. Four systems barrier are discussed below: aging out of treatment, insurance/funding, availability of care, and practice differences.

#### *Aging out of Treatment*

As found in children’s hospital mission statements and state and federal agency funding mandates, pediatric systems generally used the ages of 18 or 21 as the limit for services. Age limits were also related to service providers’ expertise and comfort with providing certain services. Examples identified by participants included the refusal of pediatric anesthesiologists to provide anesthesia services to adult patients in children’s hospitals and the licensing guidelines for pediatric nurse practitioners that limit treatment to individuals under the age of 25.

Noted earlier, family members and providers discussed how transition was often based on age rather than on maturity. As stated by 1 health care provider, “Some of our patients are ready and others are

not, but the way the system is set up, it’s defined by age and not by readiness in some disease groups” (HCP-SW).

Discharge from pediatrics was also related to the display of what were considered adult behaviors, as reflected in the following quote: “Pregnancy is an automatic . . . if you do the adult behaviors, then you earn yourself a ticket to the adult program, and that’s not a punitive measure by any means” (HCP-SW). Other behaviors that prompted transition included substance abuse, criminal activity, and behaviors inconsistent with pediatric inpatient treatment areas.

It was also noted that when young adults were transitioned to A-OM, they found themselves in a medical system that is organized for much older adults: “We have to acknowledge that a 25-year-old young adult is an old patient for a pediatric hospital and is too young for most adult hospitals, where the average is 55 or 60” (HCP-SW).

#### *Insurance/Funding*

Another age-related HCT concern was the continuation of health insurance. Although the funding of health care for children is not without problems, all of the children and young adults who were younger than 18 years and participated in this study had some form of private and/or public health insurance. Private health insurance was linked to parents’ employment and typically ended between the ages of 18 and 23. Coverage to age 23 usually depended on the young adult’s continuing formal education. “Our kids, whenever they get out of school or they hit 23, in our case they can’t be covered by our insurance any more, and sometimes they have no insurance” (Fam).

Public funding from states’ Title V Children with Special Health Care Needs Programs typically ends at 21 regardless of the young adult’s employment or education status. Some young adults had received Medicaid coverage because they were eligible for Supplemental Security Income (SSI) benefits. However, because the standards for SSI eligibility after age 18 are more stringent, some of these young adults were not eligible for SSI and as a result lost Medicaid coverage. It was also noted the amount, duration, and scope of services funded by Medicaid for individuals over 21 is significantly less than for those under 21. “Medicaid coverage drops drastically when they turn 21. They paid for fewer supplies, they were not going to pay for the ventilator, which he needed to sustain life, and he was getting 16 hours of nursing care for these 3 to 4 years up until he turned 21. The very day he turned 21, he switched over to [a significantly reduced schedule of] nursing visit, which Medicaid would pay for” (HCP-Nurse).

#### *Availability of Care: Practitioner Knowledge, Experience, and Training*

Young adults and families who sought A-OPs (either from personal desire to transition or as a result of an impending termination of pediatric services) reported that it was very difficult to find A-OPs who matched their pediatric providers in their knowledge about, training in, and experience with their disability or SHCN. This perception was confirmed by pe-

diatric providers who participated in the study. As stated by one physician, "A child with cystic fibrosis (CF) who goes to a pediatric pulmonologist and who you will see periodically, they will continue to go to that peds pulmonologist because when they go to an adult pulmonologist, they don't know what to do with them" (HCP-Physician).

Differences in pediatric and adult-oriented treatment approaches also led to negative assessments of A-OPs' medical knowledge. A nurse reflecting on the negative transition experiences of a client stated, "And truth be known that ours was a more up-to-date treatment. So it was possible that the adult treater was not familiar enough with the disorder, so he was sort of falling back on medical knowledge that he knew from way back when and really wasn't up to date on it [current treatment]" (HCP-Nurse).

It was also believed that many A-OPs had not previously treated young adults with pediatric-onset disabilities and SHCNs, and this lack of experience reduced confidence in A-OPs' ability. Family members recounted, "I've heard a lot from [adult-oriented] doctors that they've never seen a child with significant disabilities ever before" (Fam); and, "I'm apprehensive because I know he [adult-oriented physician] doesn't have a whole lot of experience with patients with CF" (Fam).

Health care providers shared a similar understanding. One physician observed, "We [pediatric providers] are better at taking care of these kids, and so they live longer, when in the past, the adult cardiologist never saw a kid with this kind of congenital heart disease because they always died before they were 21" (HCP-Physician).

Similar comments were made about the treatment of spina bifida, sickle cell disease (SCD), and other childhood-onset chronic conditions. Young adults and family members cited the A-OP's perceived lack of knowledge and experience as their reason for wanting to stay with pediatric providers. In addition, young adults and family members said that they did not want to "start all over again" and educate the new A-OP about their medical condition.

Providers attributed the A-OP's lack of knowledge and experience to the different training and residency experiences of pediatric and internal medicine residents. "The adults [oriented providers] don't necessarily have the training to take care of those subspecialty needs" (HCP-Physician). As a result, knowledge about current treatments and research on childhood-onset disabilities and SHCNs are generally limited to pediatric providers despite the fact that young adults are expected to seek care from A-OPs. It also was apparent in discussions of medical training that pediatric physicians and A-OPs were acculturated to different styles of medical practice during residency. Families and young adults were quick to notice these differences between pediatric medicine and A-OM, as is discussed in the next section.

#### *Practice Differences: Change in Service*

An observation heard consistently throughout the focus groups from all participant groups was the

perceived practice difference between pediatric medicine and A-OM. The majority of the participants had extensive experience with treatment from a pediatric perspective. Experience with A-OM was varied and ranged from accessing services for one's self or a family member to the accounts of young adults as relayed through their pediatric providers. Practice differences are organized under the following headings: organization of care, communication, and family involvement.

#### *Organization of Care*

Pediatric care was perceived as better organized for the patient and his or her family. Participants reported that the majority of pediatric medical care was provided by 1 physician provider or by a pediatric clinic that provided multiple clinical and treatment services at 1 location. However, the following observation paints a different image of A-OM: "One complaint I get from my adult CF patients that are working . . . is they already spend their vacation time and most of their sick time on health care needs and if I then transition them to a system where they have to see 5 different or 6 different doctors, it doesn't work well. One of the real problems I see is that internal medicine has not really adopted the idea of comprehensive care or specialty care that encompasses the patient's needs" (HCP-Physician).

Differences were also observed in the number and variety of staff found in pediatric medicine and A-OM settings. Pediatric patients were "used to certain level of care which incorporated social workers, nurses who understood your illness and had a much more psychosocial approach to your illness. And then you get kind of tossed into the adult role, which is very different. It is very much disease centered, quick and dirty" (HCP-Physician).

Pediatric staff were perceived to be more available for questions and support. As one pediatrician observed, "We clearly provide far more comprehensive care and emotional support to our adult patients than in the internal medicine model" (HCP-Physician). Participants also described a different feel to pediatric treatment. Pediatric providers were perceived as more supportive and involved with the patient and the family. This was reflected in the previous quotes and in the following: "There was . . . a warm cozy sort of feeling about Children's [hospital] that she didn't get there [adult setting]" (Fam).

Treatment practices and interactions between patients and providers also differed. Young adults and family members with SCD observed that the treatment of pain in adult-oriented settings was very different from that provided in a children's hospital. As one family member observed, "If it is a child, they will give them the pain medicine without questions, but when you turn adult, it's a different thing. Like you're not really in pain, you just want medications" (Fam). Young adults who had SCD and sought care in A-OM settings stated that they were treated as though they were drug addicts when they spoke knowledgeable about which pain medication and dosage would help to relieve a pain crisis.

There was also a different understanding of the

role that patient education plays in supporting the patient's adherence to a treatment regimen: "In CF, we really educate the families and the patients because I think it improves adherence, and without education, they won't take their 80 pills a day. But when one of our patients goes to an internist and says this is how I treat my CF, will you write the scripts, the sparks fly. So you can educate them [young adults] so they know what they should be doing, but the people who are receiving them don't want to hear that and say, 'I know how to do it right' " (HCP-Physician).

#### *Communication*

Participants reported that there was little communication between pediatric providers and A-OPs. This lack of communication could be observed at an institutional level. "We are literally across the street, the pediatric and the adult hospital, and yet it feels like there's a moat and a wall and maybe a couple of states and an army [between us]" (HCP-Physician). This lack of communication affected the transfer of knowledge between pediatric medicine and A-OM and also made referral to A-OPs difficult. Another concern voiced by pediatric providers was the lack of follow-up communication after a young adult had been transferred to an A-OP. One physician noted the time and interest that he had invested in a young adult patient: "When you transition them, there is very little feedback. . . . So why would I need to know what had happened to this patient that I had followed for 14 years? So there is usually very little information that comes back from the medical arena" (HCP-Physician).

Participants also reported that communication patterns between providers were influenced by residency training, continuing education, professional meetings, and the physical separation between pediatric and adult-oriented treatment spaces. This limited the sharing of knowledge, resources, and continuity of treatment practices across pediatric medicine and A-OM.

#### *Family Involvement*

Participants in the study saw pediatric medicine as being very family oriented. Although adolescent patients spent increasing amounts of time alone with health care providers, families generally saw themselves as having an ongoing role in the care of the young adult and continued to communicate with the pediatric providers. As discussed in Transition Narratives below, the relationship between pediatric providers and families was an important component of health care provided to children with disabilities and SHCNs. A-OPs' focus on the individual patient left parents without a role in their child's treatment and limited their ability to share important knowledge with the new health care providers. After many years of supporting and being involved in their children's health care, parents reported feeling excluded when their child transitioned to A-OM.

#### **Transition Narratives**

Many participants shared transition stories. These stories provided context, explanations, and insight

into the lived experience of transition and generally included 3 sections: background information, relationships with pediatric providers, and changes that occurred after going to an A-OP.

Background information included length of time that the young adult had been in treatment with his or her physician or clinic. Time in treatment was readily recalled and was frequently >10 years. Youths and families also stated that treatment success, independence, and, sometimes, life itself were attributed to the knowledge and expertise of the pediatric health care provider(s).

In the "relationship" section of the stories, participants described what made the health care relationship with their pediatric providers special. Highlighted were providers' respect for the family's and patient's knowledge of and experience with the disability or SHCN and a concern for the young person's overall development. Physicians also expressed their strong bond with patients and their families: "I don't know if I would put the effort in if I didn't feel bonded to them. . . . I'm seeing the patients 4 to 6 times a year from birth to adulthood" (HCP-Physician). Other important attributes included "rapport," "mutual understanding," and, most important and frequently mentioned, "trust." As one young person put it, "I was with Dr O and so he helped me a whole lot, ever since I was born, so I trust him a lot" (YA-16). Trust was an expected and central component of the relationship with pediatric health care providers. Trust was so much a part of the relationship that families and youths no longer reflected on it and it was viewed as a natural part of the health care relationship. Physicians also spoke about their trust in patients and families, in their knowledge and expertise that comes from living with a SHCN, and in their ability to make sound medical decisions and to determine the need for care.

In contrast to the almost idyllic context within which they described pediatric care, families and young adults described distinctly negative experiences with A-OM. All participant groups described difficulty establishing trusting relationships with new A-OPs. This was magnified when the A-OPs were unfamiliar with the youth's condition and/or current treatments and were unwilling to recognize the family's or young adult's proven expertise and work with them as "equal partners." Young adults and family members wanted to have a positive relationship with their new health care providers, but negative health care experiences with A-OPs were quick to erode trust and made it very difficult to replicate the satisfactory relationships that they previously had with pediatric providers.

Pediatric providers who had cared for young adults as children also expressed a need to trust A-OPs who would be responsible for the future care of the young adult: "I think there's a level of trust that has to be between the pediatric hematologist and the adult hematologist so that I can trust that you are going to provide the very best care. I'm a little bit afraid. I've been taking care of this child since he was an infant. [He's] doing well and I think there's some fear for really unknown reasons that I think a lot of



the pediatric providers feel. Like, once I transition you over to adult care, it's going to be blown" (HCP-Nurse).

The section that described experiences with A-OM generally began with a statement of the young adult's previous good or stable health. The stories then described how the young adult's health was jeopardized or negatively affected by A-OM. One adolescent talked about her emergency department admission for a medical crisis at an adult-oriented hospital. From the adolescent's perspective, the treatment was not comparable to her previous pediatric experiences. "So, I can't trust those people [adult providers] to know what to do. . . . Because they could have given me something that could of killed me. So, and then they didn't know what was wrong with me or how it happened. So they didn't treat me properly, so they had to transfer me here [pediatric hospital]" (YA-15). A pediatric provider spoke about 1 young adult patient who was forced by her health maintenance organization (HMO) to "see an internist and adult pulmonologist with no experience with CF, knew nothing about CF, and within 6 to 8 months had removed all of the expensive medication and treatment from the patient's regimen, saving [the HMO] about \$30 000 a year in treatment and costing the patient probably 5 to 10 years of progression in their lung disease. And the patient stayed with [the HMO] for about 4 years, in which case she got severely ill, came back here [pediatric hospital], and with the threat of a law suit, [the HMO] then decided that they would pay for care here [pediatric hospital], the rest of that individual's life because they clearly had been negligent. . . . It was a total disaster for the patient, and that's one of the concerns that I really have" (HCP-Physician). Other participants spoke about their negative adult care experiences with surgery, inpatient units, and outpatient visits.

It is well documented that the ending of long-term clinical care is an important component of the therapeutic relationship and that termination should be conducted in a thoughtful and planned manner.<sup>25-28</sup> However, many participants said that pediatric treatment services were ended abruptly. As discussed by 1 participant, "There was a sense that we had just kicked them out the door rather than talking to them about it. . . . And part of that psychological process needs to be that the staff has to say good bye and terminate, and that's a loss, and the patient also needs to be able to say good bye and terminate, and we don't really have any rituals the way we might have around other kinds of termination" (HCP-SW).

Evidence from the focus groups also supported the idea that pediatric and adult medical practices represent 2 different medical subcultures.<sup>29</sup> The following speaks to some of the differences: "There are a lot of [different] philosophies between adult medicine and pediatric medicine. That is 1 of the things and I think that both the pediatric side and the adult side have their valid points and this is why transition is so important because you can't pick a date and just stop. So I think that's why it's so important for the pediatric and the adult sides to work together to

graduate the patient from dependent care to the independent care when it's appropriate medically and developmentally. And I think both sides need to have a greater awareness of both needs" (HCP-Physician).

#### CONCLUSION: IMPLICATIONS FOR PRACTICE

Our findings regarding the lived health care experience are in keeping with those of previous studies. Furthermore, our results add to the existing literature by highlighting 4 factors that have a major impact on the transition process: transition as a developmental process; the significant differences between the pediatric medicine and A-OM subcultures; financing; and the role that reciprocal, trusting relationships among young adults, families, and providers plays in the evaluation of care and the assessment of competence and satisfaction.

Participants understood HCT to be a long-term developmental process, involving the family, the child, professionals, and the broader health care system. The process should start in childhood or at the time of diagnosis by "envisioning a future." Providers can help to facilitate transition by encouraging families to envision their child's future and promoting medical independence.

Participants identified significant differences between pediatric medicine and A-OM. This research supports the finding that there are 2 distinct medical practice subcultures that do not share a common understanding of what needs to be done operationally to facilitate the transitional process. Health care providers can help to bridge the differences between pediatric medicine and A-OM through joint training and educational experiences in the adult sequelae of childhood-onset disabilities and SHCNs. Communication can be enhanced through the use of a standard "transition note" that includes a concise and relevant medical summary, current medical references, and strategies for working with and using the medical expertise of the young adult and his or her family. Providers can also help young adults and families understand and prepare for the practice and cultural differences between pediatric medicine and A-OM.

Another significant issue is financing. HCT occurs at a time when most young adults are least likely to be covered by health insurance.<sup>30</sup> Whereas healthy young adults tend not to use health care, the loss of insurance coverage is a significant problem for young adults who have SHCNs and require ongoing medical care.<sup>31,32</sup> Young adults with SHCNs are less likely to acquire employment-based insurance because of their high rates of underemployment and unemployment.<sup>32</sup> Although insurance coverage is an important issue, it is not the sole cause of HCT difficulties, because HCT is a significant problem in countries that have national health insurance programs.<sup>11,12</sup> Advocacy on the part of the pediatric and adult health care communities is critical to providing seamless insurance coverage for all young adults.

All participant groups identified a trusting and reciprocal relationship among providers, family members, and young adults as the basis of successful pediatric health care. It was within the context of

these “trusting” relationships that evaluations of A-OPs’ medical knowledge and experience were made. Negative transition experiences with A-OM serves as warnings to transition. One bad experience was enough to make young adults, families, and providers think twice about transitioning young adults to A-OM. Resistance on the part of young adults and their families is often cited as a reason that transition is not successful. However, our results suggest that resistance on the part of young adults, family members, and providers to transition is not unfounded but is a sign that the care offered by A-OPs is perceived to be inferior to the care provided in the pediatric medical system.

The results also underscore the necessity for pediatric providers to terminate existing treatment relationships in a therapeutic manner to facilitate development of new relationships with A-OPs. Successful termination affirms the young adult’s personal responsibility and independence and provides an opportunity to verbalize important feelings and concerns. The development of rites of passage that support and mark HCT just like graduation from high school marks a significant step in the education process would serve to bring closure to the pediatric health care experience and establish new positive relationships with the adult-oriented health care system.

Inherent in the design of our study are 2 limitations that need to be recognized. First, many disability/diagnoses were represented by the participants, but only a few individuals had experience with a given condition. Thus, differences that exist in the transition experience of individuals who represent different conditions could not be identified or addressed. Also, there was a preponderance of providers from pediatrics; thus, the perspective of adult providers was not well represented, and additional research is needed to describe better the transition experiences of A-OPs.

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