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## Healthcare System Supports for Young Adult Patients with Pediatric Onset Chronic Conditions: A Qualitative Study

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### Abstract

Over 90% of children with chronic conditions survive into adulthood necessitating primary care teams to care for adults with pediatric-onset chronic conditions. This study explores practice supports and barriers to care for this population via qualitative techniques. Using in depth interviews with twenty-two healthcare providers practice supports identified include: formalizing intake processes, interoperable electronic medical records, and leveraging care coordination. Barriers identified included: definition of the medical team, lack of appropriate medical records, time and administrative burden, lack of training, and financial constraints. Themes may be utilized to design interventions and improve care coordination for patients with pediatric-onset chronic conditions.

### Keywords

Healthcare systems; Medical home; Qualitative methods

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RECENT ADVANCES IN the treatment of pediatric chronic illness necessitate adult primary care teams to facilitate the transition and ongoing care of adults with pediatric onset chronic illness into adult healthcare systems (Newacheck & Taylor, 1992). Currently, over 90% of pediatric patients with chronic medical conditions are living into adulthood with approximately 500,000 patients entering adulthood each year (Blum, 1995). Once fatal conditions such as cystic fibrosis (CF), sickle cell disease (SCD) and complex congenital heart disease now have life expectancies well into adulthood. For some pediatric onset chronic conditions there are more adults living with an illness than children (Elborn, Shale, & Britton, 1991; Platt, Brambilla, Rosse, et al., 1994; Reid et al., 2006). Despite improvements in pediatric care, adult patients with pediatric onset medical conditions often

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have complex medical and social needs as adults due to accumulated complications from decades of illness and treatment (Blomquist, 2006; Kirk, 2008).

Transitioning from pediatric to adult oriented healthcare has been set as a core performance outcome for patients with chronic medical conditions by multiple professional organizations, yet adult providers feel poorly equipped to manage this growing population (AAP, 2002; Blum, Garell, Hodgman, et al., 1993; AAP 2011; Lotstein et al., 2009; Okumura, 2009; USDHHS, 2010). Previous surveys of adult providers identified barriers to transition including patient and provider characteristics and health system constraints (Okumura et al., 2008; Okumura et al., 2010; Peter, Froke, Ginsburg, & Schwartz, 2009). Qualitative studies have explored the perspectives of patients, parents and pediatric providers on the topic of transition and ongoing care in adult healthcare systems. However, these studies have been limited by their lack of representation of adult providers and thus may not aid primary care teams who accept responsibility for these patients and provide their ongoing medical care (Huang et al., 2011; Reiss, Gibson, & Walker, 2005; Scal, 2002).

The purpose of this study was to examine current practices in the care of adult patients with childhood onset chronic illness by adult providers who have experience caring for these patients in order to elicit barriers and facilitators to their care. We also aimed to compare this population to other patients with chronic illness in order to elicit existing facilitators that may be used or adapted for this group.

## Methods

### Study Design and Population

This was a cross sectional study consisting of qualitative open-ended, semi-structured, in-depth interviews with twenty-two providers who care for adults with pediatric onset chronic conditions. The study was approved by the IRB at the University of Pennsylvania. All participants provided verbal consent at the onset of their interview. Interviews were conducted between March 2011 and August 2011.

We purposively sampled providers who care for young adults with congenital or pediatric-onset chronic conditions in an ambulatory setting. Seventeen initial providers were invited to participate if they were known by the study team to care for these patients. Another 50 participants were recruited by the snowball method, that is, referred by study participants. Sixty-seven providers were invited to participate in the study. Ten providers declined interviews and thirty did not respond to request for interview. Twenty-seven providers agreed to participate. Five did not complete interviews because of scheduling difficulties or because clinical duties were primarily hospital-based. Twenty-two providers completed an interview.

### Data Collection

Through a detailed review of relevant literature and consultation with outside experts, an interview guide was developed to elicit provider experience regarding the process of initial transfer of care, current clinical care, and practice supports for adults with pediatric-onset chronic conditions. Qualitative techniques are particularly well suited for this study to

explore physician experience and practices in detail to elicit care innovations not previously identified (Maxwell, 2005). Questions were primarily open-ended and not leading. A single interview lasting 30–60 minutes began by having the subject walk through their last interaction with a patient with pediatric onset chronic illness and identify facilitators and barriers to their care. Follow up questions aimed to highlight other facilitators and barriers not previously identified and compare these facilitators and barriers to patients with chronic illness that is not pediatric in onset. The complete interview guide is available from the authors on request.

Before the start of the study, the interviewers (an MD and two research assistants) were trained by members of the study team experienced in qualitative research and interviewing. Interviewers were then observed conducting mock interviews. All interviews were conducted by phone. The team met biweekly throughout the study to ensure interview consistency and data quality and to modify the interview guide to explore emerging themes. Recruitment was discontinued when no new themes were identified during interviews (thematic saturation) (Saldana, 2009).

We collected demographic data on providers. Contents of interviews were recorded digitally, transcribed, and entered into NVivo 10.0 software (QSR International, Melbourne, Australia) to facilitate data management.

## Data Analysis

We used inductive content coding to analyze the interviews, identifying themes without using an a priori set of codes (Kelle, 2007). Five research team members read the first five interviews and developed an initial coding scheme. An iterative process of revision was utilized to revise the coding scheme that was then approved by the entire study team. Two research team members then independently coded each transcript. Differences in coding were reconciled collaboratively. Representative verbatim comments were selected for presentation.

## Results

### Study Population

Twenty-two providers completed interviews: sixty percent were female and the mean time since completing training was 11.6 years. The twenty-two participating providers were primary care physicians ( $n = 20$ ) or subspecialists ( $n = 2$ ) who provided primary care for their patients. Providers represented practices in five different states, 8 different institutions and 11 different clinical practices. The majority of participants identified themselves as being affiliated with an academic medical center; 2 respondents worked in a federally qualified health center; and 1 respondent worked in a private practice.

### Existing or Proposed Healthcare System Facilitators to Care of the Adult Patient with Pediatric-Onset Chronic Illness

Participants identified facilitators to care for adult patients with pediatric-onset chronic conditions. Major themes identified were: (1) formalizing intake processes around new

patient transfers, (2) interoperable medical records and use of patient portals and (3) leveraging care coordination infrastructure within the patient-centered medical home (Table 1).

**Formalizing Intake Processes Around New Patient Transfers—**Providers identified formalizing guidelines surrounding the transfer of patients from pediatric to adult medical care as a useful practice. Having patients, parents, and providers “agree on when a young person is going to leave an institution and what is the understanding when they come to a [new] institution” helps set expectations that can lead to smoother transition and subsequent care.

Transition tools may also be incorporated into policy as some providers report the utility of “readiness assessments”, “developing fact sheets” and “transition checklists”. One provider discussed formalizing processes surrounding caregiver involvement through discussion and written documentation, such as signing a HIPAA compliance form.

In some policies a joint visit is used where patients see both a member of the pediatrics team “and the adult practitioner so that the patients have a sense of who the new practitioner will be”. Ongoing communication between the pediatric and adult team is also essential. The pediatrics team “has to be available for discussions, because it’s hard to get a full history and understanding of the scope of the patient just from written documentation” or an initial meeting. Transition coordinators or nurses from pediatric practices have been cited as useful contacts for both providers and families during initial contact and for follow up communication.

Most policies include communication about patients via a medical summary. Summaries are not uniform, but usually include “main medical issues” and “medication list”. Some practices modify communication expectations according to “a severity scale”: transfer of less complex patients requires only a fax of medical records, while transfer of more complex patients requires a phone call.

Finally, practices that accept high numbers of adults with pediatric onset chronic illness also have adopted policies that encourage front office staff to assess patient needs and schedule appropriate visit length at intake.

**Interoperable Electronic Medical Records and Use of Patient Portals—**Electronic medical records and electronic communication were identified as a solution to issues of failed communication. For some providers who share an electronic medical record with pediatric colleagues, “a summary letter that indicates the transfer of care” is incorporated into the electronic health record as is “disclosure of prior notes”. The summary letter that includes the main medical issues can help succinctly describe important aspects of a long or complex history. In some instances the electronic medical record is used to communicate information about complex young adult patients to practice colleagues or a hospital system by incorporating plans for common acute issues.

Patient portals also seem to be well suited for this young adult population and their families. A system where patients “can e-mail [providers]” and “see their own lab results” seems to be

beneficial to both patients and providers who utilize it. Providers state, “it actually saves me time”.

**Leveraging Care Coordination Infrastructure Within the Patient-Centered Medical Home**—Several providers and practices leverage features of the patient-centered medical home (PCMH) for care of their young adult patients with childhood onset chronic conditions. A medical home is the partnership between patient, family, and primary provider in cooperation with specialist and support from the community where the patient is the focal point of the model of care. Practices certified as PCMH, may receive higher reimbursement for documentation of transition policies and use of readiness assessments. PCMH often include nursing staff who are care coordinators, care navigators and “who keep lists of high risk patients” which are helpful for triaging and ongoing clinical care. Management of issues over the phone with “a good nursing staff who fields the calls” or can provide dedicated nursing visits between physician visits also limits additional office visits. Social workers employed in PCMH can also help identify patients as “high risk or needing extra services”.

### **Perceived Barriers to Care of the Adult Patient with Pediatric-Onset Chronic Illness**

Five major themes were identified as barriers: (1) definition of the patient’s medical team, (2) lack of appropriate medical records, (3) time constraints and administrative burden, (4) lack of training and comfort of providers and support staff in adult healthcare systems, and (5) financial constraints (Table 2).

**Definition of the Medical Team**—Most providers identified the total number of providers contributing to patient care as a barrier. A patient may be followed by pediatric primary care, pediatric subspecialists, adult primary care and adult subspecialists and be in varying stages of transitioning between care teams. They might also have varying interactions with providers depending on an acute issue. This leaves the adult primary care team as the coordinator of care for a variety of medical teams in addition to a variety of medical problems that may be managed differently by different providers. It may complicate where a patient should be seen for an acute issue and where a patient should be hospitalized.

**Lack of Appropriate Medical Records**—A medical summary is rarely provided to providers. Instead, either too much information or a complete lack of information is provided to them, both on initial contact and in subsequent episodes of care. Many providers brought up the concept of “discovery” on an individual patient—in that when a provider does not have any information or has excessive information “you just end up wasting a lot of time trying to rediscover what’s happened with the patient”. A provider often has to “spend 3 months, 6 months reinventing the wheel”.

**Time Constraints and Administrative Burden**—Many providers state that lack of time—before, during and after a visit—is a barrier to providing care. Providers state they do not have time to “read through the whole chart to become familiar” with a patient prior to an initial visit with a complex patient transferring care from pediatrics. During clinic sessions, in some models “everyone gets booked for a 30 minute new patient appointment regardless” of their medical problems. This leads providers to choose between inadequately addressing

patient needs or spending the “proper time” with patients and then “just running behind” during clinic sessions. Some providers feel they must duplicate a visit with the patient alone and then with caregivers present. During follow up visits providers feel administrative work such as “filling out forms and making phone calls” to ensure patients “get to the right referrals” and the “right services” takes more time than for other patients with chronic illness.

### **Lack of Training and Comfort of Provider and Support Staff in Adult**

**Healthcare Systems**—Providers who care for adults with pediatric onset chronic conditions find that other providers (nurses and physicians) and support staff (social work, medical assistants and clerical staff) lack training and comfort caring for this population. Sometimes specialists “aren’t comfortable with patients because they haven’t dealt with some of these conditions”. Others find provider colleagues in their own practice are “not comfortable covering patients at night” and therefore end up calling the primary team for all major problems.

Support staff in an office can also be ill-equipped to assist with patients as they often need to be “connected to support services” which are unique to their needs. Many providers feel it would be beneficial to have a knowledgeable social worker “on board to help navigate” systems more unique to young adults.

**Financial Constraints**—Many practices find it difficult to see patients because of financial constraints. Providers see the need for “higher reimbursement rates for patients who require more time,” reimbursement for specific aspects of patient care including “coordinating care”, “phone calls” and “for end of life discussions”. This view is not unique to the adult patient with pediatric-onset chronic illness: “there’s a sense that there’s a lot of uncompensated work that goes into taking care of chronically ill patients”.

Some providers find staying in an academic practice “protective” as large medical centers can absorb the costs of caring for this group of patients. One provider states it is “why I’m never going to leave academic medicine”.

## **Discussion and Implications for Practice**

This study identified several important healthcare system facilitators and barriers that may affect how pediatric nurses can support adult primary care teams caring for patients with pediatric-onset chronic illness, both during initial transfer of care as well as after transfer of care. Facilitators identified included policies to formalize processes around new patient intake, presence of interoperable electronic medical record and use of patient portals, and leveraging care coordination infrastructure within the patient centered medical home. Specific barriers identified by adult primary care teams in this survey include definition of the patient’s medical team, lack of appropriate medical records, time constraints and administrative burden, lack of training and comfort of providers and support staff in adult healthcare systems, and financial constraints. This study was unique in it identified healthcare system facilitators, not only barriers, which are already in use or being developed and it focused on adult providers caring for these patients.

Pediatric nurses can play an important role to help adult primary care teams. Longitudinal studies following patients with childhood onset chronic illness show improved survival but declining health status as patients age and transfer to adult medical care (Dill, Dawson, Sellers, Robinson, & Sawicki, 2013; Okumura, Hersh, Hilton, & Lotstein, 2013; Sawicki, Ren, Konstand, et al., 2013). Thus, there is clear need for comprehensive chronic illness management for these patients in adult healthcare settings. Pediatric nurses have the potential to moderate some of these barriers by (1) collaborating with adult providers to define the scope of the medical team; (2) compiling medical summaries; (3) providing prior letters of medical necessity and other pieces of documentation that are frequently required; (4) being available for subsequent adult provider questions; and (5) development of training materials for adult support staff. Nurses, an essential team member in primary care practice, are uniquely positioned to help fill gaps in care by serving as care coordinators, educators, consultants, and program evaluators in the transition process (Betz, 2013).

Pediatric nurses may also consider preferentially transferring care of complex patients to practices that are patient-centered medical homes (PCMH) or academic medical centers. As identified in our study, the infrastructure of PCMH may serve as a model for chronic care management for pediatric-onset chronic conditions as the PCMH is designed with chronic illness management and complex care coordination in mind (Epperly, 2011; Kilo & Wasson, 2010). Practices that capitalize on specific features of the PCMH as well as academic medical centers may be more readily able to serve complex patient populations including adults with pediatric-onset chronic illness since they can more easily incorporate practices such as care coordination, virtual medicine, and patient outreach (Reid, Coleman, & Johnson, 2010). Data suggest that these interventions can improve quality, decrease provider burnout and decrease cost for practices catering to patients with chronic illness (Pourat, Lavarreda, & Snyder, 2013).

This study is limited by the fact that it is exploratory in nature and aimed to identify themes but not able to measure outcomes of interventions currently in use. The qualitative design allowed us to uncover important and unique themes, but does not allow for testing of hypotheses. Furthermore, since providers were identified via snowball method, most providers in this study practiced in academic medical centers. Thus findings may not be readily generalizable to those in private practice.

In our study, we were able to elicit novel health system barriers and facilitators that may impact the ongoing care of adult patients with childhood onset chronic illness. These themes could be instrumental in designing interventions for young adult patients with childhood onset chronic illness that mirror but improve upon existing systems for adults with adult onset chronic illness including improving the transition process to improvements in ongoing care coordination with the addition of care navigators and improved utilization of the electronic medical record. The use of identified healthcare system supports should be further defined and studied to determine the impact on the quality of care for this growing number of patients.

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Table 1

## Facilitators: Representative quotes by theme.

Formalizing intake processes around new patient transfers	<p><i>"Having educated my office staff to ask just a couple of questions at the initial contact, key questions to A) set up a longer appointment time, which allows the opportunity to go through all the issues, and B) to make sure if there were any particular needs of the patients, such as needing to be immediately placed in a room, rather than a waiting room, etcetera, that we knew those in advance".</i></p> <p><i>"[By] developing checklists as you leave the pediatric environment, come into the adult environment... everybody understands the expectations and the process, and it makes it easier."</i></p> <p><i>There's ways of using [the electronic medical record] so it is clear for your nighttime/ weekend colleague what's going on, who is this person, what's supposed to happen if A, B or C goes wrong".</i></p> <p><i>"We use email and [our patient portal], which he feels that he's in control of, because his parents don't get the things released, he now gets some results. I feel I'm remembering who the patient is".</i></p> <p><i>"It was easy to go back and look at the information from the last few visits, because it's all there on the computer. So there wasn't the formal transition letter, but the verbal kind of summed up their care and the labs and studies and everything that we would want to see were in the computer"</i></p> <p><i>"We do pretty well with a lot of virtual visits and phone calls [with nursing] ... [When] a patient is admitted the nurse somehow figures it out and they bring the provider back into the loop"</i></p> <p><i>"We now do early morning huddles with our practice team ... with the nurse and with the medical assistants. So being able to warn them ahead of time this patient is coming in, has such and such issues and these are the things that we need to have ready, particularly for the patients with developmental disabilities"</i></p> <p><i>"There was one patient who came whose transfer was coordinated by the RN at her pediatrician's office ... that was probably the best transfer of records that happened... she came to the first appointment and also served as, you know, a contact for the family if they had any other questions"</i></p>
Interoperable medical records and use of patient portals	
Leveraging care coordination infrastructure within the patient-centered medical home	

Table 2

Barriers: Representative quotes by theme.

Definition of the patient’s medical team	<p>“Complex patients have some providers still at [the children’s hospital] and other specialists have been transitioned and I’m, of course, on the adult side trying to figure out what the acute illness is and then figuring out, ok, which of their specialists is where, and [then] making a call.”</p> <p>“It was hard to prioritize what needed to be done, because he had a lot of subspecialists and not really good primary care. So there was like the neuroendocrinologist says this, my regular endocrinologist, my ophthalmologist says this. So it was more – there was no umbrella”.</p> <p>“There are patients who straddle the two worlds, so I am taking care of them. They may have some adult sub-specialists and yet families usually take that individual back to children’s hospital and so that fragments the care.”</p>
Lack of appropriate medical records	<p>“So for me, that’s the most important thing is that documentation, the transfer of information of what happened with this patient, their whole medical history, what worked, what didn’t work. Where they’re at now, what the initial goals ... the immediate goals are now to move forward”.</p> <p>“Sometimes with a new patient [they] came with a big stack of records and ... sometimes you need a lot more time. You have to go through all the tests that have been done, try to put it together ... it’s not a diagnostic puzzle, but more just understanding their history and taking over their care”</p> <p>“If someone doesn’t come with records ... which I’d say in half the folks, I knew nothing about them before they came” [They asked] can’t you see my records? No, I can’t”.</p>
Time constraints and administrative burden	<p>“Sometimes I have to play the role of physician and social worker and case manager and that’s the biggest challenge that I have at the moment”.</p> <p>“In my pediatric practice, I never see 30 [patients] with special health care needs in an afternoon. So there’s a really different pressure on the adult system”.</p> <p>“I had scheduled him for 90 minutes and he needed probably two hours because that’s how much time I ended up spending, with him and made the others wait for the rest of the day. It’s a lot, and I always say this to families, it’s really hard to learn 21 years of history in one session”.</p>
Lack of training and comfort of providers and support staff in adult healthcare systems	<p>“Some young adult still have a number of adolescent developmental issues going on as well. My training is not such that I’ve been formally trained in that. So I think I’m always cognoscente of anything that I could be missing or could be doing better in that arena”.</p> <p>“I’m looking for a fact sheet if this is an unusual disease that an internist is unlikely to have gotten any kind of training in”.</p> <p>“I know the MAs get panicked or scared ... if it’s just someone who looks like they’re complicated. These are different kinds of patients”.</p>
Financial constraints	<p>“I don’t know how any practice could stay afloat if they saw even more than, I don’t know, three percent, five percent of their patients that are so high risk, so complex.”</p> <p>“The biggest difficulties we usually run into the patients in this category are chronic medications that were covered and now that the insurances have changed, or God forbid, have lapsed altogether”</p> <p>“It’d be nice to have more time with the patients, but that’s not a reality of the whole financial situation ... so you have to see patients more rapidly”.</p>