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The Role of Health Advocacy in Transitions from Pediatric to Adult Care for Children with Special Health Care Needs: Bridging Families, Provider and Community Services

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Abstract

Background—Youth and young adults with special healthcare needs (YASHCN) experience challenges during transition from pediatric to adult care. Prior studies have not examined how community and healthcare resources can work together to assist YASHCN in transitioning from child-focused care and services to adult-oriented providers.

Objective—To develop a theoretical understanding of how family, healthcare providers and community supports can assist YASHCN during the transition from pediatric to adult healthcare and services.

Design/Methods—We conducted 41 semi-structured interviews with YASHCN aged 16-25, their family members and healthcare and community providers. We focused our interviews on support mechanisms, both within the traditional healthcare system, and those available in the community. Using grounded theory methods, we performed a multi-step analysis process.

Results—The theoretical code “Transition Advocacy” was developed from the data. This theoretical perspective arose from three major categories, which were developed in the analysis: “Fighting for healthcare”, “Obtaining resources”, and “Getting ready to transition”. Transition Advocacy consists of the presence of, or need for, a healthcare ”advocate”’ who did or can assist the YASHCN with the healthcare transition, particularly to navigate complex health or community services. The ”advocate” role was performed by family members, healthcare or agency professionals, or sometimes the YASHCN themselves. If advocates were identified, youth were more likely to obtain needed services.

Conclusions—Parents, health providers, and community agencies are potentially well-poised to assist transitioning YASHCN. Efforts to encourage development of strong advocacy skills will facilitate better transitions for YASHCN.

Keywords

Qualitative research; Children with Special Health Care Needs; Transitions to adulthood; health advocacy

Introduction

There are increasing numbers of adolescents and young adults who report having a chronic health condition, with over 18% of adolescents reporting a special healthcare need.[1,2] With improvements in medical care and technology, these children are living longer, healthier lives. It is expected that 90% of children with chronic illnesses will survive well into adulthood. The transition from pediatric to adult healthcare not only involves transferring care to an adult provider, but calls for facilitating appropriate levels of independence and support for youth, with the goal of achieving optimal health and quality of life.[3]

Unfortunately, youth and young adults with special healthcare needs (YASHCN) are often not well prepared for the transition process.[4,5] In fact, less than half of YASCHN receive comprehensive preparation for transition, and even fewer youth from ethnic and racial minorities receive these services.[6] Multi-level barriers impede a patients' ability to maintain access to -- and continuity of -- chronic medical care as they transition from pediatric to adult-oriented systems.[7,8] Many YASHCN lack appropriate transition planning and support, or lose access to insurance, and those with intellectual disabilities may never achieve a level of independence that is expected of most youth.[4] Regarding providers, many adult-focused healthcare providers are not comfortable treating childhood-onset chronic conditions, and pediatricians may not have the resources to prepare youth for transition.[9,10] On the systems level, incompatible information technology platforms and siloed personnel and services prevent ease of information transfer and continuity between providers, insurers, and patients.[11]

A basic level of knowledge regarding barriers to care transitions has been elucidated by previous studies, however, the best means for ensuring efficient resource utilization and decreasing barriers to care during this period remain unknown. Recent studies and systematic reviews of transition programs have highlighted a lack of understanding regarding factors facilitating transition outside the ambulatory care setting -- factors which are effective in the promotion of healthy transitions, and the need for identification of the best potential targets for interventions to promote the transition process.[8,12] In addition, few studies have focused on YASHCN themselves (e.g.,asking YASHCN for input regarding what they needed for their own transition process).[13] Most studies have focused on healthcare providers and clinical-level interventions. A critical, but rarely addressed question regarding YASHCN in transition is: How can the family, community and outside supportive services work together to impact the healthcare transition process?[7,14] In order to implement effective means to improve quality of care for youth with chronic diseases in a holistic manner, we must first expand our understanding of how families and youth overcome barriers, and we must identify facilitators to chronic illness management and care beyond the walls of the healthcare system. Current recommendations, based on current evidence, are limited to generation of suggested transition planning strategies and transition programs which, ultimately, have proven not to work for many YASHCN. For example, programs which feature education or navigation strategies have mixed results in improving transition outcomes.[12] The failure of current attempts to improve healthcare transitions may be, in part, related to the myopic focus on ambulatory care and the medical system – rather than family and community assistance -- as the target for intervention.

Strategies for involving community services in transition to adult services are a missing link toward the improvment of the transition process for YASHCN. Prior studies have not adequately examined how the integration of community and healthcare resources affect youth and young adults in their chronic illness care management or what gaps remain in their care.[14] Therefore, the purpose of this study was to explore the experiences of YASHCN, their parents, healthcare providers and community agency members using grounded theory methods. Our aims were: (a) To explore barriers and facilitators to the transition from child-focused to adult oriented healthcare and services, (b) To generate a theoretical understanding of how families and supportive professionals can decrease barriers to the transition from pediatric to adult-oriented care systems. This understanding can then be used to develop programs and interventions for future testing, and (c) To develop a project map based on situational analysis to use both in validating our theoretical understanding and as a guide for developing future interventions and programs. We focused this study not only on the medical aspect of transitions, but also included community organizations which promote health and wellness to YASHCN. Better understanding of potentially effective facilitators to transitioning will help clinicians to develop patient, provider, system, and community-level improvements to promote healthcare transitions and thus enable the delivery of continuous chronic illness care for YASHCN.

Research Methods

Identification of persons for interviews: Sampling, Inclusion Criteria and Recruitment

Initial recruitment for the study was purposive. Inclusion criteria were: (a) YASHCN age 16-25 who had either recently transitioned to adult healthcare providers, or were preparing to transition their care, (b) Healthcare or community service providers who provided care to YASHCN in outpatient, inpatient, or community settings. Recruitment strategies included flyers posted in medical office and community agency settings and postings on listservs for two community-based statewide programs that offer case management and funding for programs directed toward children and young adults with chronic conditions. As data collection and analysis proceeded, sampling became more theoretical and patients and providers were recruited by asking for referrals from providers in specific clinical or service settings to more fully explore aspects of the theoretical framework that were being developed. For example, in order to fully explore advocacy efforts of parents and providers, we recruited parents and youth referred by specific providers, and providers identified by enrolled youth and families to participate in interviews.

Data Collection

Data collection included interviews and field notes generated by interviewers for an in-depth examination of the experiences of YASHCN during the transition to adulthood.[15] Interviews were done with participants by the study investigators and staff [MO, KT and MS] either in the subspecialty clinic, community agency, participant's home, or in private interview rooms, depending on participant preference. Participants were compensated with $25 for their contributions. Interviews were tape-recorded and professionally transcribed. Each interview took approximately 30-60 minutes. The researchers’ university Institutional Review Board approved this study and all participants signed informed consent forms, with minors giving assent for participation with parental consent. If a youth had severe intellectual disability, only the parents or family care providers were interviewed.

Interview Guide

The interview guide was developed through literature review and previous research program findings by the authors.[3,9,16] Interviews for the study included open-ended questions and semi-structured probes to provide an in-depth look at barriers and facilitators to chronic illness care for youth and young adults with chronic disease, focusing on the interface between healthcare providers, youth and family, school and community agencies.[17,18] Topics of questions included past and current experiences with the healthcare system and community services, current and past experiences with specific providers, and youths’ and parents’ perceptions regarding what would improve their care, including what things they needed currently to obtain care, what impeded care, and what they thought they would need in the future. We also asked families and youth about what other supports they needed outside the medical system in order to explore the gap in knowledge about community services. We also asked parallel questions of healthcare and community service providers, by asking them to reflect on their experiences caring for or providing services to adolescents with chronic diseases, and what they perceived to be barriers and facilitators to obtaining care during the transition to adulthood. Interview guides were modified to pursue areas of interest expressed by participants, and used for subsequent interviews.

Data Analysis

We used a grounded theoretical approach including situational analysis for the data analysis.[12,15,19] Data were uploaded into a qualitative data analysis software program Atlas Ti for organization and management. Specific steps in the analysis included: 1) Review of each transcription and construction of a participant summary, 2) Open coding of each transcript to identify salient issues, 3) A second round of focused coding for analysis of major categories built from step 2, 4) Based on the focused coding, we developed a theoretical code, Transition Health Advocacy, which facilitated conceptualization of the association of the basic social processes encapsulated in major categories affecting barriers and facilitators to care during transition, and explained both positive and negative experiences of the transition process described by participants.[15] 5) Finally, we performed a situational analysis to generate a project map based on the interview data, as a check that major components of data were accounted for in the theoretical code development.[19] Open coding was performed by the study investigators [MO and MS] with each code reviewed by the study team [MO, KT, MS and RR] for agreement of interpretation. After early analyses were conducted on the first five interviews, preliminary results and the draft situational analysis project map were shared and discussed with all subsequent informants during their interviews to gain iterative feedback to the study and analysis with continuous adaptation of the model. After development of the theoretical code and situational analysis, results were discussed with a group of clinicians, parents, YASHCN and researchers with expertise in transition to adulthood care and issues, and their feedback was used to finalize the situational analysis project map (see figure 1).[19,20]

Results

We conducted a total of 41 interviews of YASHCN, parents, and providers in the San Francisco Bay area. The overall sample characteristics are shown in Table 1. There were 13 YASHCN aged 16-25 (mean age 19, standard deviation (SD) 2.2), who represented a diverse group of conditions (cystic fibrosis, congenital heart disease, diabetes, spina bifida, intellectual disability, cerebral palsy, inflammatory bowel disease, and myasthenia gravis). We interviewed nine parents of children with inflammatory bowel disease, developmental disabilities, mental health conditions, spina bifida, myasthenia gravis and congenital heart disease (mean age 53, SD 8), 12 healthcare providers (mean age 51 SD 8, representing both adult and pediatric nurses, nurse practitioners, social workers and physicians from various fields (diabetes, nephrology, cystic fibrosis/pulmonary, general practice, hematology and gastroenterology) and seven community service providers representing state entitlement programs, parent advocacy groups and vocational services (mean age 48, SD 12). Interviews from these participants elicited a variety of issues, but most interviews reflected common concerns. After open and focused coding, three major categories describing important social processes within transition were predominant in these interviews. These were “fighting for healthcare”, “obtaining resources” and “getting ready to transition”. These major categories were then developed into a theoretical code of “transition advocacy” across the complex health and social system. This “transition advocacy” is critical for an effective transition. Below we provide sample triangulated quotes representing the voices of YASHCN, parents, providers and community service agencies that were used to develop each category, followed by the overarching theoretical code and situational analysis map generated from the coding.

Fighting for Healthcare

Perhaps the most striking of the major categories was the constant “struggle” that YASHCN found necessary to gain services or have their needs met. We termed this category “Fighting for healthcare”, because there seemed to be a constant conflict between families, service providers, healthcare providers, youth, and suppliers of medical resources. This conflict was described as generating major barriers and also inspiring facilitators to healthcare transitions. In other words, a facilitator to transitions resulted from having a parent develop strong advocacy skills in the process of overcoming significant barriers. One mother explained, “Well actually my experiences have been fairly good, mostly I think because of my personality, and I like a good fight and so I've been able to make things work for us.” This mother could navigate transitions between agencies and providers because she was willing to “fight” any barrier that was placed before her child. Another mother acknowledged that her success was due to her ability to advocate and fight for her child, who was doing well and was also able to navigate transition services:

> But you know not every parent's like me. I was lucky because I was well-educated, and you know I'm aggressive and I'm a good advocate for my kids. What about parents who can't speak and do things for their kids? How are the kids going to get help?

Unfortunately, many parents and family members did not have that level of ability to fight the system. In fact, conflict was found on various levels. A community service agency worker who often fights and advocates for families, observed this conflict first hand:

> What we've found is that a lot of families, if they're skilled and have time, have resources, can often negotiate, although it's a struggle because the systems are so confusing. Although there are resources, we really are resource rich, it's still not enough, and those people in agencies that are supposed to help advocate for families end up being gatekeepers. And so families and providers kind of end up with some friction between them.

A healthcare provider and director of a medical unit noted a significant shift of responsibility toward the families to fight for services “I think every agency's under fire. The Regional Centers [Entitlement provider for California state program for developmental disabilities] are certainly- their case managers they're all social workers there too, so they've been helpful in some regards as well but it's still, they're very busy. They [have had] significant budget cuts as well so it's, I think with the budget climate as it is, the onus, a lot of it, has been put back on the families.”

Across the interviews, there was an aspect of having to fight for health access and services. A host of barriers were reflected in the need to fight for every resource. Even school-based services could be a resource that had to be fought for, despite being considered a societal entitlement. “So if the school district and the Regional Center aren't working well together kids can drop out of services and not be able to get [what they need]”. The need for ensuring that school-based services were actually being utilized was also emphasized by a mother, who described the need to help her daughter acquire self-advocacy skills. “[I] have to go to [my daughter] with a lot of appointments and do a lot of things to check out like job core and all this different stuff. I was doing it. Going to school meetings, and I think [my daughter] should take a more active role.”

Youth who were successful usually had someone else fighting for them, whether it was a provider, social worker, counselor or another family member, as illustrated in this parent interview:

> His counselor in school, and the after-school programs, worked together with him, and they got him involved in this internship for the Cartoon Museum while he was in high school. It was a job as well as going to classes. And this was all through the Special Ed programs.

For a youth with developmental disabilities and chronic illness, despite being over the age of majority, having someone else to speak up for him was important in his care. Though he could articulate his needs, he still relied on his mother to ensure that his voice was heard by the healthcare team:

> Like, telling [the healthcare team]- when I don't like to be poked before surgery and stuff. I need her [his mother] help to tell the doctors to do the IV in surgery, like I got this one [points to IV]. Cause I really don't like being poked.

Sometimes advocacy has to be external, as stated by this community agency worker:

> Going back to families who maybe do not have the language skills, maybe cultural barriers, ...they're not the individuals who necessarily will step up and fight what their rights are, or fight for that appeal, or they have gotten the paperwork in English, and that is not a primary language for them, even if they speak English. So some of that comes my way too like, “Well, what is this? How can I do this?” I was talking to the dad and I said, “You know you have a right to appeal that,” and he said, “You know, we just go along with it.” And they are Arab- they are from Yemen. He said, “We just go along with it, and we don't fight it. We just take what we can get.”

Overall, families, youth, providers and community service agencies found that having someone fight for healthcare, educational supports and important life opportunities was key to ensuring the YASHCN were cared for during the transition process. If the YASHCN or their family member could not fight for services, or have an ally to fight for them, they would find themselves losing services.

Obtaining Needed Resources

The next major category was “Obtaining needed resources”, which was distinct from fighting for resources. In this category youth, providers, and families were faced with the complexity of agency processes and lack of transparency about resources available. Fighting for resources could not start until the YASHCN need was identified. Barriers could arise in identifying or obtaining resources, and also in assuring that the resource was appropriate for a particular individual. For example, a mother needed equipment to help her son stand and transfer from location to location. She had requested the equipment close to her son's birthday, when he was about to lose services from California Children's Services (CCS), the insurance that covers chronically ill children up until age 21 (California Title V program). Unfortunately, after age 21, there is no “adult” equivalent which provides of the same services. Since the equipment arrived after her son's birthday, this mother could no longer use CCS services and had no one to turn to when the equipment did not work for her son. She said:

> I have no idea, it just came after Bob fell off the CCS, so actually I have no idea who the actual person was. I know when we were with CCS we had talked about a four-pull [lift system], *this is not what we-, I mean he can't* use it because it's an adult sling and Bob is about the size of your generic eleven or twelve year old.

The mother knew about the need for durable medical equipment, but received no guidance about how to use the materials and what to do when the equipment was too large for her son. The provider had written the prescription for the equipment, the insurance company had already approved the item, but it now fell to the parent to take care of the rest. Unfortunately in this case the mother did not have any recourse to return the sling as it had already been paid for and there was no way to 'refund' or 'exchange' the item. The mother's frustrations only grew when a well-meaning therapist suggested an alternative therapy, but the mother was not offered assistance to obtain the equipment and was frightened to use it because she had not been properly trained. She said:

> Right, and so we can't find a pharmacy that will provide them so that's challenging; and so she wanted me to go ahead and get him back in his AFO's [Ankle Foot Orthosis] so at least he can have his use of a stander which I'm so afraid to do. I mean these things look-, I mean they look-, it was very frightening.

This excerpt describes a complex interplay of multiple providers' uncoordinated attempts to help a patient: a physician ordered a piece of specialized equipment, but the original order did not work for the patient because the patient was not a typical size for his age. Furthermore, and it was difficult to locate a vendor for the replacement therapy. Once the mother was able to get the equipment, there was no mechanism for a provider to go out into the community and assist the mother in how to use it. Not only does the mother have to navigate the different vendors in the community to find the equipment for her son; but there is no one to guide her in picking up the equipment and using it. This resulted in the mother's fear and intimidation. The lack of coordination and follow through in services resulted in delays and potential orthopedic complications for this youth as he left the child-focused health system and attempted to navigate the adult services realm.

Just as parents want to have equipment to help them and their child live their lives, for youth, having something that fits into their lives is critical to gaining their own independence. This type of consideration is key and yet sometimes neglected.

> It was more of like me and the doctors at the clinic, we were conversing about what do I need to help me, personally, because the vest- the machine that I had before was a vest and it was just very big and bulky. It weighed like sixty pounds, and you had to take it from one place to another, and was very inconvenient. So I definitely give it to the clinic- the new [adult] clinic that I started with-they were definitely looking for anything to help me. They were very helpful. They gave me new, just a bunch of new machines. They were lighter and more compact. They were definitely more convenient for me and to help me to get things done and carry out with my day, carry out throughout the day without worrying about things. So I definitely think I'm taking care of myself better now because it's definitely more convenient for me to do my medicines. It's a lot easier now.

For those who come from lower socioeconomic status, the gap in knowledge, lower existing resources, and lower entitlement for services can be overwhelming barriers for seeking resources for a YASHCN. This African American father, who spent time in a homeless shelter, required help for his child, but explained that he didn't want to ask for help; rather he wanted the system to be accessible and for the system to reach out to help his child during the transition period. He explained:

> But to have somebody actually come up and, you know, counsel you, console you, about what your opportunities are, and what avenue you can take to improve your life, you know, that would be a big help. I know, especially with a lot of poor people, they're not as outgoing, and feel a little intimidated, especially in hospitals with doctors and stuff. ...I think people speaking to them personally would help a lot.

For him, having a standard mechanism to offer support was critical for obtaining services for his child. The most effective mechanism was when he was offered something specifically, “Would you like this service?”, rather than being asked generically “What do you need?” The latter question presumes a level of knowledge and confidence that may not be present for all families. Common reasons for not obtaining resources included parental, youth, or provider's lack of information, inability to get insurance to pay for services, and lack of knowledge about how to gain the services requested. For the provider, a barrier to care may be the lack of recognition of the patient's need. To overcome this barrier, a mechanism needs to be developed so that families feel safe and entitled to ask for needed services. In addition, a key facilitator was building mechanisms that help families bridge service agencies, which is often limited in healthcare, even with the appropriate case management. This community service agency provider suggested that YASHCN need more services like the one he described for younger children:

> ...Even though we can provide information and education to families about how systems work, the systems don't work well together, and families get bounced in between and we've had opportunities to take on projects such as [community council], which brings mandated agencies together for families of kids birth to five, and we work with them to identify issues, prioritize ways to- strategies to address those issues, and then work together to solve the problems. So if the school district and the Regional Center aren't working well together kids can drop out of services, so we bring them together to say, “So how can we improve this,” and it's amazing.

Getting Ready to Transition

The final major category identified was “Getting ready to transition”. While the medical literature states that youth are “not prepared”[21], there are different levels of preparedness. Poor preparedness includes lack of transfer planning to adult providers, poor preparation in gaining self-management skills and a general lack of medical knowledge, all of which are frequently cited as barriers to transitioning.[5,22] But, preparation for adult roles was more important than medical management in many of the interviews. The medical, legal and social structure of society has made “adulthood” an arbitrary designation, starting at age 18-21. Many youth found switching gears from being a chronically ill child to a chronically ill adult difficult. Young adults did not know how to navigate the system, and many were apprehensive about the abrupt change in expectations as they transferred to adult-oriented programs and services. Many young adults have been protected or treated as children, and thus, are not developmentally prepared to be independent adults. As described below, many felt that there is not a “switch” that makes a child into an adult, and that the process of preparation has to be started earlier. A pediatric provider recognized this and said, “But you have to realize you can't go from being this chronically ill child up until you're twenty and then all of sudden you're this completely responsible, independent person”.

A youth found the transition process extremely difficult and did not find the preparation or support she required to pursue her adult schooling:

> I need to realize that I'm not just a sick person, because that's the way I've been seeing myself since I was eleven. I'm not just a sick person. I am also whatever else I am and so I need somebody to just help me to deal with the stuff I need to deal with but then kind of get going because I'm still afraid to leave the house. I'm still afraid to move out on my own, which I'm going to, because I feel like I need to just be thrown into it and I'm still afraid to do anything really big because I don't know, I've never been able to travel. I've never been able to-, I tried going to college, I went to school about three months and then I had to drop out because of my health issues and so I'm just afraid because every time I try something it blows up in my face; so I need to get past the fear and I need somebody to help me get past the past and then get on with my life.

The issue of becoming an adult was especially poignant in terms of the legal aspects of being an adult. While parents can shelter children from responsibility for some things, once their children reach age of majority, the young adult will be forced to take on adult responsibilities. A young woman gave a moving example of this from her first hospitalization after turning 18. She said: “That was the hardest thing, like the hardest thing to deal with, because usually when you turn eighteen it's fun, it's happy, like I can move out, I can vote and that was cool, I could vote. That was really cool but normally a teenage person, like a teenage person does not have to decide how they're going to die.”

Before the youth turned 18, , her parents had conducted the do not resuscitate (DNR) conversations with providers, but without the input of their daughter.. When the youth turned 18 she was legally required to state her own preferences, and the discussion abruptly fell to her. She was completely unprepared to have the discussion of her DNR status. Understanding her own needs, and how she could advocate for her own future, which may include a discussion regarding how she wants to die, would have been an important part of this patient's transition experience. Unfortunately, there is currently no systematic method for teaching young adults how to advocate for their own “adult” decision-making processes and needs. Many people, including providers, youth, and their families, may be unprepared for uncomfortable conversations or difficult decisions which may fall to them.

Getting ready transition also means letting go as part of the preparation process. While many interviews discussed needing support, support can be both a facilitator and a barrier to the transition process. An adult social worker that was trying to help a youth transition to adult care had this experience:

> I mean she [Pediatric provider] didn't really do anything except to come and visit him [patient], which is not a small matter, but that was to me just a really remarkable demonstration of how at least this one nurse practitioner dealt with her patients and how I see my team dealing with patients, and it was confusing to the

> patient I think because here he's on our [adult] service. Here comes this person that has known him for quite some time telling him she loves him and sitting on the bed with him and where do we fit into that? It's a kind of undermin[ing]. I'm sure it wasn't intentional and it's probably how she deals with all of the kids but it wasn't helpful. It wasn't helpful in facilitating a structure where this is the transition now, you were [there] and now you're here and it just didn't help but it left an impression on me.

In this case, a pediatric provider was trying to support the youth, but becomes a barrier to building a relationship with the adult team. Having the adult and pediatric providers better understand their relationships with their patients and work together to advocate for their patients' transition to adult care and services may be a potential way to improve the transition process.

As this provider stated, if the advocacy, support, and autonomy building are done well:

> [If they are] really consistent with their pediatric care if they're kids who were well supported either because they kind of innately and intuitively took on more of that responsibility as kids, or they were well supported because they had support of guardians and parents or siblings, extended family, then those are the kids who transition well.

As part of continued transition readiness, a father of a child noted that some of his greatest supports were to assist his daughter look forward to the future, to be ‘normal’.

> [My daughter] had this fantastic nurse, this young guy, it seemed like he was in his twenties or something like that, really good looking guy and just really hip and cool and just it meant-, it was so helpful for [her] to be able to see somebody who was sort of in her age universe because all the doc's and the nurses and us, of course were these old people, to see this kind of young, cool guy really meant a lot in terms of her experience of care and it turned out the guy disclosed that he has Crohn's...He sort of said this is why he became a nurse, was because he felt that he could give better care than he had been given. I mean there may well be a time in which [my daughter's] career choices will be affected by not only the need to get insurance but also by her experience with the medical care system, which it should.

Finally, a community service worker mirrored the views of providers, patients and family members, as they also noted that ensuring the needs of the youth are met and ensuring that the needs of the youth are heard was critical in transitioning:

> So the 16 to 22-23-year-old range. I think the best skill that I have developed - the skill is being able to really listen and ask those questions so I can hear what that person [youth] is really looking for and what they need - because up until this point, everyone has been doing that question-asking for them, and the answering of those questions for them, and the planning and development for them.

Often times, the voices of the youth themselves are not heard, and the need for ensuring that we prepare YASHCN appropriately and ensure that their needs and voices are heard, will assist in ensuring an appropriate transition process.

Transition Advocacy: Ensuring healthcare, supports and services are provided in a family and patient centered way

The theoretical code of “Transition Advocacy” was developed to tie together the categories of “Fighting for healthcare”, “Obtaining resources” and “Getting ready to transition”. Transition advocacy appears to be a key resource that transitioning youth, families and providers need to ensure care. Through advocacy, youth, parents and providers are enabled to fight for assistance, bridge processes to obtain needed resources for patients and families, and help youth, parents and providers prepare for the transition and ultimate transfer process. This advocacy bridges access to these resources by overcoming the barriers of lack of knowledge, poor developmental preparedness, and understanding of a child's condition/ disability and needs going forward into adulthood. Advocates linked various important resources that were important to youth, parents and providers, overcoming key barriers that transitioning patients faced (Figure 1). In addition, effective advocates serve as role models and educators for young people, assisting them to optimize their own potential as self-advocates. Finally, effective advocates ensure that the voices of the youth are heard, and that they learn to speak for themselves whenever possible, so that developmentally appropriate transitioning to adult-oriented services can occur in a timely manner.

Discussion

Transitioning is a complex process for families and providers, and focuses on activities that go well beyond simple chronic disease management. If the transition process is executed poorly, YASHCN have poor health outcomes with loss of health access.[23-25] A holistic treatment of transition incorporates many different entities[26], as well as the cognitive development of the emerging adult[27], but how to most effectively bridge gaps that occur when child-focused services end, and how to effectively engage YASHCN is still poorly understood.[7] While the literature has focused on healthcare delivery,[28,29] ways to keep YASHCN insured,[24,30-33] ways to improve developmental readiness,[21,34,35] and the ability of the YASHCN to become an adherent patient within the adult healthcare system,[12,36], the families and youth in our study focused on how the YASHCN could be supported medically and in their adult lives (vocation, school).

Based on the interviews and coding, the theoretical code of “Transition Advocacy”, with the interplay between health providers, agencies, schools, and community resources has been developed. The role of Transition Advocacy in linking and facilitating successful interactions is reflected in the project map of the various players involved in healthcare transitions. This work expands on the theoretical frameworks of transition described in the literature[37], and the project map can be useful in identifying opportunities for future interventions to address transitions. As the interviews have shown, healthcare transitioning requires us to expand our transition framework beyond insurance, or differences between adult and pediatric providers or even the differences in the healthcare system. There is a complex interplay between health policy, legal issues, medical suppliers and the social context of youth and families.[26] Figure 1 depicts the various entities in the project map that was formed through the interviews. This diagram's central components of barriers and entities prevelant in transition have been identified in previous research and models,[5,8,38] but we have built upon this work by developing the theoretical code of “Transition Advocacy” to address the barriers and facilitators to transitioning. The inner components in the diagram indicate the barriers that were identified in the interviews. This project map illustrates the linkages required and how “Transition Advocacy”, can be the process that ensures linkages between health, community, vocational and educational resources in the context of the lives and future activities of a YASHCN, providing personalized assistance during the complex transition from child-focused to adult healthcare and services.

The findings of the study suggest that transition research and clinical practice could focus on youth working towards their own autonomy, but also potentially involve other stakeholders for youth who cannot gain full autonomy. For example those with developmental and intellectual disabilities may need an advocate, which could be found with parents, providers or community agencies. While healthcare providers may focus on chronic disease management, families may require help and an advocate to manage their child's health. Simply providing or educating families about available resources is not enough to ensure successful transition; assisting with navigating and managing resources is critical for many families. Youth also require significant guidance and help, not just in their chronic illness care, but also in their ability to function in society, to be an active and participating adult. Thus, transition advocacy is a theoretical entity that facilitates the work of services that support YASHCN, and thus is a critical component of successful transition, to overcome the barriers that were found by youth and parents. When present and effective, transition advocacy assisted with navigation of complex health and community systems for YASHCN, providing role-modeling and education for youth for future interactions. When transition advocacy was absent, or ineffective, families and YASHCN were left with frustration, difficulty accessing services, and they experienced delayed transition to adult healthcare and community services. The entities who can provide this level of advocacy could be the youth, family, healthcare provider, social worker, or community service provider. Individual advocates fight for services, identifies gaps in knowledge and gaps in healthcare. Individual advocates ensure that a youth can be successful in transitioning from pediatric to adult focused care and optimize the assumption of adult roles, potentially enhancing quality of life. Future work is still required to understand whether including persons who can perform transition advocacy during the transition process by linking YASHCN to healthcare, vocation, education and community resources can improve transition outcomes for YASHCN.

Limitations

Interviews were limited to individuals from California, and may not represent experiences of YASHCN in other parts of the United States. The sampling frame was based on a purposive sample and thus may not be generalizable to all chronic conditions or YASHCN. Information presented is based on self-reported experiences of participants, and thus interviews may not have captured all relevant categories or theoretical codes. We were limited to English speaking participants in this study and therefore further work is needed to identify issues that may be especially relevant to those who do not speak English.

Implications for healthcare and community providers

Transition programs have grown in number and various modalities have now been generated to improve transitions of healthcare. Many programs try to include ways to improve self-efficacy of youth and families, but the need for advocacy for youth and parents cannot be ignored. Whether advocacy is performed through the development of patient self-efficacy or through the family, or provided by professionals, it is a needed component, especially for families with fewer resources. This advocacy includes a trust building process and coaching in advocacy skills for the youth and familial or professional advocates, to ensure that every step is taken to ensure a smooth transition process. Integrating social services, vocational activities, community resources, as well as standard healthcare supports are critical for the success of young adults with chronic diseases. Advocating for patients and ensuring that supports are available for youth and families during the transition process is critical in ensuring a smooth transition to adult based healthcare.

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Bibliography

1. [May 14, 2015] 2009/2010 National Survey of Children with Special Health Care Needs. http://childhealthdata.org/browse/survey/results?q=1792&r=1&g=376.
2. Perrin JM, Bloom SR, Gortmaker SL. The increase of childhood chronic conditions in the United States. JAMA : the journal of the American Medical Association. 2007; 297(24):2755–2759. [PubMed: 17595277]
3. Rehm RS, Fuentes-Afflick E, Fisher LT, Chesla CA. Parent and youth priorities during the transition to adulthood for youth with special health care needs and developmental disability. ANS Adv Nurs Sci. 2012; 35(3):E57–72. [PubMed: 22869218]
4. Lotstein DS, McPherson M, Strickland B, Newacheck PW. Transition planning for youth with special health care needs: results from the National Survey of Children with Special Health Care Needs. Pediatrics. 2005; 115(6):1562–1568. [PubMed: 15930217]
5. Rutishauser C, Akre C, Suris JC. Transition from pediatric to adult health care: expectations of adolescents with chronic disorders and their parents. Eur J Pediatr. 2011; 170(7):865–871. [PubMed: 21174123]
6. [May 20, 2015] Outcome #6: Youth with special health care needs who receive the services necessary to make appropriate transitions to adult health care, work and independence -- CSHCN age 12-17 years only by race: 2009/10 National Survey of Children with Special Health Care Needs. http://childhealthdata.org/browse/survey/results?q=2048&r=1&g=88.
7. Ferris ME, Ferris MT, Okumura MJ, Cohen SE, Hooper SR. Health care transition preparation in youth with chronic conditions: Working towards translational evidence with a patient perspective. Journal of pediatric rehabilitation medicine. 2015; 8(1):31–37. [PubMed: 25737346]
8. McPheeters, M.; Davis, AM.; Taylor, JL.; Brown, RF.; Potter, SA.; Epstein, RA. Transition Care for Children With Special Health Needs. Technical Brief No. 15 (Prepared by the Vanderbilt University Evidence-based Practice Center under Contract No. 290-2012-00009- I). AHRQ Publication No.14-EHC027-EF. Agency for Healthcare Research and Quality; Rockville, MD: Jun. 2014
9. Okumura MJ, Heisler M, Davis MM, Cabana MD, Demonner S, Kerr EA. Comfort of general internists and general pediatricians in providing care for young adults with chronic illnesses of childhood. J Gen Intern Med. 2008; 23(10):1621–1627. [PubMed: 18661191]
10. Sharma N, O'Hare K, Antonelli RC, Sawicki GS. Transition care: future directions in education, health policy, and outcomes research. Acad Pediatr. 2014; 14(2):120–127. [PubMed: 24602574]

11. Care coordination in the medical home: integrating health and related systems of care for children with special health care needs. Pediatrics. 2005; 116(5):1238–1244. [PubMed: 16264016]
12. Crowley R, Wolfe I, Lock K, McKee M. Improving the transition between paediatric and adult healthcare: a systematic review. Arch Dis Child. 2011; 96(6):548–553. [PubMed: 21388969]
13. Betz CL, Lobo ML, Nehring WM, Bui K. Voices not heard: a systematic review of adolescents' and emerging adults' perspectives of health care transition. Nurs Outlook. 2013; 61(5):311–336. [PubMed: 23876260]
14. Reiss JG, Gibson RW, Walker LR. Health care transition: youth, family, and provider perspectives. Pediatrics. 2005; 115(1):112–120. [PubMed: 15629990]
15. Charmaz, K. Constructing grounded theory. Sage Publications; London ; Thousand Oaks, Calif.: 2006.
16. Okumura MJ, Kerr EA, Cabana MD, Davis MM, Demonner S, Heisler M. Physician views on barriers to primary care for young adults with childhood-onset chronic disease. Pediatrics. 2010; 125(4):e748–754. [PubMed: 20231189]
17. Milshler, EG. Research interviewing, context and narrative. Harvard University Press; Cambridge, MA: 1986.
18. Silverman, D. Interpreting qualitative data: Methods for analyzing talk, text and interaction. 2nd ed.. Sage; Thousand Oaks, CA: 2001.
19. Clarke, A. Situational analysis : grounded theory after the postmodern turn. Sage Publications; Thousand Oaks, Calif.: 2005.
20. Lincoln, YS.; Guba, EG. Naturalistic inquiry. Sage Publications; Beverly Hills, Calif.: 1985.
21. McManus MA, Pollack LR, Cooley WC, et al. Current status of transition preparation among youth with special needs in the United States. Pediatrics. 2013; 131(6):1090–1097. [PubMed: 23669518]
22. Park MJ, Adams SH, Irwin CE Jr. Health care services and the transition to young adulthood: challenges and opportunities. Acad Pediatr. 2011; 11(2):115–122. [PubMed: 21296043]
23. Scal P, Davern M, Ireland M, Park K. Transition to adulthood: delays and unmet needs among adolescents and young adults with asthma. J Pediatr. 2008; 152(4):471–475. 475, e471. [PubMed: 18346498]
24. Okumura MJ, Hersh AO, Hilton JF, Lotstein DS. Change in Health Status and Access to Care in Young Adults With Special Health Care Needs: Results From the 2007 National Survey of Adult Transition and Health. J Adolesc Health. 2012
25. Lotstein DS, Seid M, Klingensmith G, et al. Transition from pediatric to adult care for youth diagnosed with type 1 diabetes in adolescence. Pediatrics. 2013; 131(4):e1062–1070. [PubMed: 23530167]
26. Betz, C.; Ferris, M.; Woodward, J.; Okumura, M.; Jan, S.; Wood, D. The HCTRC Health Care Transition Model: A Framework for Research and Practice Pediatric Rehabilitation Research. in press
27. Arnett JJ. Emerging adulthood. A theory of development from the late teens through the twenties. The American psychologist. 2000; 55(5):469–480. [PubMed: 10842426]
28. Visentin K, Koch T, Kralik D. Adolescents with Type 1 Diabetes: transition between diabetes services. J Clin Nurs. 2006; 15(6):761–769. [PubMed: 16684172]
29. van Staa A, van der Stege HA, Jedeloo S, Moll HA, Hilberink SR. Readiness to transfer to adult care of adolescents with chronic conditions: exploration of associated factors. J Adolesc Health. 2011; 48(3):295–302. [PubMed: 21338902]
30. Okumura MJ, McPheeters ML, Davis MM. State and national estimates of insurance coverage and health care utilization for adolescents with chronic conditions from the National Survey of Children's Health, 2003. J Adolesc Health. 2007; 41(4):343–349. [PubMed: 17875459]
31. White PH. Access to health care: health insurance considerations for young adults with special health care needs/disabilities. Pediatrics. 2002; 110(6 Pt 2):1328–1335. [PubMed: 12456953]
32. Willoughby LM, Fukami S, Bunnapradist S, et al. Health insurance considerations for adolescent transplant recipients as they transition to adulthood. Pediatr Transplant. 2007; 11(2):127–131. [PubMed: 17300489]

33. Nicholson JL, Collins SR, Mahato B, Gould E, Schoen C, Rustgi SD. Rite of passage? Why young adults become uninsured and how new policies can help, 2009 update. Issue Brief (Commonw Fund). 2009; 64:1–20. [PubMed: 19658271]
34. Kingsnorth S, Healy H, Macarthur C. Preparing for adulthood: a systematic review of life skill programs for youth with physical disabilities. J Adolesc Health. 2007; 41(4):323–332. [PubMed: 17875457]
35. Naugle K, Campbell TA, Gray ND. Post-Secondary Transition Model for Students with Disabilities. Journal of School Counseling. 2010; 8(40):31.
36. Wojciechowski EA, Hurtig A, Dorn L. A natural history study of adolescents and young adults with sickle cell disease as they transfer to adult care: a need for case management services. J Pediatr Nurs. 2002; 17(1):18–27. [PubMed: 11891491]
37. Betz CL, Ferris ME, Woodward JF, Okumura MJ, Jan S, Wood DL. The health care transition research consortium health care transition model: a framework for research and practice. Journal of pediatric rehabilitation medicine. 2014; 7(1):3–15. [PubMed: 24919934]
38. Schwartz LA, Tuchman LK, Hobbie WL, Ginsberg JP. A social-ecological model of readiness for transition to adult-oriented care for adolescents and young adults with chronic health conditions. Child Care Health Dev. 2011; 37(6):883–895. [PubMed: 22007989]

Highlights

- Our qualitative study engaged youth, family, health care and community service providers.
- Our work elucidated the overarching theme of navigation of complex health and community systems requiring focused advocacy of youth with special health care needs.
- Community agencies and social programs, along with clinic-based support structures are well-poised to help transitioning youth with special health care needs.

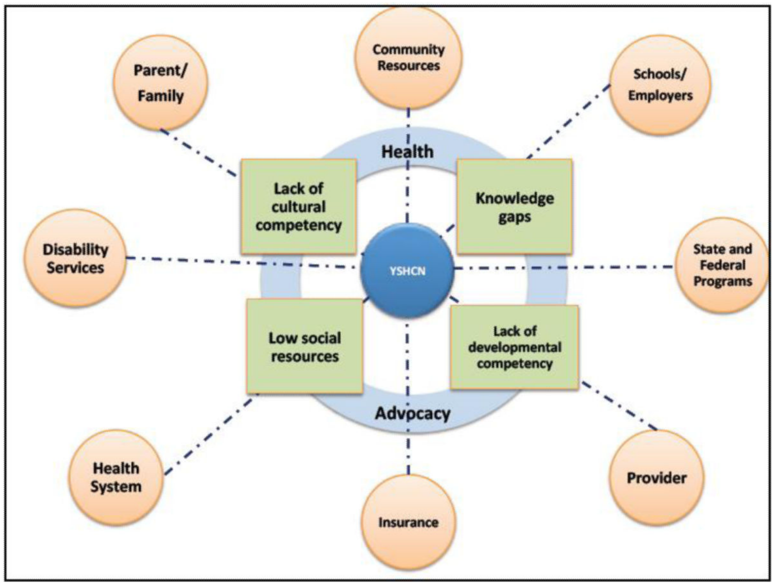

Figure 1.

Project map from interviews

Table 1

Demographic Profile

	N = 41
Overall sample	
Mean age in years	40 (SD 16.9) Range (18-69)
% Female overall	27 (65.9%)
% Mother for parents (n=9)	77.8%
Racial background n (%)	
White	28 (68.3%)
Black	5 (12.2%)
Hispanic	5 (12.2%)
Asian	3 (7.3%)