Promoting Self-Management in Adolescents with Chronic Health Conditions: Understanding Parent Support Needs

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Abstract

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For adolescents with chronic health conditions, developing self-management abilities is an ongoing process that may affect their future health outcomes. Parents are inextricably involved in this process and have the opportunity to act as key players in promoting self-management as youth progress towards becoming young adults. The aim of this study was to understand the support needs of parents working to promote self-management in their adolescent children with chronic health conditions, and to elaborate on a previously published Ecological Framework for transitioning to adult healthcare. Five major themes were identified: (1) Ease of navigating health systems, (2) Education on adolescent development, (3) Coaching for parents and adolescents on communication strategies and self-management skills, (4) Connecting parents and adolescents with peer support, and (5) Clinical strategies to increase the child's involvement in medical care. Using these findings, we provide specific recommendations for future research and program development at both clinical and health system levels to support parents in promoting self-management in their adolescent children.

Introduction

For adolescents with chronic health conditions, the process of transitioning from pediatric to adult health care has been associated with decreased appointment follow-up and worsening of health status (Sheehan 2015, Lotstein 2008). Transitioning to an adult healthcare model requires a successful transfer to adult providers as well as sufficient preparation of the adolescent to effectively manage their own health needs, a process that should occur in accordance with the adolescent's developmental trajectory (Rosen 2003, AAP 2011).

Prior qualitative research with adolescents has identified several gaps in transition preparation. Multiple studies have specifically highlighted gaps in adolescents' understanding of normal development and risk behaviors, such as drug use and sex, with one teen expressing a need to learn "things on alcohol and misuse, 'cos I've not had much information, well, nothing in fact. I don't know how I'm supposed to go about it with my condition" (Wang 2010, Tong 2013, Burstrom 2016). Another identified gap in preparation has been in learning self-management skills, which are often not addressed until the adolescent enters adult healthcare systems (Tong 2013). Additionally, adolescents have expressed a need for support from peers who are navigating similar healthcare transitions (Garvey 2014). As one adolescent stated, "I would have liked to have had some kind of support system when I entered into adult care. I remember asking my doctor, 'are there any other college students that are doing this as well?'" (Garvey 2014).

For most youth with chronic health needs (YCHN), parents play a large role in managing the child's health needs during childhood. Premature shifts toward child-driven disease management have been theorized to be detrimental, and have been associated with poorer disease control and morbidity in patients with asthma and diabetes (Kieckhefer 2000, Warman 2006, Anderson 1997). During adolescence, some parents gradually decrease their level of involvement and some maintain an ongoing supportive relationship into adulthood (Schilling 2006, Buford 2004, Williams 2007, Gee 2007, Christian 1999). This time of shifting responsibility can be a period of opportunity for parents to promote the adolescent's growing independence and skillfulness in health self-management (Heath 2017). While some YCHN may desire a level of continued interdependence with their parents, many perceive parental over-involvement to be unsupportive (Iles 2009, Babler 2015). As one adolescent with diabetes said about her

mother, “she doesn’t want to give up and let go but I’m not just going to let her do it either, I’m not going to let her take care of me because I need to be able to function as a normal person” (Babler 2015). Additionally, some theories suggest that parental overprotectiveness of adolescents may lead to ineffective self-management in adulthood (Heath 2017). Studies involving parents of adolescents with chronic health conditions have shown that parents have fear and anxiety about the health consequences of letting go of responsibility, and often are not sure of how much responsibility is appropriate for them to give their adolescent children (Heath 2017, Akre 2014).

For parents of YCHN, the child’s transition to adulthood is also a major time of transition and support needs for the parent, and yet this is often when parents become less included in conversations with healthcare providers (Allen 2011). Some studies have examined the ways that parents attempt to teach self-management to their children, including role-modeling, allowing mistakes, actively teaching skills, and prompting treatment when needed (Heath 2017). It is likely that these broad strategies are disease-generic, crossing boundaries between different categories of illness (Heath 2017). With sufficient resources, these specific strategies may be taught and reinforced at a health system level, thereby easing parental anxiety and potentially improving health outcomes (Williams 2007, Heath 2017).

Prior programmatic interventions have shown promise in supporting parents. A pilot-tested peer support group for parents showed increase in parent knowledge, future thinking, and preparation for transition (Kingsnorth 2011). An education program for parents of children aged 2-11 led to increased parent-child shared management (Kieckhefer 2014). An intervention involving Behavioral Family Systems Therapy was associated with improvement in communication between adolescents with diabetes and their mothers (Wysocki 2008). Yet, little research has focused on identifying the specific system support and programmatic needs that parents perceive as they work to promote adolescent self-management.

Wang and colleagues have developed a framework for transition to adult healthcare using Bronfenbrenner’s Ecological Model (Figure 1). This model demonstrates the impacts that each “nested environment” of an individual’s contextual experience can have on more proximal levels. As parents and caregivers operate within the child’s “microsystem,” they are sensitive to the impact of factors that exist in the child’s “mesosystem” and “exosystem,” including healthcare providers, teams, and systems. In other words, healthcare providers and systems can work together with

parents as partners to keep parents informed and achieve the shared goal of promoting self-management in the adolescent (Wang 2010).

The purpose of this study was to use one-one interviews to extend understanding of the supports parents need to effectively promote self-management skill development in their adolescent children. We then sought to utilize findings to expand the existing Ecological Framework model of transition and to develop a set of recommendations for future research and interventions to support parents in their efforts to promote their adolescents' self-management abilities.

Methods

This study was approved by the Seattle Children's Institutional Review Board. We conducted semi-structured interviews with 16 parents of adolescents ages 15-24 with chronic health conditions.

A semi-structured interview guide was developed with the assistance and review of Drs. Kym Ahrens, Laura Richardson, and Cari McCarty. The interview guide was informed by literature review and focused on identifying parent support needs within the healthcare system for promoting self-management. Table 1 lists the specific interview prompts that were used. The interview guide was reviewed and modified after each set of five interviews based on preliminary themes identified and the interviewers' perceived need to explore specific topics in greater depth.

All participants completed a brief survey including parent and child demographic information as well as information about the child's diagnoses, medications, and hospitalization history.

Sampling Strategy and Data Collection

The sampling frame for this study included parents of adolescent patients who are seen (or have previously been seen) at Seattle Children's Hospital. Participants were recruited through several routes: 1) flyers posted in Seattle Children's Hospital waiting rooms, 2) referrals from medical providers at Seattle Children's, and 3) review of patient charts in the Seattle Children's electronic health record. When a potentially eligible family was identified, we contacted one or both parents to discuss the study with them and determine if they were interested and eligible for participation. This strategy allowed for recruitment of a diverse sample spanning multiple chronic health conditions, child

age ranges, and included parents who were not motivated to respond to a research study flyer.

Written consent was obtained before each in-person or phone interview. All interviews were audio recorded.

Study Setting and Participants

Potential parent participants were contacted by phone for eligibility screening to ensure the following prior to enrolling participants:

1) Their child had a chronic health condition, which we defined as the parent responding 'yes' to the question "does your child have a chronic health condition that has lasted for at least 12 months?"
2) Their child was between ages 15-24,
3) The parent was a legal guardian of the child (or formerly legal guardian, if the child was over 18),
4) Their child did not have physical or cognitive limitations that would prevent the development of eventual autonomy, which we determined by asking, "Does your child have any specific limitations that would prevent them from eventually being able to manage their condition independently?"

We excluded parents who did not speak English fluently, as we did not have the necessary resources to analyze interview data in a foreign language or to have transcripts translated.

Interviews were conducted both in person and by telephone. Interviews lasted 1-1.5 hours. All participants received a $30 gift card. Recruitment concluded when we determined that no new thematic content was being collected during interviews (Yin 2016).

Data Management and Analysis

Interview recordings were professionally transcribed and reviewed by the interviewer for quality assurance. Cleaned transcripts and survey data were uploaded into Dedoose, a web-based mixed-methods research software, for analysis (Dedoose.com). Electronic data was also stored electronically in a secure Seattle Children's server, and paper data was stored in a locked cabinet in a locked office, where it will remain until additional analyses are completed.

Coding and analysis were performed by Raina Voss and Bridget Whelan. We used a Theoretical Thematic Analysis process to identify key patterns and themes in the data (Yin 2016, Braun 2006). This process includes six phases: 1) familiarizing oneself with data, 2) generating initial codes, 3) searching for themes among codes, 4) reviewing themes, 5) defining and naming themes, and 6) producing the final report. During phase one, both coders reviewed the first five transcripts, noting and discussing themes that emerged. During phase two, we used the themes identified in the first five transcripts to generate an initial codebook. We then used this codebook to code all transcript data using Dedoose, making adjustments to the codebook as needed to accommodate new concepts that emerged during the coding process. The first five transcripts were coded by both coders and discussed to resolve discrepancies. We achieved an inter-rater reliability of 80% agreement by the end of coding of the first five transcripts. Transcripts of subsequent interviews were coded by one of the two coders. Interviews were concluded when no new concepts were identified over three consecutive interviews. During phase three, we reviewed coded data by code category to identify key themes in the data. During phases four and five, we met together to review and define key themes and describe them using representative quotes. This document, which presents findings and includes recommendations for future research and program development, represents phase 6, the final report. Upon completion of data analysis, we returned to the Ecological Model in order to further refine its details using our findings. Phases 3-6 were performed primarily by Raina Voss with input from Bridget Whelan.

Results

Description of Participants

Participant (n=16) and child (n=15) demographic information is detailed in Table 2. Two parents were married and discussed their experiences with the same child during separate interviews. Seventy-five percent of participants were female and 67% of their children were female. The average age of participants was 47 years old (range 37-58). Average age of the children of participants was 18 years old (range 15-21). Eighty-one percent of participants were white. Their children had a wide range of primary medical diagnoses (Table 2).

Themes

We identified five key themes pertaining to parent support needs, each of which related to or expanded on the Ecological Model for transition previously developed by Wang and colleagues (Figure 2). Key themes included 1) improving ease of navigating health systems; 2) providing education on adolescent development; 3) coaching for parents and adolescents on communication strategies and self-management skills; 4) connecting parents and adolescents with peers for emotional and logistical support; and 5) using clinical strategies to increase the child's involvement in medical care. Below, we detail each theme and describe subthemes. Table 3 provides an outline of themes and subthemes as well as additional exemplary quotes.

Improving Ease of Navigating Health Systems

Nearly all participants felt that their adolescent children could benefit from improved ease of access to the medical system. Parents described challenges that they experienced themselves as being even greater barriers for adolescents learning to navigate the healthcare system. One mother discussed her challenges with reaching her daughter's doctors to discuss her diagnosis and care plan.

> "As a parent, I was always on them and always calling and stuff. But I think that a lot of parents don't do that, and kids don't know how to do that." – Mother of 21 year old with VACTERL syndrome

Four parents described scheduling of appointments as a specific challenge. They cited specific issues including long waits for appointments and limited provider clinic schedules. As one mother stated, "my kid's doc is in the endocrine unit… half a day, one day a week. You've got to be kidding me." Two parents had positive experiences with scheduling, including automated reminders or the option to set up recurring appointments, and one suggested making this routine for adolescent patients.

> "I think it would be comforting, as a parent, to know that just like how the dentist calls you or sends you that postcard and says, 'It's time for your appointment'…I think that that kind of thing would be comforting as a parent to know that the doctors are following up with them or sending them a reminder postcard or calling to schedule the next appointment." - Mother of 15 year old with juvenile arthritis

Challenges with making contact with the healthcare facility expanded beyond scheduling to include making contact with healthcare providers when medical questions or concerns arose. Over half of parents discussed this topic; while two-thirds of these

participants felt that their providers were very accessible, one-third felt that there were barriers that made it challenging to contact providers.

> "Whoever decided that there has to be that many layers between patient families and their physicians should take home a really sick kid for a month and then be told, 'Now you can only use the system that you created.'" – Mother of 15 year old with type 1 diabetes

Parents placed high value on having provider emails and receiving prompt callbacks when they had questions, "so you don't feel like you're completely out there in the woods trying to figure it out yourself." Nurse phone lines were an important aspect of support for questions or other needs between clinic appointments. One parent described mental health providers as being more accessible than other healthcare providers. Parents appreciated proactive communication between multiple providers. Describing a lack of communication between providers, one parent described "feeling like I was putting puzzles together."

Two parents suggested strategies for engaging adolescents using phone or video visits. These were described as a way to engage a younger generation by "bringing it to their level." One parent suggested phone appointments as a way to provide ongoing support for self-management goals between traditional appointments.

> "After an appointment, a follow-up call or communication in some way would be helpful. Just to say, 'Hey, how are things going? What's working? What's not working?'…'Are you doing these things? Remember we talked about this, this, and this…What's challenging you for that?'" – Mother of 16 year old with migraines

Half of participants discussed logistical challenges such as distance to medical providers and limited hours as barriers to their adolescents' success in managing their own care. One parent discussed mail-order medications as a way to avoid driving long distances to a specialty pharmacy. Another suggested weekend or evening hours as a potential support strategy.

> "Why don't they have Saturday hours? Why does a place that specializes in treating children, and children's number one job is to do well at school, ask them to miss school and come in and be treated?" – Mother of 15 year old with type 1 diabetes

One parent extensively discussed financial challenges as a barrier to her ability to support her daughter's self-management. While she praised the healthcare facility for

providing uncompensated care and assisting with obtaining medications, she described challenges with obtaining insurance coverage and diabetes supplies (Table 3).

On some occasions, the patient's age led to specific barriers that inhibited the child's development of self-management skills. One participant discussed the challenges that arose when both parent and child lost access to their online healthcare portal between the ages of 13 and 18 (Table 3). Another parent discussed issues with her son picking up his own prescriptions as a minor.

> "I will try to encourage him to be independent and go pick up his own medicine. And they've denied him doing it because it's a controlled substance, and he's a minor… 'I'm right here. You can see my ID, but we're trying to encourage independence. Can you just work with him and give him the meds himself? Because he's the one getting them, and it's his name'… Different places have different policies that are completely arbitrary." – Mother of 17 year old with epilepsy

Providing Education on Adolescent Development

Three parents of children who had reached adulthood reflected on a need to learn about adolescent cognitive development and its implications for their children with chronic health conditions. One mother suggested that parents need to "understand what's happening with their kid's brain" to recognize that some support needs persist into young adulthood. Parents indicated that this information would be best communicated via handouts or pamphlets mailed to the home that could be read at the parent's convenience. This was viewed as a helpful strategy to reach parents with busy schedules or those who lived far from the healthcare center.

> "You get something at 18 months that says you're part of your development of your baby and says by 18 to 24 months they should be doing this and that and the other....For teenagers, you could say, 'Okay. Appropriate adolescent development from 15 to 17' and don't stop it when they turn 18. Keep going until they're 21." – Mother of 20 year old with type 1 diabetes

In addition, parents desired information on how their adolescent's development would be impacted by their health condition.

> "I wanted to be prepared. I wanted to know – this is going to send you through the roof for all I know blood-sugar-wise because of all the adrenaline. Your first kiss, your first big make-out session, or it's going to cause you to tank. And I needed to know what alcohol is going to do." – Mother of 15 year old with type 1 diabetes

Several parents described uncertainty about how their role should change as their children developed more independence over time. While many parents discussed their individual attempts to "push away" and gradually turn over responsibilities to their children, several expressed a lack of understanding about how to do so and a desire for support in this process (Table 3).

Coaching for Parents and Adolescents on Communication Strategies and Self-Management Skills

The majority of parents discussed needs and recommendations for training on communication and self-management. Several participants reported a desire to learn strategies to communicate effectively with their adolescent children. There was a sentiment that adolescents and adults do not understand each other's perspective and that facilitation could help them understand one another better. One parent cited generational differences between adolescents and their parents as a source of communication challenges. Another suggested that training could help adolescents talk with their parents about the level of support their parents were providing. Both group and individual approaches were discussed.

> "If they're with other kids and they can group together and say, 'This is what we feel,' I think that would be easier for the child to say that. I think the same way for the parents…I think if the parents can get together and talk about it as well with the children, that that might help the parents and the children better understand each other's emotions." – Father of 16 year old with autoimmune hepatitis

Three parents (all female) cited a need to learn skills for dealing with their child's resistance to illness management without becoming frustrated, and to learn strategies for motivating their child. One parent desired feedback because when trying to encourage her daughter, "sometimes we made it worse."

> "If they're resisting doing everything that they're supposed to be doing to maintain their condition, how do you deal with that? What is a good way to approach that? Or what can you say to make the situation better rather than getting frustrated?" – Mother of 18 year old with asthma

In addition to facilitating communication, parents suggested designing workshops, classes, or clinics focused on teaching adolescents to become effective managers of their health conditions. Topics discussed included knowledge about health conditions; the importance of consistent adherence to treatment plans; specific disease

management skills; strategies for coping with a chronic diagnosis; and increasing ownership and self-efficacy. One parent suggested that these training sessions could provide opportunities for adolescents to learn about the health impacts of behaviors such as sex and drug use. Another mother acknowledged that adolescents might have different approaches to health management than their parents (for example, different appointment tracking strategies) that they could explore and develop in these settings.

> "There could be clinics offered…that identify, 'Here's how to make sure your medicine's being dosed properly,' or 'Here's how to coordinate all of your multiple visits'…And then a teaching with kids of what it looks like when they're getting enough support or how to communicate…if you feel like you're getting too much support from your parents and you need them to back off." – Mother of 17 year old with epilepsy

Connecting Parents and Adolescents with Peers for Emotional and Logistical Support

The majority of participants had a desire to connect with other parents raising adolescents with chronic health conditions. Some parents had found this type of support outside of the healthcare system through social connections, while others felt that healthcare systems should help to facilitate connections between parents. As a hybrid approach, one parent suggested that the healthcare facility should provide parent names to a peer facilitator who could then organize and moderate support groups.

> "I don't feel it's the hospital's job, but if they could help us with it, it would be wonderful because I can't find the pool of other diabetic families." – Mother of 15 year old with type 1 diabetes

Parents expressed the desire to utilize peer groups for emotional support. Speaking about his daughter's autoimmune hepatitis, one father described his experience as "every bit as emotionally taxing on the parent."

> "You can be stronger for your child if you can talk it out with other people that are going through it, and this might be something [Children's Hospital] can form." – Father of 16-year-old with autoimmune hepatitis

Parents also desired the support of peers to learn practical strategies for disease management and for parenting a YCHN. Specifically, a parent with diabetes felt that peers would be helpful in navigating school issues, and parents of youth with gastrointestinal and renal conditions viewed peers as important sources of information on managing their child's diet.

> "I feel in the community there is that desire but it's just how do we make that happen?...How do the other parents deal with the diet and their other kids, or their whole family? And there's no perfect answer but it's good to talk about it." – Mother of 15 year old with kidney failure.

Most parents expressed a preference for peer support from parents whose children had similar diagnoses. Many parents discussed an increased need for peer support in the immediate period following diagnosis, when they had a lack of information on available resources and strategies for managing the health condition. There was a desire to learn from more experienced parents whose children had already gone through adolescence.

Participants expressed a variety of logistical barriers to participating in support groups, such as time and distance. Four parents suggested or had experience with using online forums to connect to peers. They viewed these as tools that they could use on an intermittent basis when questions arose.

> "Maybe if there were online community type things or something where people can go and throw out a question…And then you have other parents, like someone like me, who has experience…just try to provide support for each other." – Father of 21 year old with type 1 diabetes

Additionally, two parents valued peer support that could be available regionally so that it was accessible to those living far from a healthcare center.

In addition to desiring support from their own peers, many participants expressed a desire for their children to have peer support. This was suggested as a way to help teens cope with and normalize their illness, avoid disease burnout, and learn how to manage their disease during adolescence. Additionally, peer support could serve as a way for adolescents to address common adolescent challenges. As a mother of a 15 year old with type 1 diabetes stated, "He needs to talk to other diabetics. 'So what do you do on a date?' Or, 'what do you tell your coach?'" Three parents suggested strategies to combine parent and youth peer support groups by developing parallel sessions. Many online support forums were described as having both parent and youth spaces.

Parents of children with Crohn's and diabetes cited disease-specific camps as a key source of peer support for their children, who often built long-lasting relationships with fellow campers. Camps were viewed as opportunities to practice independent disease management, normalize chronic health conditions, and for older children to mentor younger children.

> "The other thing that's helped her, I will tell you, and this is really important. The school nurse gave us a flyer for diabetes camp the first year she was diagnosed. We sent her the very first time she was eligible, and she's been going ever since…they call us normies, and normies can never understand." – Mother of 20 year old with type 1 diabetes

One mother suggested also developing spaces for parent support when parents dropped youth off at diabetes camp.

Using Clinical Strategies to Increase the Child's Involvement in Medical Care

Three main clinical strategies were identified as helpful by parents encouraging their adolescent children to increase their involvement in their own care. These included the enactment of confidentiality rules, direct communication to the adolescent, and partnering with parents to reinforce consistent messaging.

Privacy and confidentiality rules that take effect at age 13 and 18 were seen as both challenging and helpful in creating boundaries between the role of the parent and the role of the adolescent patient. At age 13, two parents lost access to their child's online healthcare portal, which one described as a way to "help parents realize that kids need to take responsibility for their health." At age 18, two parents reported that the clinic began contacting adolescents directly to start scheduling their own appointments. One mother described her daughter turning 18 as an opportunity for her daughter to embrace an increased level of independence.

> "All of a sudden, when she becomes 18, she wants to take over and do everything…The fact that she knew she could do things on her own, and that was kind of the time where's she's like, 'I've got this. I don't need your help anymore.'" – Mother of 19 year old with kidney transplant

Parents also discussed the importance of providers interacting directly with the adolescent "instead of [treating] the parent as the patient." This included suggestions that staff speak to the adolescent at the appropriate developmental level, ask direct questions to test the youth's knowledge about their health condition, and, as one mother suggested, "tell her to make her next appointment, maybe have her make it." These strategies allowed providers, rather than parents alone, to increase the adolescent's engagement in their care. One participant explained that her daughter had gradually developed increasing trust and rapport with her provider so that "she really takes it to

heart and believes what they have to say." Private visits with medical providers were one strategy that supported parents' efforts to promote self-management.

> "They started talking about sexuality and stuff, and they started to kind of say, 'Mom, you don't need to come in to the appointment.'…The pediatrician kind of taught them that that was okay, and that was good." – Mother of 20 year old with type 1 diabetes

Parents appreciated continued involvement so that they understood the child's care plan and how they could continue to be supportive. One mother appreciated "coming in at the end…and just sort of getting a little bit of a recap…to figure out where my role in the thing works." Another mother expressed distress that her daughter stopped allowing her to attend appointments when she turned 18.

Four parents discussed the sentiment that adolescents were more likely to take advice from healthcare professionals than from their parents. One mother proactively reached out to her daughter's providers to notify them of challenges that her daughter was having so that providers could address these issues in an upcoming appointment without the adolescent becoming frustrated.

> I've reached out to both local doctors and the Children's doctors, or nurses, and letting them know, '[she's] not doing very well on her fluid intake, can you touch base with her, and kinda talk to her and help her get better?' Because I knew it wasn't going to come too well from me, being her mom, because we never know anything." – Mother of 19 year old with kidney transplant

Discussion

Participants identified several support needs in their role as parents of YCHN. These needs spanned across the levels of the Ecological Framework to include navigation of the healthcare system; structured training and education on adolescent development, communication and self-management; structured peer support; and partnerships with providers to enforce self-management goals and empower adolescents as managers of their own health condition(s). All of the key themes identified included aspects of healthcare services and systems change, or the "exosystem" of the adolescent's environment (Wang 2010). Several suggestions, such as training adolescents on understanding their condition and its impact, contained strategies for improvement at both the system level and the provider level. Parents suggested strategies for providers to work directly with the adolescent (i.e. through confidential visits and directing communication to the adolescent) and for providers to

partner with parents to emphasize important self-management goals and messages, thus addressing both the adolescent's "mesosystem" and "microsystem."

Several of the support needs identified by parent participants reflect areas that have been identified in prior research as gaps in service during the transition to adult care, including education on adolescent development, training on communication skills, and training on self-management skills (Wang 2010, Tong 2013, Burstrom 2016, Wysocki 2008, Kieckhefer 2014). Participants recommended several new strategies for addressing gaps in transition preparedness that should be explored in future research. Participants frequently discussed the importance of reducing barriers to navigating healthcare systems, with a novel suggestion for adolescents to participate in telephone or video visits. The need for peer support has been previously identified (Kingsnorth 2011, Garvey 2014); however, participants in this study uniquely identified value in creating parallel support strategies for adolescents and parents, either using simultaneous sessions or creating systems for both youth and parents to access support systems. The degree to which parents highlighted a need for support from other parents was striking and adds emphasis to this strategy as a way for parents to promote self-management. Parents emphasized the previously established importance of collaborating with providers to remain included in the adolescent's care, and recommended developing private lines of communication between parents and providers to ensure that the provider addressed shared goals during clinic appointments (Wang 2010, Allen 2011). Additionally, participants emphasized that their adolescents were empowered by direct communication from their provider as well as increasing confidentiality (through private visits and legal changes in confidentiality occurring at ages 13 and 18).

This study was limited by its convenience sampling strategy, which although typical for qualitative studies may have led to selection of parents who have had more extreme positive or negative experiences with their adolescents' healthcare experiences. In an attempt to reach a more varied sample, we did recruit 50% of participants using chart review and directed contact. Additionally, our sample did lack diversity, with 81% of participants being white, 75% of participants being female, and most being highly educated.

This study is unique in that it included parents of adolescents with a wide variety of health conditions, which allowed us to search for themes and recommendations that

can be applied across healthcare systems. This study had an improvement-focused approach, prompting parents to reflect upon their healthcare experiences in order to recommend strategies for program design. This allowed us to create recommendations that can directly incorporate parent input into future program development.

Based on the findings above, we recommend that healthcare providers and systems develop and test programs that include the following features:

- Strategies for directly facilitating adolescents' engagement with healthcare systems, including appointment reminders, extended clinic hours, and phone or video visits
- Parent education on adolescent development and its unique implications for YCHN
- Individual and group forums for developing parent-teen communication skills and allowing open and safe communication to occur
- Trainings for both providers and adolescents focused on teaching adolescents skills for disease management and healthcare system navigation
- Accessible lines of communication between parents and providers regarding the adolescents' degree of self-management success and ongoing needs
- Provider education on gradual transitioning of communication from parents to adolescents
- Forums for parents and adolescents to connect with peers, both in person and online, for emotional support and peer-led education on disease management strategies

Our findings support prior recommendations that the transition to adult healthcare should occur in a developmentally informed way and include parents as key partners in the adolescent's care (Rosen 2003, AAP 2011, Heath 2017). The recommendations outlined above provide an elaborated version of the Ecological Framework for transition to adult care and provide concrete suggestions for supporting parents at both a direct clinical and healthcare system level to promote self-management in adolescents with chronic health conditions (Wang 2010).

Figure 1. Ecological model with transition-related concepts and themes. Adapted from Wang and colleagues, 2010.

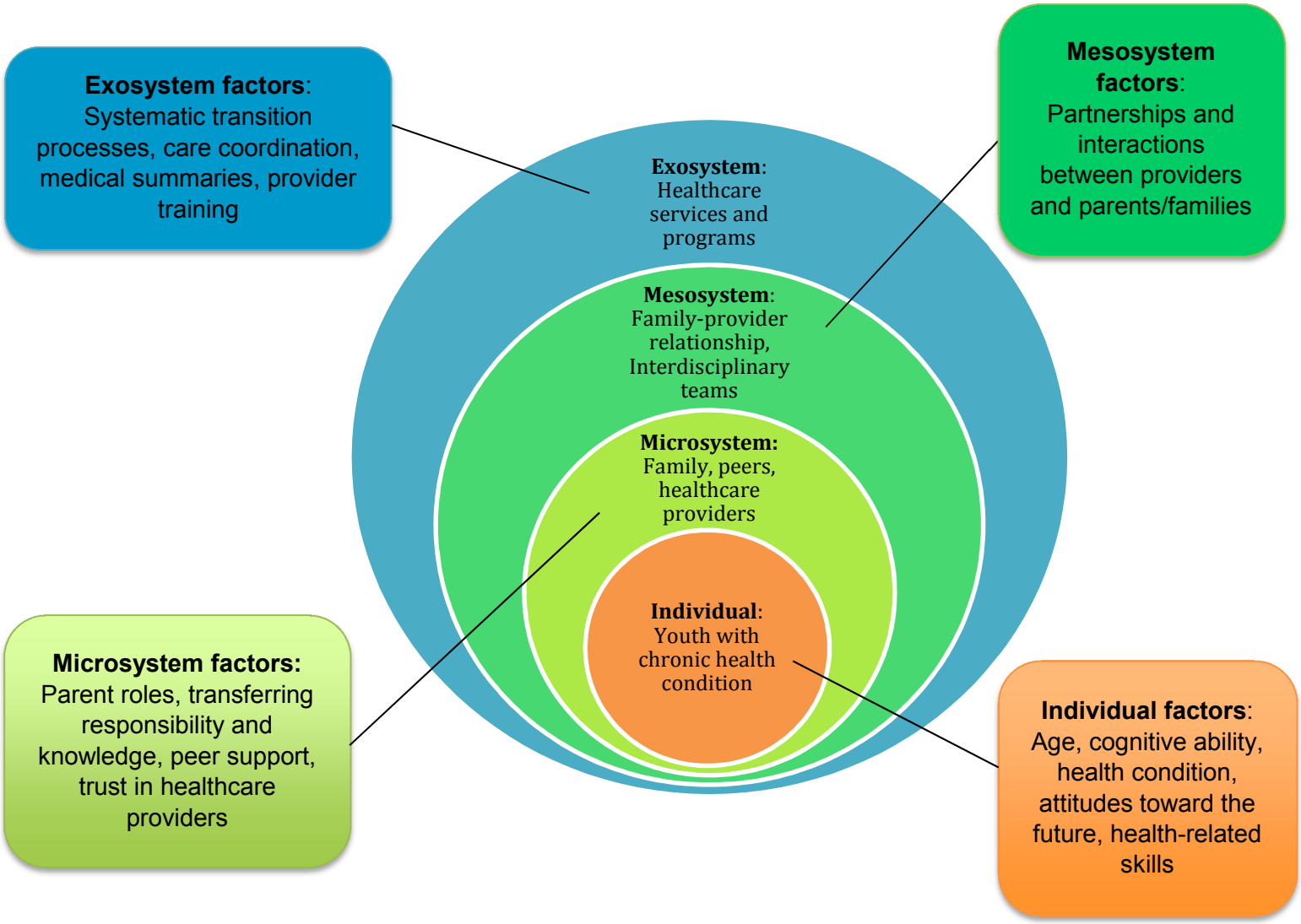

Figure 2. Elaborated conceptual model, including key themes and their placement within an ecological framework

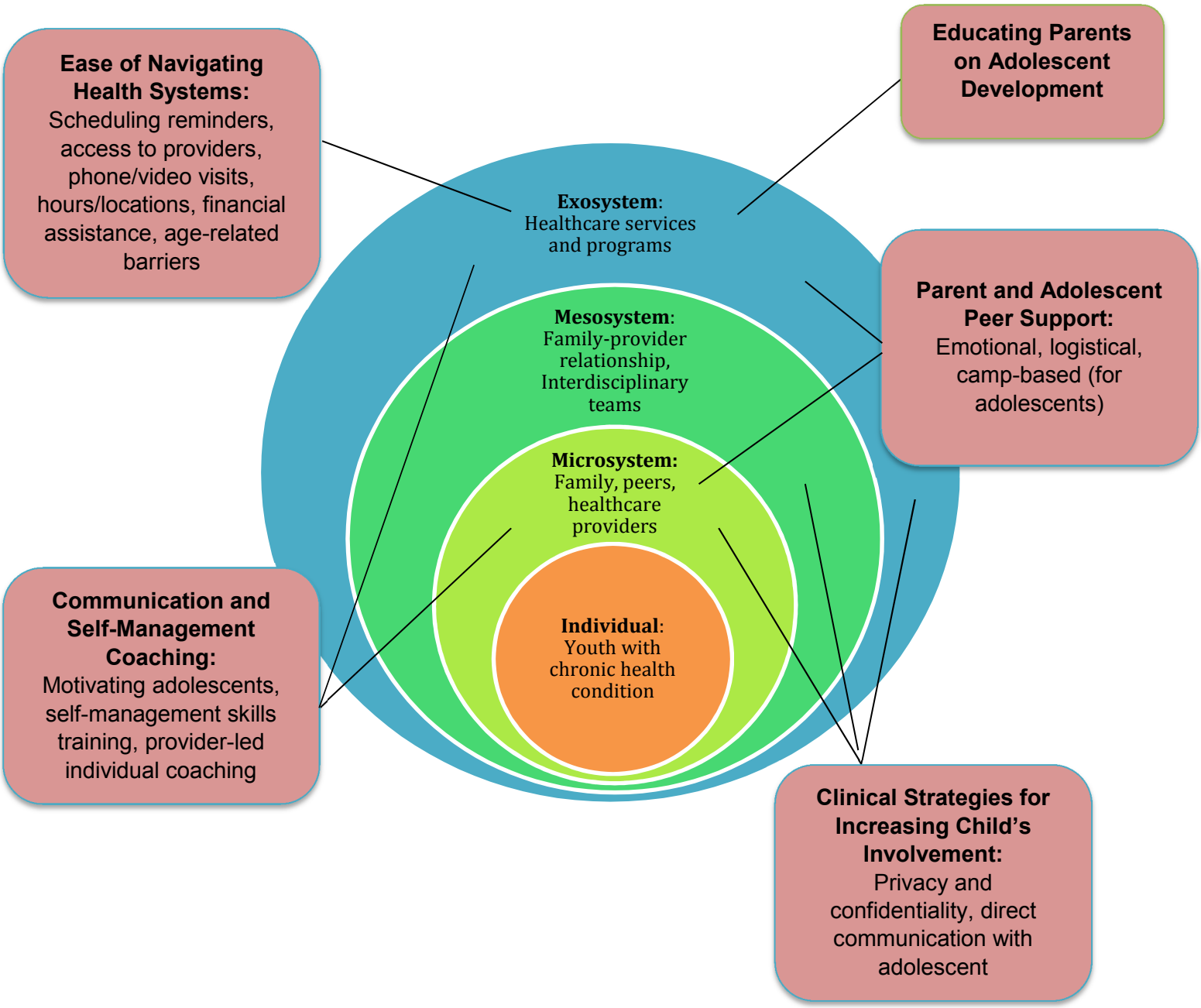

Table 1. Interview Prompts

What things did you notice that your providers (or the hospital, or others) did that helped to support <u>you as a parent</u>, when it came to helping with your child's process of taking over responsibility for the health? What things did you *not* see happen that you wish had happened?
Our team is interested in developing strategies to support parents as their teen learns to take care of themselves. As we think about how healthcare providers or health systems could better help families with this process, what things should would keep in mind?
If you were to develop a program or system to guide families through this process, what would you want to make sure you included?

Table 2. Participant Demographics

	Youth (n=15)	**Parents (n=16)**
Age, Average (Range)	18y (15-21y)	47 y (37-58y)
Race, N (%)	White, 11 (73) Other, 5 (27)	White, 13 (81) Other, 3 (19)
Gender Identity, N (%)	Female, 10 (67) Male, 5 (33)	Female, 12 (75) Male, 4 (25)
Parent Education, N (%)		GED/HS Diploma, 2 (13) Some college, 4 (25) Bachelor Degree, 9 (56) Doctorate, 1 (6)
Annual Household Income, N (%)		$10,000-25,000: 1 (6) $25,001-50,000: 4 (25) $50,001-100,000: 7 (44) $100,001-250,000: 3 (19) >$250,000: 1 (6)
Primary Health Condition	ADHD (1) Asthma (1) Autoimmune hepatitis (1) Crohn's disease (1) Epilepsy (1) Kidney Failure (2) Migraine Headaches (1) Rheumatoid arthritis (2) Type 1 Diabetes (2) Unspecified lung disease (1) VATER syndrome (2)	

Age at Diagnosis, Average (Range)	6.4y (0-16y)	
Number of Medications, Average (Range)	3.2 (0-10)	
Number of Hospitalizations, Average (Range)	4.8 (0-30)	
Is your child limited or prevented in any way in his/her ability to do the things most young people the same age can do?	No – 6 Yes, only a little bit – 1 Yes, quite a bit – 6 Yes, a great deal – 3	

Table 3. Themes, subthemes, and exemplary quotes

Theme	Subtheme	Exemplary Quote(s)
Improving Ease of Navigating Health Systems	Appointment scheduling and reminders	"We have no appointments scheduled in his future and he should have two or three out on the books...And what will happen I guess is my kid won't be seen this year. And once again, the burden falls more heavily on the family." – Mother of 15 year old with type 1 diabetes
	Contacting healthcare providers	"I can't even leave a message for my physician. I mean the hospital thinks I can but I've tried. I mean I would ask these people, "So if my son has his one and only seizure and is having symptoms for two weeks after, and I can't call and leave a message and get a return phone call? Are you proud of that? Is that supporting?" – Mother of 15 year old with type 1 diabetes
	Phone and video visits	"Our generation, it was you called and got an appointment. And I think that possibly a video appointment kind of thing when it's not quite necessary to be on-site, that type of thing." – Father of 20

		year old with ADHD
	Expanded hours and locations	“She hates going up to [city] as much as I do. If we could get somebody that came down to the clinic once a month even, I think that would be huge just on her emotional – on both of our emotional – I don't know a good way to phrase that.” – Father of 16 year old with autoimmune hepatitis
	Financial and insurance assistance	“Knowing that if a practitioner at [Hospital] says, "This is the best thing for your child," that [Hospital] as an organization will find a way to make sure that that child gets that thing. That's very important.” – Mother of 20 year old with type 1 diabetes
	Reducing age-related barriers	“At age 13 in most places…I no longer have access to her medical record, but she also doesn't either until she's 18. And that doesn't make any sense to me. If you're going to remove it from the parent and determine that the child is old enough now to make their own decisions medically, then they should have access to their record, and they should be able to communicate with their providers.” – Mother of 16 year old with migraines
Providing Education on Adolescent Development	Printed materials on normal developmental expectations	“It's like if the parents could understand what's happening with their kid's brain along the way…mail something to her that she might read…because there's a divide between…the parents that understand your kids need your support until they're on their way, and the parents that think, ‘Oh, I'm done,’ because they turned 18.” – Mother of 20 year old with type 1 diabetes
	Understanding how health condition is impacted by adolescent behaviors and development	“They're going through puberty. They're trying to gain their independence. What does that mean in the sense that, how do we step back and let them do more of their medical care? How do we counsel them when their friends ask them, ‘Well,

		what's going on?'" – Mother of 21 year old with VACTERL syndrome
Coaching for Parents and Adolescents on Communication Strategies and Self-Management Skills	Facilitating communication between adolescents and their parents	"The doctors should facilitate open conversations between the parents and the child… I think that would be very helpful to kind of be, I don't know-- a mediator…even if it's the doctor's nurse that can sit there and facilitate and talk them through it, that would be a big plus… I don't think a lot of kids and parents would open up in a group setting. I think individual would be the best." – Mother of 21 year old with VACTERL syndrome
	Parent training on motivating adolescents and dealing with resistance	'I think it would be helpful if I knew someone else who was dealing with the situation and had something that they could say that was helpful. I think that that would feel supportive to me. I feel challenged because I'm a single parent, and so I don't feel like I have enough time or energy to really commit to pushing her as much. I think sometimes I give up because I'm just exhausted." – Mother of 16 year old with migraines
	Training for adolescents on self-management skills, coping, self-efficacy	"They sat him down…and he said, 'You're 19 now…What are you doing about your healthcare? What surgeries have you had? Can you tell me?...Because Mom ain't going to always be there.'" – Mother of 19 year old with VACTERL syndrome.
Connecting Parents and Adolescents with Peers for Support	Peer support for parents - emotional	"I think that's what it comes down to, is just people sharing their experiences to maybe make you feel not so alone, or maybe make it a little smoother." – Mother of 18 year old with Crohn's
	Peer support for parents – logistical (parenting strategies, disease management)	"I need to trade problems and I need to hear how other people are solving them." – Mother of 15 year old with type 1 diabetes

	Online or regional forums for peer support	"Some community-based support close by…if there was something regional, closer to me, then that would be very helpful." – Mother of 16 year old with migraines
	Peer support for adolescents	"There is a group that they started with other teens that are on the spectrum that can get together and share stories, what they like and don't like, and what's trending. And at the same time, it reinforces the fact that there's other people that are struggling with the exact same things, and that gives a lot of comfort." – Mother of 17 year old with epilepsy
Using Clinical Strategies to Increase the Child's Involvement in Medical Care	Privacy and confidentiality rules	"As far as her appointments, she makes her appointments now… [Hospital] kind of made it happen. 'You're 18 now.' So [Hospital] started calling her phone instead of our phone since she turned 18. So they would call her and she would talk back and forth, and she would make the appointments." – Father of 19 year old with rheumatoid arthritis
	Directing communication to the adolescent (including one-on-one visits)	"I just don't think they were listening, and I think that they want to listen to the adults more than they do the children at that age." – Mother of 21 year old with VACTERL syndrome
	Provider reinforcement of self-management goals	"Kids don't want to listen to mom, but when the doctor or the nurse is encouraging and supportive, then it's kind of like the magic. It's just what she needed to hear, and it works." – Mother of 15 year old with juvenile arthritis

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