



Perceptions of transitional care needs of adolescents and young adults with special healthcare needs and their parents

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ABSTRACT

Background: As children with special healthcare needs (SHCN) mature, they will transition from pediatric to adult healthcare providers. Close to 80% of adolescents with SHCN reported not receiving services necessary for transition to adult health care. The purpose of this study was to examine the perceptions of the transition experience of Adolescents and Young Adults (AYA) and their parents. Participants were diagnosed with either inflammatory bowel disease or a congenital heart condition.

Methods: A qualitative descriptive study was conducted with participants recruited from specialty pediatric care clinics that served patients with inflammatory bowel disease and congenital heart conditions. Study procedures (recruitment, consent, interview guide) were approved by the clinic staff, the hospital steering committee, and the University IRB. Interviews with AYA and with parents were conducted separately, transcribed, and then coded to identify themes.

Results: Interviews were completed with 8 AYA and 8 parent dyads. The identified themes were Transfer of Care, Mastery, and Support. The Transfer of Care theme reflected participants' worries about moving from their pediatric provider to the new adult provider. The Mastery theme revealed participants lacked confidence in their self-management skills. In the Support theme, participants wanted to be prepared and familiar with the transition process and to become comfortable in the new adult world.

Conclusions: Recommendations shared with clinic providers were to start conversations that directly addressed the transition process early, to provide information and to encourage the AYA to ask questions. In addition, the clinics could encourage AYA to start being responsible for the routine clinic visit paperwork with guidance from the parent.

1. Introduction

Nearly 1 out of every 5 children in the United States has a special healthcare need (SHCN).¹ A SHCN includes intellectual, physical, and developmental disabilities as well as long-standing medical conditions like diabetes, blood disorders, muscular dystrophy, or asthma.¹

Developmental transitions happen throughout the human lifespan but one of the most important is when an adolescent or young adult (AYA) transitions to adulthood and becomes less dependent on their parents/caregivers for support. This is something that all AYA must go through. Adolescence is an important time of both psychological and biological changes and is second only to childhood in the breadth and rate of developmental change.² During this period, the brain develops rapidly, and other biological systems interact with social development that affects new behaviors and allows for many transitions that are

important for a person to function as a productive adult (e.g., health transitions, pubertal changes, changes in personal and social responsibilities, education and employment opportunities).² Adolescence is followed by an intermediate life stage that Arnett labeled as emerging adulthood or young adulthood. Young adulthood occurs between the ages of 18–25 and is a period where life can go in many different directions, little about the future has been decided, independent exploration is greatest, and these are the most volatile years of most people's lives.³ It is during these turbulent times that we ask AYA with SHCN to take on the added stress and responsibility of learning to manage their own health care.

Health Care Transition (HCT) is the movement from a pediatric to an adult model of health care with or without transferring to a new clinician.⁴ Risk and vulnerability encompass many aspects of the transition from adolescence to adulthood, transitioning from pediatric

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parent-supervised health care to an adult model of care is no exception.⁴ The need for HCT programs is becoming more recognized, but according to the 2020–2021 National Survey of Children's Health, a staggering 83.1% of Texas children with SHCN did not receive services necessary for transition to adult health care compared to the 79.5% of children with SHCN across the United States who did not receive services necessary for transition to adult health care.⁵ One way to improve the HCT process is by having structured transition programs in specialty clinics.

HCT programs are designed to support transition from pediatric to adult care.⁶ Although the evidence on HCT outcomes remains limited, a systematic review of studies published between 2015 and 2019 identified 8 (out of 321 full-text review articles) that found 169 quality indicators related to transition.⁷ Quality indicators are measurements used to evaluate the quality of health care delivery⁷. Of these articles 56% were illness specific, 43% were patient level focused, 44% were related to the transition process and 51% were patient centered. The common themes of these indicators included education (12%), continuity of care (8%), satisfaction (8%), and self-management/self-efficacy (7%)⁷. However, evidence that supports optimal systems of care that can lead to smooth transitions for AYA with SHCN has not been established.⁸ Although having a structured HCT program is beneficial for AYA with SHCN, there have only been a few studies of pediatric hospital systems that have established policies and protocols for AYA during their transition process (Doucet et al., 2022).

Along with the lack of established systems for HCT, there is no consensus on what variables predict readiness for HCT of AYA. Different studies have pointed to such variables as ecological disparities (e.g., sex or gender, income, language spoken in the home), age, disease self-management, self-efficacy, increased patient provider transition-focused communication, social support, social position, trust, interdisciplinary cooperation and many more.^{9–12} In a systematic review, Varty and Popejoy identified modifiable factors (i.e., psychosocial, self-management, and transition education factors) and non-modifiable factors (i.e., demographic, ecological and disease factors) associated with transition readiness.¹³ This lack of consensus of which variables affect the transition process is not necessarily concerning; however, what is important is the need to determine which of these factors predict or influence successful HCT. Thorough assessments must be done with the population of interest to determine which variables are most important to successful transition and AYA and their families must be included in these discussions to ascertain their viewpoints of the transition process.

The purpose of the study was to examine perceptions of the transition experience of AYA with inflammatory bowel disease or congenital heart conditions and their parents, in the hope that findings could provide insights for how providers can better aid them. Two research questions guided the study: (1) What are the views of AYA with SHCN and their parents about their HCT experience? (2) What needs, challenges and/or barriers to the transition process are identified by AYA with SHCN and their parents?

2. Methods

2.1. Setting

Two specialty care clinics located in a large city in a southern US state that indicated their interest in research on the transition process were the settings for recruiting the participants. One clinic focused on gastroenterological problems and one clinic focused on heart conditions. The clinic staff expressed high interest in learning about their patients' needs related to HCT and suggested that web-based information on HCT might benefit their patients. There are no formal HCT programs in this city, although the providers stated they discussed the upcoming move to adult care with patients and their parents during regular office visits. This study was approved by the University Institutional Review Board.

The researcher also obtained the necessary site approval from the hospital system to recruit from the clinics.

2.2. Sample

The study used a convenience sample of parent-AYA dyads. The sample inclusion criteria were a) AYA aged 16–25 with SHCN, (b) able to read, write and speak English, (c) AYA with a diagnosis of Inflammatory Bowel Disease (IBD) or a heart condition, and (d) being the parent of an AYA who enrolled in the study. Only intact parent-AYA dyads were enrolled in the study. The sample exclusion criteria included being cognitively incapable of understanding and answering interview questions.

2.3. Recruitment

Participants were recruited with flyers posted on exam room doors. Some providers handed flyers directly to their patients and referred eligible families to the researcher. Recruitment occurred from September to mid-October 2021.

2.4. Enrollment

Interested families either contacted the researcher directly using the email address or phone number listed on the study flyers or were recruited during clinic visits. The researcher set up time to talk with them about the study, answer their questions, and then, if they agreed to participate, scheduled meetings to obtain consent and to conduct the interviews. Parents provided consent for themselves and permission for their adolescents who were less than 18 years of age to participate in the study. Assent was obtained from the adolescents who were less than 18 years old. Adolescents who were 18 years or older provided consent for themselves.

2.5. Participants

Participants included 8 parent-AYA dyads. The AYA were between the ages of 16–25 years, 6 were male and 2 were female, and their race/ethnicity breakdown included 4 non-Hispanic whites, 1 Black/African American, and 3 mixed-race individuals. The parents included 2 fathers and 6 mothers. Conditions included inflammatory bowel disease (Crohn's disease $n = 3$ and Ulcerative Colitis $n = 1$) and a variety of congenital heart defects ($n = 4$). The AYA in the GI group had not transitioned into adult care and were all 17 years of age or younger. For the cardiology group, they were being seen by adult providers that worked in pediatric cardiology and adult congenital heart disease. Most participants in the cardiology group were transferred to this current provider by their previous pediatric specialist once they reached the age of maturity, while one patient had been seen by the provider since they were a child.

2.6. Data collection

This study used a qualitative descriptive design. The goal of qualitative descriptive studies is to provide a summary of events that is comprehensive and close to the original source material.¹⁴ Consistent with qualitative descriptive design, data were collected through semi-structured face-to-face, or virtual (e.g., zoom/online) interviews with the AYA and their parents. Separate interviews were conducted with parents and with AYA on the same day. Each interview was done individually, but only two AYA participants conducted their interview without their parents in a nearby location. The interview guide included questions about their views surrounding the transition process (e.g., "What do you think about changing from a pediatric doctor to an adult doctor?") and their challenges, needs and/or barriers. The interview guide was developed based on *Got Transition*®¹⁵ resource documents

and recommendations from pediatric researchers and clinical experts. The guides were the same for both parents and adolescents with some words changed to reflect asking a question to the AYA vs. the parent (see Table 1). Prompts were used to encourage more in-depth responses and to obtain further clarification. Additional questions arose based on the responses provided by the participants. Adolescent interviews ranged from 5 to 27 min (average 11:30), while parent interviews ranged from 7 to 60 min (average 20:09). A brief demographic tool was used to collect information about ethnicity/race, gender, education level, insurance coverage, marital status, income level, chronic condition, age and other demographic information (see Table 2).

2.7. Data analysis

Interviews were recorded on an iPad then uploaded to a virtual file and transcribed verbatim using otter.ai¹⁶, an artificial intelligence transcription service. The recordings were listened to by the researcher (BA) who simultaneously reviewed the transcripts. Any discrepancies between the recording and the transcript were corrected and the final file was exported into Microsoft word where independent coding of the interviews was completed. The cleaned interview transcripts were analyzed qualitatively using thematic analysis, followed by constant comparative analysis across interviews. Key ideas were analyzed (by BA) through intensive readings and coded and divided into themes and subthemes. Both authors (BA & SH) discussed the research texts and the relationships among the themes and agreed upon the synthesis presented in this study. Validity of the interpretation was achieved through close reading and rereading of the interviews. Excel was used as a record keeping file for storing and sorting codes.

3. Results

Thematic analysis yielded three main themes, Transfer of Care, Mastery, and Support (see Table 3). Direct quotes from the adolescents and young adults are identified using AYA# and quotes from parents are identified using P#.

Table 1

Interview guide.

Interview guide for AYA
<ol style="list-style-type: none"> When you think about changing from a pediatric doctor to an adult doctor, what do you think a successful transfer would look like to you? <ol style="list-style-type: none"> Have you had opportunities to go to doctor's appointments without your parent? Have you talked with anyone about the differences between going to see a pediatric doctor and an adult-care doctor? What do you think you need to transfer to adult care successfully? <ol style="list-style-type: none"> Do you think you're receiving what you need? Do you feel ready or prepared to change to an adult provider? What is your biggest worry about leaving your current doctor for a new one focused on adults? What do you anticipate will be the hardest part of transitioning to adult providers? What will help you feel more comfortable when it comes to managing your health condition independently? (e.g., more practice/opportunities, more independence, etc.) Are you comfortable talking about your health with others? <ol style="list-style-type: none"> If not, why/what might help you feel more comfortable (e.g., peer support, coaching)? Do you have connections with peers with a similar diagnosis? Are there cultural beliefs that are a factor in your approach to HCT? <ol style="list-style-type: none"> If so, what and how can they best be understood and addressed? What would you like your current care team to know about your feelings around changing from pediatric to adult care? <ol style="list-style-type: none"> What would you like to know about them transferring care from pediatric to adult care?

*Questions slightly modified for parent interview guide to differentiate parent vs AYA questions

Table 2

Demographics.

Sample Characteristics	N =
Chronic Disease	
Crohn's Disease	3
Ulcerative Colitis	1
Heart Defects	4
Age Ranges	
16	1
17	3
19	1
20	1
23	1
25	1
Gender	
Male	6
Female	2
Demographic Data Answered by Parents/Caregivers	
Race/Ethnicity of Child	
White	4
Black or African American	1
Mixed-race	3
Marital Status (If applicable)	
Married or domestic partnership	3
Single, never married	2
Divorced	3
Insurance Status	
Private	6
Prefer not to answer	1
Not answered	1
Occupation	
Employed for wages	6
Homemaker	1
Retired	1
Educational Level Completed	
Some college credit, no degree	1
Associates degree	1
Bachelor's degree	4
Master's degree	1
Professional degree	1
Total yearly household income	
50,000–59,999	1
80,000–89,999	1
90,000–99,999	1
100,000–149,999	1
150,000 or more	3
Prefer not to answer	1

Table 3

Definitions of Themes.

Theme	Definition
Transfer of Care <ul style="list-style-type: none"> Coordination of care Potential gaps in care 	AYAs' concerns about changing to new adult providers. This includes pediatric providers communication about the transition and transfer process, worries about the coordination of care and possible lapse in care, and worries about new adult providers possible lack in knowledge and expertise about their condition.
Mastery <ul style="list-style-type: none"> Skills for the healthcare encounter Time and opportunity to practice skills 	The knowledge and understanding about their health condition. Mastery advances as one develops skills in the healthcare encounter.
Support <ul style="list-style-type: none"> Preparation Parental concern Familiarity with the healthcare provider 	The assistance given to AYA through the transition process. Can include but is not limited to such actions as providers instilling confidence in patients, dependence on their parents, or the amount of control parents have regarding their health and being at ease with the transition process.

3.1. Transfer of care

Transfer of care includes two subthemes that reflect participants' concerns about changing to an adult provider. These subthemes include

coordination of care (specifically how the coordination of care would be handled) and concerns about possible lapses in care that might occur during the transition. The second subtheme included participants concerns about their new adult healthcare providers' understanding of their health problem and healthcare needs, in essence a gap in provider knowledge and lack of expertise concerning their condition. Concerns or questions about the transfer of care was heard in several interviews. When asked explicitly if anyone had ever talked to them about transition, fourteen of the participants indicated that no one had talked to them about transition before the interview.

3.1.1. Coordination of care

When participants were asked about their biggest worry about going to an adult provider, continuity of care was brought up. They did not like the idea of starting from the beginning and having to repeat all their history with a new person, especially if it was a complex one as can be seen from this AYA's statement:

Um probably the history. It's, it's kind of like, it's kind of like getting a new therapist after working with someone for a while and you're like, God, I gotta restart with all of this kind of saying (sic) knowledge...it's always hard to catch someone up when I have this complicated history. (AYA6).

Being tasked with the responsibility of communicating a complicated health history to a new care team can be a formidable endeavor for this population.

A common suggestion made by participants was the need for consultations between the two providers to facilitate coordination between the two clinics. As was expressed by this participant "Um, I think a successful transformation (sic) could have been, like my mom said, having my pediatric cardiologist and my adult cardiologist have a discussion ahead of time" (AYA8). We see that this AYA would have felt better about transferring care if her two providers had a conversation before she moved into the adult care world. A parent also shared this sentiment, parent #5 said:

So maybe have a sit down with both doctors with the patient and their parents to understand that this is where we're going. That you know, the transition is you're not kicking, kicking him out the door. But this is who's going to be your doctor from now on, I think that would be the easiest thing is a consultation with both of the doctors together. (P5).

In this example, it would not only be a discussion between the providers but would include the parent and AYA in the consultation. This would reassure the parents and AYA that everyone agreed before the actual transfer process happened.

3.1.2. Potential Gaps in Care

The AYA expressed concerns about the level of knowledge and skills their new adult-focused providers would have about their condition, they questioned the new adult healthcare providers' capabilities related to their condition. Will they know how to deal with their complex history? Will they see the whole big picture and not just focus on one system? As exemplified in this comment from P7, "...making sure the doctor understands all the challenges involved, because he has neurological as well as cardiology issues. I guess making sure that's the biggest one, making sure that cardiology, that they understand the whole big picture" (P7).

3.2. Mastery

Mastery is having the knowledge and understanding about their condition. Mastery evolves as one develops skills for the healthcare encounter. Two subthemes comprise mastery, including the skills needed for the healthcare encounter and the time and opportunity to practice these skills.

3.2.1. Skills for the healthcare encounter

When asked what they believe a successful transfer would look like,

the participants described the need for mastery. When asked what they need to handle a visit to the doctor without their parent being present, the AYA responded with the need to fully understand their health condition, knowing how to make an appointment, knowing what is needed when checking in for an appointment (e.g., completing paperwork, insurance documents, etc.) and feeling prepared. As indicated by this participant, "Yeah, I guess when you transfer over to adult doctor, you'd probably want it to be able to go by yourself and feel comfortable asking questions. And being able to understand the answers they give you" (AYA5). Or as explained by the following participant, "I think making an appointment, coming in, checking in for an appointment, having like, the knowledge of what paperwork I need to fill out, like even just asking for a school note, it doesn't always cross my mind" (AYA1). To help them feel more comfortable in handling their condition, responses included having knowledge, "Just knowledge, knowledge, and a good team behind me. Yeah, for sure" (AYA6).

To them, a successful transfer included being able to understand their health condition, knowing what questions to ask and understanding the answers that the providers gave them.

3.2.2. Time and opportunities to practice skills

When some individuals talked about the transfer part of transitioning, they did not experience it as a smooth change, rather they experienced it as an abrupt change. They did not receive the resources or guidance needed to master this process as can be seen from AYA8:

It's between a yes and a no. Like, for example, I got a call from them one day when my mom and I are both trying to figure out the transition from seeing my previous doctor to an adult cardiologist. Yes, that was the first time they talked to me about it. And they told me that I can no longer see my previous doctor. But I don't think I had a choice. I'm looking back I don't think I had a choice of who I saw. (AYA8).

This introduction to transitioning happened on the last day AYA8 saw their pediatric provider, she felt like she did not have a choice on who she could see as an adult. This example emphasizes that providers should not assume the AYA will know how to maneuver in adult care. AYA6 expressed similar concerns:

And me now, being in the hot seat and being like, well, you're an adult now. So, what should we do? I'm like, I don't know, dude, I've been having this be decided for me for 25 years. What do you mean? Who cares about my decision, you guys have a good streak going on. So that's the con of like playing catchup. (AYA6).

This perception of having the responsibility thrust on them without preparation can lead to feelings of being overwhelmed.

In asking about what they need for making a successful transition to adult care, participants mentioned a guide, a kind of scaffolding filled in based on the specifics of the child and family. Uncertainty and lack of specific knowledge are some of the biggest worries that the participants had in terms of changing to adult care. The lack of knowledge spanned simple tasks like managing the check-in clinic paperwork to not knowing all the details of their health history like their parents knew. The hardest part and the biggest worry the participants had about transition is not being able to manage for themselves, getting to know the process and having to set up important things like procedures by themselves as expressed by AYA6:

Actually, having procedures of actually going through a heart cath of a surgery. That's the hardest. It's one thing if you're just going to appointments and having checkups, and you know, and that kind of thing that real general thing. But when it comes to something big, I mean even to the point of choosing, choosing where do you want it done? (AYA6).

3.3. Support

A desire for support in the healthcare transition process was identified by participants. The theme of support includes being prepared for the transition process, the parents' concerns about their role in the transition process, and the AYAs' familiarity with the healthcare

provider.

3.3.1. Preparation

Participants wanted to be prepared and familiar with the transition process, and have it streamlined. "I think a successful transfer would be feeling prepared. And then once I'm getting into it feeling familiar, because at the point I am now I really have not received a lot of resources or guidance on what that will look like" (AYA1). Not receiving resources is seen as a lack of support needed for transition. As demonstrated from AYA1 she feels as if she is not properly prepared for the transition process. The participants wanted to be comfortable with their new adult provider because some had been with their pediatric provider their whole lives.

3.3.2. Parental concern

Parents are concerned about having their AYA visit their healthcare providers alone and expressed that they still want to be involved to a certain degree. The parents want to be involved in some capacity, but many recognized that their child needs to start taking control over their health and that the care team needs to look at their child as the primary driver in their health. P4 describes the kind of scenario that would make her comfortable with her child visiting the doctor without her "the first few appointments, you know, I would love to do with him, making sure I'm just being the one sitting back and he's driving things" (P4). Parents recognize the importance of having support during clinic visits, a second ear during an appointment with the provider, then following up with the parent, as described by P4:

But I think the care team, asking the child primarily, and then following up with the parent, you know, as the child is older, probably helps them most, because then he knows, oh, yeah, I need to drive the conversation and answer the questions" (P4).

Being an adult does not necessarily mean that an individual wants to go to their healthcare visits.

alone, especially if they have a complex care need.

3.3.3. Familiarity with the healthcare provider

A big worry for these participants is losing the support of a familiar healthcare provider that they have known for years. Some feel that their long-term pediatric providers will have more of an emotional investment in their wellbeing than the future adult provider. The hardest part of transitioning to an adult provider was the sense of leaving all you know and having to become familiar and comfortable with a new set of people as is explained by AYA8:

Well, I've been able to see my. I was seeing my previous doctor ever since I was tiny. Maybe since I was born. I'm not sure. But you just kind of, it's not attachment, but you definitely feel more comfortable with them. And you've gotten to know them over years, 18 years, and then restarting just out of the blue is kind of it's different. (AYA8).

A question concerning cultural beliefs was included in the interview guide. A few patients and parents responded with the need for providers to be aware of differences between groups. As noted by AYA8 who is biracial:

I don't believe so. But I do know, I don't know if it's focused on more now. And I may ... have learned this from Grey's Anatomy, but some, some people who are African American or Black can have different...are more susceptible to certain heart conditions or heart issues. And I'm sure, or I hope that my cardiologist has the best interest in me and my health. But I definitely have noticed that I have to stay aware of that. (AYA8).

A white parent, P4, recognized that providers do not always have all the answers and that they can have blind spots:

I think doctors are human too, and they can't know everything, and you shouldn't expect them to remember everything about you...it's just good to keep in mind, you know, everyone's going to have their blind spots and going to have their strengths. And, you know, you should always trust your own knowledge about what's worked for you or not.

This participant spoke specifically about the concept of individuals knowing more about their body and what has helped them, than a provider might know about them. Furthermore, this parent emphasized the importance of how being paternalistic in relation to a patient's care might not always be the right path to take while providing care. As exemplified by AYA 1 who noted that providers did not address her directly and she thought this was due to her young age.

I have had experiences while go (sic) to a doctor and they're like talking directly to my parents and not to me, and especially as I get older, like, I would like to have that kind of communication relationship where I feel like I'm being involved (AYA1).

4. Discussion

Fourteen of the sixteen participants reported that no one in the clinics had ever talked to them about transition. From the many examples, it was clear that the AYA were not prepared to transition into adult healthcare, and they were not confident in their ability to manage the processes involved in making appointments, answering questions about their health history, and lacked confidence in new providers' knowledge in managing their health problem.

In this study, support is the assistance that is given to the AYA through the transition process. Support can include such actions as doctors educating/empowering patients, AYA's reliance on their parents or the amount of parental control, having advocates come to medical appointments, and collaboration between AYA, parents, and providers. Healthcare providers making assumptions that AYA should already know how to maneuver in adult care can be detrimental to the patient-provider relationship and adult providers might be left with the task of catching them up. It would be good practice for providers to tell or show AYA and their parents what to expect once they leave the pediatric healthcare setting so they can become familiar with the differences expected in the adult care environment. Providers need to help parents learn when to take a back seat, if not it can lead to the AYA having too much reliance on their parent and will ultimately lead to an AYA feeling as if they are not knowledgeable about their condition, which can bring on added stress, anxiety and may lead to fearfulness. For adult providers, receiving patients from a pediatric environment, it would be beneficial to determine how much independence and ownership they have regarding their health condition during appointment visits.

In the GI group all the participants were still under the care of their pediatric providers, and all were under the age of 18. In the cardiology group, the youngest participant was 19 and most had already gone through a transfer process with their previous pediatric provider because they had reached the age of maturity. While all in the cardiology group are technically adults, they still faced the same concerns and fears about not having enough knowledge, not feeling prepared and realizing they must take accountability and ownership of their own conditions. This emphasizes the importance of distinguishing between a transfer versus a transition. Even for patients that do not have to physically transfer to a new provider, there still needs to be attention given to the mental transfer that must be done for those patients to take the lead in managing their health. The responsibility of communicating details about their health history can be overwhelming especially if one is not used to advocating for themselves. This sense of being overwhelmed can lead to increased anxiety and stress as the AYA reflects on a vast, complex medical history and their worry that they may fail to share important information or that information might be lost in this handoff process.

The semi-structured interview guide contained a question about cultural beliefs, the researchers wanted to identify if there are differences in transition based on cultural beliefs. As seen in the larger literature, patients from underrepresented backgrounds can experience biases that originate from cultural stereotypes in ways that can perpetuate health inequalities.¹⁷ These biases can also affect patient-clinician interaction. Patients with lower socioeconomic status have expressed a

decrease in decision making, poor patient provider communication and overall poor healthcare experience when compared to high income individuals.¹⁸ Participants identified the need for providers to be aware of their biases or possible issues that affect certain segments of their patient population, this awareness could help them gain insight into how to better care for these patients. Conversely, a participant talked about the need for patients to also be aware of possible inequalities in health care.

A deeper look into this question in future studies can elicit responses that might help when planning HCT programs, especially since culture affects every layer of life. The reason for so few in-depth responses to this item could be due to the patients and clinical teams' familiarity with each other which has fostered good relationships. Especially since some patients had been seeing the providers for years.

When providers were told that 14 of the 16 participants had not heard about transition, some were taken aback because they stated they had talked with their patients about transition. This disconnect could mean that the participants do not distinguish these conversations as transition discussions due to a variety of factors and providers may have to be more straightforward and direct when they are having transition discussions or even make the appointment specifically about transition.

While most researchers make recommendations for implications of study findings. This pilot study resulted in recommendations that are feasible to implement in busy clinics. The pilot study results and recommendations were shared with the providers (see Table 4). One such recommendation was to start discussing the transition process with patients and families early on. Easy strategies to build into clinic processes is encouraging AYA to start filling out clinic visit paperwork independently, with the advice or guidance of their parents, long before they would need to transition to adult care. Providers were also given resources that might be beneficial to provide AYA and parents during the transition process. These included links to various readiness assessment tools, links to documents with sample questions that AYA and parents could ask providers, and links to timeline, medical summary, and health monitoring application websites. *Got Transition®* created a timeline for AYA, sorting tasks that they should master according to age. Table 4 expands on this and includes a list of tasks that AYA, their parents and providers can begin to incorporate into their healthcare visits.¹⁵

Similar to previous studies, the parents and AYA feel unprepared, they want guidance about the transition process, and are uncertain about what the future holds.^{19,20} Studies exploring AYA and parent perspectives on the transition and transfer process are typically limited

to a particular health condition and findings can be difficult to generalize to other ailments.^{21–24} Researchers often provide high-level recommendations for interventions instead of simpler recommendations that might require less resources for implementation.^{21–24} This focus on low resource interventions is especially valuable as lack of resources is cited as a barrier to transition care.²⁵ The needs of the AYA and their parents identified in this pilot study are not specific to any diagnostic group and therefore have potential application across conditions. Also, the recommendations, based on the study findings (see Table 4), are designed to address the AYA's, and parents' concerns through simple changes that can be done during clinic visits to prepare AYA, their parents and providers for the transition process.

Research implications from this study include implementing and designing transition programs based on readiness and determining if readiness can be supported by starting preparation for transition earlier. This would involve periodically measuring AYA's readiness for transition and determining which variables lead to increased readiness. Resources for readiness preparation could include implementing the items identified in Table 4 or providers creating web-based content around transition via sites like YouTube, Instagram, or others.

Limitations of the current study include the small sample size and the qualitative nature of the interview, which makes the conclusions garnered from the participants more difficult to apply to the general population of AYA and parents. Also, the focus on only two specialty pediatric clinics might leave gaps in the transition needs, challenges, or barriers facing other AYA and their parents. The same interviewer conducted all the interviews, but due to the semi-structured nature of the interview, different prompts emerged during the process which contributed to more in-depth interviews with some patients compared with others. Also due to most interviews being conducted during clinic visits, it was difficult to interview the participants independent of their child or parent, and the interviewer had to be cognizant of not taking too much time away from the main purpose of the clinic visit. All these factors could have influenced the richness of the data collected.

In conclusion, it is clear from this needs assessment that the participants had various worries, ranging from their own knowledge and skills, the new providers competence and skills, and changing to a new environment. The desire for support and resources to prepare them for transition was discussed by all participants. Future studies should identify factors that are amenable to change and would be good targets for interventions.

Table 4
Health Care Transition Preparation Recommendations.

Tasks	For Parents	For AYA	For Providers	For Clinic Staff
By age 14 years: Introduce the concept of Transition. Prepare the AYA to be their own health reporter.	Review AYA's history of surgeries, procedures, hospitalizations, and other health issues. Review family health history to provide the broader background that the AYA will need in adult years.	Ask questions about health history that are not clear. Take an active role in answering healthcare providers' questions.	Introduce the concept of transition, define it, identify tasks that the clinic will be having the AYA do to prepare them for transition. During healthcare visits, begin asking the AYA to report current/recent health issues (parent is back-up informant).	
Age 14–16 years: Practice completing clinic paperwork	Allow AYA to take the lead in filling out clinic paperwork, answer questions.	Begin filling out routine healthcare visit paperwork	Flag patients' files that are ready for transition conversations (can be based on age, maturity, other factors).	Front desk staff should be advised to give office paperwork to AYA to complete and allow parents to review.
Ages 15–18 years: Prepare for a change in healthcare providers; learn about healthcare insurance.	Continue to allow AYA to take the lead in routine healthcare visits (paperwork, talking with providers).	AYA to begin scheduling office visits, consulting with parent. Complete screening questionnaire.	Include Transition Review in healthcare visits. Review readiness survey – and discuss any items of concern. Discuss the timing of transition to adult health. Invite questions.	Clinic staff review insurance questions with parent & AYA together. Have AYA fill out screening survey (health questions; readiness for transition survey). Provide handouts with resources to AYA and parents.
Ages 18–21 years: AYA is responsible for managing healthcare visits.	Support AYA with information about health insurance; answer history questions.	AYA should schedule healthcare visits, complete paperwork, answer health questions.	Transition Review – invite questions. Schedule pre-transition meeting with adult care provider and family.	Review paperwork with AYA. Provide handouts with resources to AYA.

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Ethical statement

Study procedures (recruitment, consent, interview guide) were approved by the clinic staff, the hospital steering committee, and the University IRB.

Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Data availability

The data that has been used is confidential.

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