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More Than Simply “Letting Go”: Stakeholder Perspectives on Parental Roles in Health Care Transition

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More Than Simply “Letting Go”: Stakeholder Perspectives on Parental Roles in Health Care Transition

Cover Page Footnote

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Abstract

The transfer from pediatric to adult health care for youth with special health care needs (YSHCN) is a vulnerable period. Parents play a pivotal role in the transition process, however, little is known about the specific ways they may support YSHCN in negotiating the transition to adult services. A qualitative supplementary secondary data analysis was conducted to explore stakeholders' perceptions about parents' roles in health care transition. Thematic analysis was used to analyze individual and focus group interviews. Four themes were identified: 1) Parents are crucial; 2) Changing roles; 3) Interdependence rather than independence; 4) One of many transitions. These themes may serve as the basis for planning future intervention studies directed at parents of YSHCN.

Keywords: health care transition, parents, youth, young adults, emerging adulthood

More Than Simply “Letting Go”: Stakeholder Perspectives on

Parental Roles in Health Care Transition

Multiple life transitions, psychosocial stressors and developmental considerations make the transfer to adult care for some youth with special health care needs (YSHCN) a particularly vulnerable period (Kaufman, Pinzon, Canadian Paediatric Society, & Adolescent Health Committee, 2007). Many youth and their parents feel unprepared for this transfer of care, are fearful of the unknown and face challenges navigating the transition period from adolescent to adult services. Parents play a pivotal role in supporting and advocating for their children in pediatric health care, where the dominant model is family-centered care (Kuo et al., 2012). This approach to care aims to meet the needs of the adolescent in the context of his or her family, recognizing family members as partners and collaborators in decision-making (Kuo et al., 2012). This is particularly relevant for children with pediatric-onset and genetic conditions, who rely on parents for ongoing support until they develop the skills needed to manage care more independently (Pinzon, Harvey, Canadian Paediatric Society, & Adolescent Health Committee, 2006). According to the shared management model, YSCHN are increasingly responsible for managing their own health over time, ultimately becoming the chair or ‘CEO’ of their own care, with parents acting as ‘consultants’ and health care providers as ‘resources’ (Kieckhefer & Trahms, 2000). Despite advances in transition interventions and research over the last 20 years, the literature shows that parents and health care providers continue to underestimate the importance of the parental role in promoting self-management and independence (Clark, Kauffman, Singer, Matos-Moreno, & Davis, 2015). For example, one report found that 70% of parents continue to complete health history forms and make health care decisions on behalf of their adolescents, thereby limiting the space for YSHCN to practice important skills and develop

confidence in their abilities (Clark et al., 2015). This dynamic may contribute negatively to adherence to treatment plans for YSCHN. It is clear that this shift in responsibility can be challenging for parents and youth alike.

Several theorists and researchers have written about adolescent development in the context of the family (Arnett, 2004; Erikson, 1959; McGoldrick, Carter, & Garcia-Preto, 2013). In his classic theorization, Erikson (1959) proposes that all adolescents must undergo the task of developing a sense of identity in the ‘identity versus role confusion’ stage. Arnett’s (2004) theory of emerging adulthood further expands on these ideas by articulating a unique developmental period where older adolescents and young adults explore their identity, experience instability, are self-focused, feel “in-between” and undergo a period of possibilities. In this period, multiple life transitions occur including the move to post-secondary education or employment, transition to independent living and the development of romantic relationships. Similarly, McGoldrick, Carter and Garcia-Preto (2013) articulate the concept of “launching” young adults from the family of origin as an important phase of the family life cycle. The family life cycle outlines a series of stages, transitions and tasks that occur within a family based on developmental milestones. Emotional processes take place within each phase of the family life cycle. Examples of these include acceptance of new roles and renegotiation of relationships when young adults are launched into adulthood (McGoldrick et al., 2013). For parents of YSCHN, this “launching” phase can be particularly stressful (Dorner, 1975).

Literature specifically exploring the impact of chronic health conditions on this developmental trajectory is emergent. The presence of a chronic health condition can make this already complicated developmental period more challenging (Dimitropoulos, Tran, Agarwal, Sheffield, & Woodside, 2012; Pinzon et al., 2006; Yeo & Sawyer, 2005). It can be further

compounded by transition out of familiar pediatric services, emergence or worsening of symptoms for some young adults (i.e. diabetes, sickle cell) and expectations of self-management in the adult health care system (Brousseau, Owens, Mosso, Panepinto, & Steiner, 2010). Additionally, frequent hospitalizations during adolescence can result in disconnection from peers, academic lag, and difficulties developing a sense of self outside of the illness (Dimitropoulos et al., 2012; Findlay et al., 2008).

Some young adults, including those with cognitive impairment, require continued parental support, given the aforementioned complexities (Anderson & Wolpert, 2004; Reiss, Gibson, & Walker, 2005). For young adults with severe disabilities, parents, young adults and health care professionals need to work collaboratively to establish the right amount of independence appropriate for the capabilities of the young adult (Hallum, 1995). Evidence suggests that family and social supports are crucial to the development of self-management skills in young adults with chronic conditions (LaGreca et al., 1995). Medication adherence in young adults with diabetes, for example, is improved when parents provide supervision and support (Ellis et al., 2007). The types of interactions between young adults and parents, however, in the context of transition planning are very important (Viklund & Wikblad, 2009). Parental anxiety and over-involvement are viewed as unsupportive by young adults and health care providers post-transfer to adult care (Dickinson & O'Reilly, 2004; Iles & Lowton, 2010). Demanding behaviours from parents are also unhelpful as they may be perceived as threats to youth's autonomy (Karlsson, Arman, & Wikblad, 2006). Parental collaboration with youth, as opposed to overtly controlling behaviours, is shown to result in improved metabolic control in youth with diabetes (Weibe et al., 2005). In addition, tangible support from parents (Hanna & Guthrie,

2001) and parental encouragement allows youth with chronic conditions to gradually progress toward self-management (Karlsson et al., 2006).

Despite what is known about the challenges associated with ‘launching’ YSCHN into the adult health care system, literature exploring the specific ways parents may support these youth in developing the skills needed to negotiate the transition to adult services and to adulthood more broadly is lacking. The purpose of this paper is to identify and collate recommendations from health care providers working with transition-age youth about parents’ roles in supporting transition for YSCHN.

Methods

This is a secondary data analysis of a qualitative study designed to elicit perceptions of health care providers regarding the responsibilities of a patient navigator in supporting YSHCN. In the primary study, participants spoke at length about their experiences working with parents of YSHCN. In either individual interviews or focus groups, the health care providers identified how they conceptualized parents’ roles in the transition process. Thus, the researchers sought to explore the concept of parental roles in health care transition in further depth by conducting a supplementary secondary data analysis (Heaton, 2008).

Sampling and Recruitment

Purposive sampling (Etikan, Musa, & Alkassim, 2016) was used to identify key stakeholders, policy makers, clinicians, or administrators who work in pediatric and adult systems within Alberta Health Services, the sole health authority responsible for health service delivery in the Canadian province of Alberta. Participants were recruited from primary and tertiary health centres in the province of Alberta, Canada. At the outset of this study, two authors

(GD, SS) presented the research project and distributed recruitment materials to a provincial network focused on transition issues for young people in Alberta (Samuel & Dimitropoulos, 2017) consisting of approximately 50 health care providers and stakeholders. A total of 37 individuals who expressed an interest in participating were screened. Although all 37 met inclusion criteria, three individuals were unable to participate in an interview or focus group within the recruitment period, thus 34 individuals were included in the final sample.

Key informants were included in the study if they provided transition support and/or services to individuals between the ages of 16 to 24 with a chronic health condition in Alberta. The majority of the final sample consisted of females (79%) between the ages of 40 and 60 years (82.4%), working with adolescents (59%), both adolescents and adults (21%) or adults only (18%) in urban settings (92%). Their occupations included policy makers/researchers ($N = 15$), nurses ($N = 8$), social workers/family advisors ($N = 5$), physicians ($N = 5$), transition coordinators ($N = 5$) and dieticians ($N = 4$), where some participants identified as belonging to more than one of the aforementioned categories. Informants in our final sample worked in a variety of clinics including hematology, chronic pain, diabetes and cardiology.

Participants were invited to participate in a focus group during specific dates and times. If they were unable to attend a focus group, they were offered an individual interview either by phone or in-person at a time that was convenient for them. At the time of the interview or focus group, a brief screen for inclusion was facilitated by a team member to ensure that they worked with young people with chronic health conditions. Practitioners who cared for patients with mental health and neurodevelopmental disorders solely were excluded from this study, as these individuals typically work in community-based organizations outside of tertiary care centres. All

participants provided written informed consent prior to participating in the study and ethical approval was obtained from the research ethics board at the study institution.

Data Collection Procedures

A semi-structured interview guide (Dimitropoulos et al., 2019) was developed in consultation with national experts in transition issues with YSHCN and refined based on pilot-testing with two clinicians. The same guide was used for both the individual and focus group interviews. Questions in the interview guide centered around participants' perceptions of barriers and facilitators to successful service transitions and how a patient navigator could support YSCHN and their families during the transition from pediatric to adult services. Informants were also asked to describe their experiences working with YSCHN and their families and how service transitions could be improved. It was these two areas that commonly elicited discussion of the role of parents and family members in the transition process. The results presented in this secondary analysis will focus on the portions of the interviews and focus groups where participants spoke to their experiences working with parents of YSHCN.

Two focus groups were conducted at the Alberta Children's Hospital, facilitated by two members of the research team (GD, EM) and lasted approximately 90 minutes. Interviews were conducted by the same team members (GD or EM), lasting 40-60 minutes. One individual interview and one interview with two participants were conducted in-person at Alberta Children's Hospital and the remaining 23 individual interviews took place by phone. All interviews and focus groups were audio-recorded and transcribed verbatim.

Data Analysis

Although researchers identified the role of parents in supporting transition as a central theme in the primary study, it was not the focus of the original study. Accordingly, the team developed a new coding strategy and conducted a supplementary secondary analysis, wherein a particular issue emerging from the data, which was not the focus of the primary study, is explored in-depth (Heaton, 2008). Thematic analysis as described by Braun and Clark (2006) was used to analyze the interviews and focus groups. The research team paid particular attention to how participants in the focus groups and individual interviews described the role of parents in health care transition, given these are different methods of gathering data. Upon careful review of the transcripts, the research team agreed that no significant differences arose in the participant responses related to our area of interest in this study, thus the transcriptions from both sources were analyzed simultaneously (Dimitropoulos et al., 2019). Two coders (BA, EM) immersed themselves in the data by reading and re-reading transcripts, and then used memos to document their impressions of the data and independently generated and assigned codes to the interviews. Codes refer to words that describe the researchers' thoughts about ideas that emerged within and across interviews (Guest, MacQueen, & Namey, 2012). The data were then collated based on codes initially established. Inter-coder agreement was determined when both coders agreed on the codes utilized for quotes/segments gleaned from the data (Creswell, 2009). The team also debriefed the codes generated by each coder and only codes that received consensus were included. Codes were grouped into major themes and descriptors, in order to better represent the data. The themes were then reviewed and refined to ensure they were representative of the data. Finally, the research team analyzed and described the themes and subthemes. Several steps were undertaken to maximize trustworthiness of the data by following the guidelines for publication of qualitative research (Elliot, Constance, & Rennie, 1999).

In the supplementary secondary data analysis, all transcripts were reviewed along with the initial codes from the primary analysis (Dimitropoulos et al., 2019) to elicit information regarding the phenomena of interest for this inquiry. We took an inductive approach to thematic analysis in the second review of the data to identify information about parental roles in health care transition and subsequently considered how themes mapped onto existing theories of adolescent development. Initial codes from the primary analysis were re-organized and further categorized based on the new coding strategy.

Results

Twenty-four individual interviews, one interview with two participants, and two focus groups (with three and five people in each, respectively) were conducted between July and November 2017. Four major themes were identified: 1) “Parents are crucial” to the transition process, particularly in preparing youth for transfer out of pediatric services; 2) Changing roles: “doing to advising”; 3) “Interdependence rather than independence”; 4) Health care transition is one of many transitions. Each theme is described in detail with illustrative quotes, attributed to the participant study ID and their role, drawn from the transcripts in the following section.

Theme 1: “Parents are crucial”

In the context of transition planning in pediatric care, “parents are crucial” (physician, KS14) was a sentiment expressed by many participants. Recognizing the contrast between the priorities of service providers and the capacities of YSHCN, informants pointed out that often, “we are in too big of a rush to get the parents completely away from them, make them independent, make them choose everything and yet they don’t even buy their own groceries” (nurse/transition coordinator, KS15). They advocated for involving parents “as aids” (physician,

KS14) in the transition process and gradually shifting responsibility to YSHCN as they approach transfer out of pediatric services, assuming the youth has capacity. Participants pointed out, however, that differences exist in families' needs for support "depending on advocacy and abilities of the parents" (physician, KS21) within complex systems and differences in the complexity of the youth's condition. Some recommended tailoring the type of support health care providers offer to families in light of these issues, recognizing that some families may require more support than others.

Despite the importance of parental involvement in transition planning, participants also noted that the role of the parent becomes more peripheral as YSCHN enter the adult system. Following transfer to adult care, participants commented that:

The onus needs to be put on the young adult. Because if you don't, you negate all the work we've done on the pediatric side to get this kid to a point where they are more independent. You don't want to go backwards. (social worker, KS27)

They emphasized that transfer into the adult system is fraught with challenges for parents including fear of the unknown, a lack of confidence in new providers following prolonged attachment to pediatric providers and difficulty shifting responsibility to their young adult. This was conveyed by a nurse (KS01) who stated:

When we transition them it's sometimes harder on the parents leaving than it is on the actual patient. Because they've been with the same cardiologist for 18 years and the thought of moving [on]...and letting go can be very challenging for parents.

Theme 2: Changing roles: "Doing" to "advising"

Participants articulated that parents need support with their changing role from that of “doing” to that of “advising” (administrator, KS09) and, if their child has capacity, allowing him or her to become the “CEO” (nurse/transition coordinator, KS15) of their own care. Having parents facilitate a shift in their adult child “towards independent thinking” (social worker, KS10) arose as an important theme. The idea of having health care providers offer concrete support during the health care transition was endorsed by several participants, but ultimately parents “should be the ones to facilitate independence and autonomy” (physician, KS14).

Key informants highlighted that parents may require guidance on how to incrementally provide their child space to practice self-management skills. This was conveyed by participant KS05 (policy maker):

An important point is that it’s not really just navigation for youth. I think [health care providers] should also help the parents and the families as well. Help educate them around letting go. It’s difficult for them, letting go of some of the things as their child has to take over. And it’s a process their child has to go through to gain independence and gain self-management skills.

Participants recommended that health care providers introduce transition concepts to parents early, when their child is between 12-15 years of age. Specifically, providing anticipatory guidance, information about transition and education about relevant resources several years prior to transfer were identified as central tasks for pediatric providers when working with parents.

Participants unanimously agreed that “letting go” can be very challenging as some parents “still want to be in control” (dietician, KS03) thus necessitating the need to focus on providing guidance on the concrete steps parents can take in shifting responsibility while working through their own emotions surrounding transition. One administrator (KS09) referred to this as

“coaching from a family view”. Others advocated for framing the health care transition as one part of the larger context of moving into young adulthood, comparing it to other life transitions their child has successfully navigated like starting school, taking responsibility for household chores, and getting their driver’s license, for example.

Importantly, changes to parental roles differed between those having children with intellectual or developmental disabilities compared to those whose children have capacity for decision-making. A nurse (KS08) commented, “So making sure, especially if you’ve got kids who are really developmentally delayed, and parents who have to go from being guardians as a parent to a guardian as an adult. That’s quite complicated for a lot of families.” In cases where the YSHCN does not have capacity to assume independence, parents will remain responsible for navigating changes to funding, guardianship, home care as well as other legal responsibilities and medical record access as they age. Participants also underscored the difficulties in this stage for parents who may be unfamiliar with the various systems and funding bodies, as “funding is a huge issue” (nurse, KS08). All of these changes occur within the context of the exit from pediatric care, which further complicates the process and puts pressure on parents to become experts across several areas. Consequently, key informants articulated that caregiver burnout can arise when parents are not adequately supported by health care providers and other family members as they undertake new roles and responsibilities. When there are “time constraints and [parents] are doing multiple things throughout the day, they burnout.” (nurse/transition coordinator, KS15).

Theme 3: “Interdependence rather than independence”

One participant (nurse, KS02) eloquently captured the idea of interdependence by using the analogy of having parents remain in the car when their child is learning to drive but taking a

backseat as they gain the confidence to operate the vehicle more independently. She recognized the challenge for parents in taking the backseat when they are accustomed to driving the car, but this process of sharing responsibility and having the parent remain present should questions or issues arise was described as interdependence.

“Transition of control takes time” (dietician, KS03), therefore, parents should provide YSHCN space to “make mistakes while they are in pediatric care, where we have lots of safety nets” (social worker, KS27). Participants advocated for having parents incrementally shift responsibility for specific health-care related tasks to YSHCN, such as phoning the pharmacy to refill prescriptions, while remaining available should they require guidance. Interventions should be aimed at “targeting parents to help them enable their children to become more independent and successful” (nurse/transition coordinator, KS15). She further alluded to the balance between dependence and independence, identifying interdependence as the goal, “within pediatrics, there is a real range in maturity and level of responsibility, so I try to [promote] interdependence rather than independence” (nurse/transition coordinator, KS15).

Participants identified that some parents struggle to strike a balance between promoting independence and the need for continued support with managing their illness due to their developmental stage and capacity. Parents are expected to determine this balance within a plethora of complex factors including complexity of their child’s illness, household income, number of children in the home, immigration status, gender or sexual identity issues and mental illness within the family. Participants agreed that the ultimate goal is to achieve a developmentally appropriate shift in responsibility, but that the roadmap for getting there may differ based on the aforementioned factors as well as parenting style. For example, a social worker (KS27) commented that parents “who are helicoptering around their kids and are so

worried their kids are going to forget something don't allow their kids to express that independence". Whereas, in other cases, "responsibilities are being punted onto kids too quickly and parents aren't realizing they need to take things back when it's not going well." (nurse/transition coordinator, KS15). In these cases, parents should be coached on how best to incrementally relinquish control, and health care providers should be aware that they may need to encourage parents to step in and provide support to their child.

The transition was different for different families as respondents suggested: "Either a family that is not allowing them to take responsibility for their own care, or a family that has totally advocated at the age of 14 and said you have to deal with this yourself" (KS08) and "sometimes you have very involved families and sometimes you have families that are pretty much burnt out and [the parent] had to step back from the close relationship with the [youth] because they burnt out" (KS11). Respondents recommended that interventions aimed at supporting families successfully transition should be tailored to each family while encouraging developmentally appropriate shifts towards independence.

Theme 4: One of many transitions

Informants noted that health care transition does not happen in isolation for YSHCN and that this is but one of multiple life transitions that occur around the age of transfer to adult services (i.e., transition to university or independent living). Consequently, other aspects of youths' lives should be taken into account when working with youth and their families. For example, in collaboration with health care providers, participants suggested parents help to promote an increased understanding of how the illness may "affect their future choices like family planning and university" (nurse/transition coordinator, KS15). Indeed, holistic support which views the whole person in the context of their family and social network (Farre et al.,

2016; Lavdaniti, 2017) was emphasized as a critical component of the transition process. In light of this, participants recommended that parents support YSHCN in developing the “tools to manage their lives with a health condition, or illness or disability. So, it’s not separating health from life. People are one big package” (administrator, KS26). Focusing work with the family on preparing youth for living with a chronic disease, learning how to navigate relationships, and understanding how their disease may impact their future arose as an important theme. Informants conveyed that supporting youth in their transition to adult services was only one small piece of what parents accomplish in helping their children launch into adulthood. It is important that YSHCN develop their interests, goals, and ambitions outside of the illness and that parents provide guidance in this process. This was conveyed by an administrator (KS26):

When I look at it from a parent perspective, that’s really only one very small part that I as a parent want to accomplish. I really want to do much the same for my child as would any other parent, and that is to give them the tools to grow up successfully and manage all aspects of his life, his health, his finances, relationships, all of those kinds of things.

Discussion

This study sought to investigate how health care providers working with transition-age youth and their families view the role of parents in health care transition of their children. Although some parents have difficulty shifting and relinquishing responsibility to their young adults, others embrace the transition and progress through it with ease. The findings of this study emphasize health care providers’ perceptions of the vital role of parents in providing ongoing support for YSHCN and offers strategies for promoting interdependence from an early stage while taking into account the unique situations of each family. Our results highlight the importance of taking a holistic approach to transition planning which takes into account the

needs of YSHCN and the advocacy skills of their parents in order to offer the appropriate level of support. Although psychosocial assessments which would illuminate unique youth and family factors are regarded as a core principal of transition planning, research shows that these are not always included in transition readiness assessments (Stinson et al., 2014). This study supports the integration of psychosocial assessments into routine practice, which would allow health care providers to identify families at risk and subsequently offer the appropriate level of transition support. This holistic approach advocates for looking beyond an individual's illness and integrating social, psychological, vocational and developmental aspects into health care (Farre et al., 2016; Lavdaniti, 2017).

In order to provide comprehensive care, transition planning must involve parents and caregivers and ensure they feel supported in the process of moving from the role of “manager” to that of “advisor” (Kieckhefer & Trahms, 2000). These concepts arose directly in the data, underscoring the importance of embedding principles of the shared management model (Kieckhefer & Trahms, 2000) into practice. The idea of having parents step in and out as needed was an important sentiment expressed by informants. Two of the key principles of the recently published American Academy of Pediatrics Transitions Clinical Report are an “emphasis on self-management, self-determination, and family and/or caregiver engagement” and a “need for parents and caregivers to support youth and young adults in building knowledge regarding their own health and skills in making health decisions and using health care” (White et al., 2018, p.2). The results of this study garner support for best practices in the transition field surrounding parental involvement and highlight some of the challenges with striking an appropriate balance of interdependence.

Arnett (2007) describes the process of emerging adults accepting responsibility for themselves, making independent decisions and achieving financial independence as a gradual process, rather than occurring in discrete stages. This closely aligns with the findings of this study, which suggest that parents can support YSHCN to incrementally achieve responsibility over certain aspects of their health care (and their lives more broadly) by initiating the process at an early age, and relinquishing control over time in a developmentally appropriate manner. Our findings also emphasize that this process should be flexible and responsive to instances where YSCHN benefit from increased parental involvement and support (i.e., during health crises). By adopting a developmental lens, where emerging adulthood is conceptualized as a unique stage, it is possible to approach the transition process with flexibility, given that there is “great heterogeneity” (Arnett, 2007, p. 68) in this stage. Considering the time constraints and a need to prioritize medical needs in outpatient appointments, we recommend that health care providers weave these principles into their practice by providing anticipatory guidance, making appropriate referrals (i.e. patient navigator, social worker) and offering resources (i.e. self-help guides, parent groups).

This research echoes the findings of other qualitative studies surrounding parental anxiety about the transition process and ambivalence about promoting independence when parents are accustomed to supporting their children (Burstrom, Ojmyr-Joelsson, Bratt, Lundell, & Nisell, 2016; Davies, Rennick & Majnemer, 2011; Shaw, Southwood, & McDonagh, 2004). Indeed, parental fears about their child exiting pediatric services came up as a key theme in this study. Shaw and colleagues (2004) also report that when parents observe a trusting relationship between their child and the pediatric health provider, they feel more confident promoting youth’s independence, a concept which did not emerge in our interviews and focus groups.

A strength of this study is that participants came from a variety of professional backgrounds in both the pediatric and adult care settings and possessed a wealth of knowledge in the transition field. This study, however, was a secondary analysis, and the role of parents was not the focus of the interviews and focus groups. Therefore, participants were not asked to elaborate on parental roles in supporting YSHCN transitions in as much detail as they would have been had it been the primary goal of the initial study. Instead, their responses surrounding the role of parents arose naturally throughout interviews and focus groups, with researchers probing based on an emerging interest in this area. Additionally, parents' and YSHCN's perceptions about parental roles were not explored in this study; if they had, this would have provided richness and depth. Another limitation of the present study is that it focused on parents and did not examine the roles that other natural supports, including siblings and peers or community agencies, may play in supporting YSCHN whose parents are not involved. In recognition of the fact that youth come from a variety of backgrounds, the next steps of this project include interviewing a diverse sample of parents and YSHCN who may be disenfranchised, including those without parental involvement. The authors also plan to expand on this work by looking at different populations across various sectors in Canada.

While transition planning should focus on YSHCN and allowing them to develop their self-management skills, the critical role parents can play in facilitating these skills should not be overlooked. Their role should not be underestimated in the transition preparation process, and unique familial circumstances should be considered in implementing interventions. Parents are embedded within a web of complex factors; thus, socioeconomic status, mental health, immigration status, and literacy, for example, should be considered when designing and implementing family interventions. The results from this study may inform transition practices

for health care providers working with parents of YSHCN. This study suggests that health care providers proactively build discussions about how parents can promote independence and cope with their own emotions surrounding transition into routine clinical care from an early age. Further research is needed to develop tools and resources providers can use to better support parents in this complex process. The perspectives of YSHCN and their family members surrounding the developmental tasks associated with transition to adult health care and adulthood more broadly should also be explored. This research highlights the critical role of parents in health care transition planning and offers practical strategies for health care providers working with YSHCN and their families in striking the appropriate balance of interdependence. It emphasizes the importance of considering unique familial features and taking a holistic approach to care in order to promote successful transitions.

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