

You never transition alone! Exploring the experiences of youth with chronic health conditions, parents and healthcare providers on self-management

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Abstract

Background Recent evidence suggests that fostering strategies to enable youth with chronic health conditions to work towards gradual self-management of their health is key in successful transition to adult healthcare. To date, there is limited research on self-management promotion for youth. The purpose of this study is to explore self-management from the perspectives of youth, parents and healthcare providers in transition to adult healthcare.

Methods Part of a larger longitudinal transition (TRACE-2009–2013) study, interpretive phenomenology was used to explore the meaning of the lived experiences and perceptions of youth, parents, and healthcare providers about transition to adult healthcare. Purposeful sampling was utilized to select youth with a range of chronic health conditions from the TRACE cohort (spanning 20 diagnoses including developmental disabilities and chronic conditions), their parents and healthcare providers.

Results The emerging three themes were: increasing independence of youth; parents as safety nets and healthcare providers as enablers and collaborators. The findings indicate that the experiences of transitioning youth, parents and service providers are interconnected and interdependent.

Conclusions Results support a dynamic and developmentally appropriate approach when working with transitioning youth and parents in practice. As youth depend on parents and healthcare providers for support in taking charge of their own health, parents and healthcare providers must work together to enable youth for self-management. At a policy level, adequate funding, institutional support and accreditation incentives are recommended to allow for designated time for healthcare providers to foster self-management skills in transitioning youth and parents.

Keywords

adolescence, child development, chronic (health) condition, health services research, qualitative research methods, transition

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Introduction

Becoming an adult represents a critical developmental stage for all youth as they experience multiple concurrent transitions

including leaving high school and beginning post-secondary education, pursuing employment and getting a job, forming new social networks and personal relationships and moving out of parents' homes to independent living (Gorter *et al.* 2011;

Nguyen & Gorter 2014). For youth with chronic health conditions this experience is complicated by the additional transition from paediatric services to the adult healthcare system. Healthcare transition is defined as the purposeful, coordinated and planned movement of youth with chronic conditions from child-centred to adult-oriented healthcare (Blum *et al.* 2003; Betz 2007). A review of the literature reveals that healthcare transition can be challenging for youth, families and healthcare providers, and there are negative outcomes in terms of population health, costs and experiences with the healthcare system (Taylor *et al.* 2012; Prior *et al.* 2014). The experience of transitioning from a familiar paediatric healthcare setting to an unfamiliar adult setting is often described as a 'falling off a cliff' by youth and parents (Stewart *et al.* 2014). Thus research to improve transition experiences between these two systems of care is of priority for many professional institutions and organizations in Canada and around the world (While *et al.* 2004; American Academy of Paediatrics, American Academy of Family Physicians, American College of Physicians 2011; Fletcher-Johnston *et al.* 2011; Lugasi *et al.* 2011). Effective self-management of one's health is considered essential for everyone, particularly for emerging adults with chronic health conditions (Modi *et al.* 2012). This consideration is in line with the work of Huber and colleagues (2011) who propose shifting the focus from health, in a strictly medical sense to emphasize the ability to adapt and self-manage in the face of physical, social and emotional challenges encountered by individuals with chronic disease (Huber *et al.* 2011). This shift is critical when youth enter adult healthcare services where they are expected to take on responsibility for their medical needs (Crowley *et al.* 2011; Kraus de Camargo 2011; Modi *et al.* 2011; McDougall *et al.* 2015). The importance of self-management for chronic conditions and illnesses has garnered attention from researchers and clinicians, which has promoted for a re-examination of current views of health and well-being to extend beyond medical diagnosis (Sattoe *et al.* 2015). However, to date, there is limited research on self-management promotion for youth with chronic diseases (Miller *et al.* 2015; Sattoe *et al.* 2015).

Research evidence from a recently completed longitudinal study (Transition to Adulthood with Cyberguide Evaluation—'TRACE') suggests that fostering strategies among youth, parents and healthcare providers to empower youth to work towards gradual self-management of their healthcare may be key in facilitating autonomy and successful transitions (Gorter *et al.* 2015). Although increasingly more research suggests the importance of collaboration among youth, parents and healthcare providers for self-management and transition plan-

ning, few studies have examined all three perspectives to identify strategies to enable these processes. Furthermore, limited description exists about the 'how' or strategies to enable self-management and collaboration. The objective of this study is to explore self-management from the perspectives of youth, parents and healthcare providers involved in the transition to adult healthcare services through an in-depth analysis of the qualitative portion of the larger TRACE study (Gorter *et al.* 2015). The novel aspect of this study lies in the examination of the experiences of key stakeholder groups in order to learn from each perspective and triangulate the findings regarding self-management promotion from a collaborative perspective.

Methods

Design

The qualitative method chosen for this study was interpretive phenomenology as it provided the best fit to explore the meaning of the lived experiences and perceptions of youth, parents and healthcare providers about transition from paediatric to adult services (Creswell 2015). This approach explored the emergent phenomenon of self-management and ways it relates to the transition process. The study obtained ethics approval from participating institutions (09-124), and informed consent was obtained from all participants prior to enrolment in the study. It is important to note that all participants were enrolled in the larger TRACE study; they were offered two transition supports (transition planning kit and an online mentor) to assist them with transitioning planning, which is not available to all youth.

Sample

Purposeful sampling was utilized to select youth with a range of chronic health conditions from the TRACE cohort (spanning 20 diagnoses including developmental disabilities and chronic conditions), their parents and healthcare providers across 13 clinics at two major paediatric hospitals in Ontario, Canada (Gorter *et al.* 2015). Purposeful sampling is an approach to recruiting participants who are considered to be champions or experts on the topic of interest in order to provide rich descriptions of their experiences. In this case, individuals who have experienced the transition process were targeted in order to encourage reflection and to identify key lessons (Creswell 2015). Maximum variation strategy was employed to ensure a range of demographic variables (age and gender), type of health condition or clinic attended, and experiences. The only exclusion criterion

for the qualitative part of the study was inability to answer open-ended questions in English.

Data collection

Four trained professionals conducted telephone interviews during March and April 2012. Semi-structured interviews unique to youth, parents and healthcare providers were administered after the youth had made the transition into adult healthcare services. Interview questions were focused on eliciting the experiences of youth, parents and healthcare providers about their roles, expectations, needs and concerns, empowerment and enabling self-management during the transition process through self-reflection and awareness. Examples of interview questions included:

Youth:

- *Can you make any comments yet on how you see yourself changing over time in terms of making decisions about your own health, and directing your own health care?*
- *What would help or support you to make these changes or transitions easier?*

Parents:

- *How do you perceive your role in your youth's care at this stage? In the future?*
- *Can you comment on where you feel your youth is in terms of managing their own medical needs?*

Healthcare providers:

- *How do those other transitions influence their health care?*
- *What else would help you and your youth with these transitions?*

All interviews were tape recorded and transcribed verbatim for analysis. The interviewers wrote reflection memos after each interview that also became part of the qualitative data for analysis. Member-checking was conducted with participants to verify accuracy of their transcripts and to ensure that their responses to interview questions were captured accurately.

Qualitative analysis

A conventional inductive content analysis process was used for data analysis following the guidelines of Elo and Kyngas (2007). This process involved reviewing transcripts, highlighting key concepts, developing a coding scheme and comparing

coding and analysis for agreement. All four interviewers coded each transcript independently between meeting as a group for discussion and consultation. Agreement of at least three of the four interviewers was considered to be acceptable, and any discrepancies or disagreements were discussed among researchers until agreement was reached. Triangulation among researchers enhanced trustworthiness of the results (Creswell 2015). An audit trail outlining decisions and actions taken in the analysis process was also completed to ensure credibility and reliability (Creswell 2015).

Results

A total of 11 youth, seven parents and seven healthcare providers consented to interviews. Participants enrolled in this study were diverse and represent a range of conditions and experiences. The age range of youth participants enrolled in the study was 18–21. Participant demographics can be found in Table 1.

Three themes emerged from analysis including those related to increasing independence of youth; parents as safety nets and healthcare providers as enablers and collaborators. Supporting quotes from participants (in italics) are provided to illustrate and validate these sub-themes, with participant type indicated in parentheses after a quote: Y = Youth Participant; P = Parent Participant; HCP = Healthcare Provider Participant.

Theme 1: Youth and increasing independence

The majority of youth participants provided descriptions of the ways in which they felt they were independently managing their health needs. For instance, in discussing what was going well during the healthcare transition, one youth participant reported increased self-management:

Table 1. Participant demographics

	Youth	Parents	Healthcare providers
Total # of participants	11	7	7
Gender			
Male	5	1	4
Female	6	6	3
Clinic			
Children's developmental rehabilitation programme	2	2	2
Eating disorders	1	0	0
Endocrinology	0	0	1
Epilepsy	3	2	0
Inflammatory bowel disease	2	2	1
Lipids	2	0	1
Nephrology	1	1	1
Spasticity	0	0	1

‘Well I am able to kind of manage my health myself now. I find I am able to do my own thing. I learn things when I used to go to the adult clinic and the children’s clinic, so I find I am able to use those recommendations still.’ (Y01)

Similarly, some youth participants reported that they were attending their appointments with adult healthcare providers alone. For example:

‘I see myself being more independent all the time. I am pretty independent as it is. I attend most of my appointments by myself, and I already direct my own care pretty well.’ (Y03)

Many youth participants reported that they were starting to manage their medical needs independently in preparation for their transition to adult services and that they saw themselves becoming increasingly independent in decision-making and directing their own care in the future.

‘I think I’ve just become more independent, I don’t have to rely on my parents at all, which is nice, because there is no middleman. It’s just me making my appointments around my schedule. So in a sense it’s a lot easier doing that way.’ (Y11)

The majority of parents reported also that, overall their youth were managing more of their healthcare needs during the transition to adult services, as well as general life transitions.

‘She’s certainly quite capable of taking care of herself, she medicates herself on a daily basis and she stays on top of things, she’s good at telling us when things don’t seem right, and if it came right down to it, she and her sister, who insists on being with her, could easily handle going down to [hospital] or going down to [clinic] and, ah, and taking care of things.’ (P10)

However, despite recognition of their youths’ increasing independence, parents described many experiences in which they still provided support, and this became the second theme. Interestingly, healthcare provider participants made no specific comments about increasing independence of youth.

Theme 2: Parents as safety nets

Many parent participants reported willingness on their part to encourage their youth to become more independent and accept more responsibility in terms of managing their medical care.

‘At this point, there’s really not much that is really required of me because he is full grown. I can just encourage him to stay on track and, you know, not go out every single night. Just keep a general eye over him...’ (P02)

Although the majority of parent participants recognized the value of promoting independence in their youth to manage their own medical needs, there were many experiences reported by youth and parent participants that indicated that the youth continue to rely on parents to provide different types and amounts of support (emotional support, transportation, medication and appointment reminders, general reminders for daily social activities, and lending advice for medical and non-medical decisions). For example, many parent participants continued to schedule appointments, drive their youth to medical appointments or attend appointments with their youth. To illustrate,

‘Well when it comes to meds we still have to tell her to take them. She knows she has to take them but it’s just like: “Did you take your pills today?” “No I forgot.” So we still have to—I have them out in one of those daily—like weekly pill pack things—but we still have to tell her: “Did you take your pills? Take your pills.” And when it comes to making appointments we still have to do that.’ (P15)

The majority of healthcare provider participants recognized the need for balance between the youth gaining independence and the parents embracing the process of ‘letting go’ but still providing a ‘safety net’ to enable their youth to gradually take on adult roles and responsibilities. They acknowledged that this individualized process may vary among youth and parents.

‘...it’s a time of a lot of change, and there’s a time of testing as far as autonomy goes and taking over their own health care and a struggle between where the parents are and where the kids are. Sometimes the parents are ready for the kids to move on faster than the kids are, and sometimes the exact opposite is true’ (HCP23)

Theme 3: Healthcare providers as enablers and collaborators

Several healthcare provider participants recognized the importance of the idea of a gradual, developmentally appropriate transition process rather than a sudden and abrupt one. For example, one participant stated:

'I think that there needs to be more of a transition—that word is a very good word—on the adult side too, that we have to let go but they also have to pick up.' (HCP23)

Despite acknowledgement from many participants that the development of self-management requires a gradual and balanced approach, some parent participants reported that the current practices of healthcare providers, particularly in the adult system, did not reflect this recommended approach. Parents shared experiences of being suddenly shut out of their youths' medical care once in the adult healthcare system instead of a gradual transition towards independence for the youth. For example, one parent described a difficult experience in the adult healthcare system when her son required an emergency procedure:

'He ended up having to go in the surgery while I was not there...I arrived expecting that he would be out of surgery—well I didn't know exactly when he was going in...So there was no information like that... I was left off at this room, where I was to wait for the doctor to come and give me the results or that he was done the operation and how it went. Nobody ever came. I was left in that room to wonder about [youth] for so many hours and the whole room emptied and there was no one in the halls...' (P04)

One healthcare provider participant acknowledged that service providers need to be aware of their own expectations for youth self-management, as positive expectations can enable a smooth transition to adult healthcare. An example from a teen clinic supported this idea:

'At the end of the appointment, I always give the youth their appointment directly to them, not to the parents...And the next time they know. It's all about expectations...not expecting him to take charge of everything at one time but developmentally appropriate and work towards that..' (HCP21)

Another healthcare provider participant identified a simple strategy that healthcare providers in both paediatric and adult service systems could use to enable youth, and their parents, to transition gradually towards self-management:

'...a lot of times in teen clinic, what we are trying to do is [identify] what are some small steps that teens can start taking on in terms of managing their health care.' (HCP09)

In addition to acknowledging an enabling role, several healthcare provider participants also emphasized the impor-

tance of collaboration between providers in paediatric and adult healthcare systems to support a gradual and developmentally appropriate transition process. One participant described this as partnerships:

'I think better partnerships with the adult health care providers is something that would make a big difference overall in transition as well.' (HCP22)

Discussion

Key findings

The emerging themes about the development of self-management for transitioning youth with chronic health conditions indicate that the experiences of youth, parents and service providers are interconnected and interdependent. The role of parents can be analogous to a bridge that connects the youth between services, whereas health care providers' role can be analogous of a navigator that guides parents and youth through the transition process to successfully land in adult services. Our findings suggest that youth depend on their parents and healthcare providers to support them with the self-management of their condition during transition, while parents and healthcare providers depend on each other to support and enable the youth in self-management during transition. Thus, healthcare providers and parents play a crucial role in self-management promotion by enabling youth to take on more responsibilities for their healthcare needs.

The most significant relationship is between youth and parents. The majority of youth reported feeling fairly independent in managing their healthcare needs; however, parents continue to provide significant support 'behind the scenes', including emotional support, transportation, medication and appointment reminders, general reminders for daily social activities and lending advice for medical and non-medical decisions. Parents contribute to youths' development by thinking about the future and medical needs—a concept that the youth themselves may not yet be reflecting upon (Ellis *et al.* 2007). While parents recognized the need to gradually encourage their youth to self-manage, they also saw the importance of their role as a safety net for times when youth are in need of support (Reiss *et al.* 2005; Chin *et al.* 2009). Research has shown that the role of parents and family characteristics has been linked with self-management. Several studies have shown that effective self-management is positively influenced by parental involvement in a youth's healthcare and greater levels of family support and relations, while other studies

have shown that single-parent families and lower socioeconomic status are associated with decreased self-management (DeLambo *et al.* 2004; Reed-Knight *et al.* 2011). However, in current practice, parents are not involved enough as healthcare providers may not always recognize parents' contributing role in self-management promotion. It is important, therefore, for healthcare providers to foster collaboration with parents to equip them with transition information and resources to enable youth for self-management, before, during and after the transition to adult healthcare.

To improve preparedness and efficiency of transition planning, healthcare providers need to facilitate collaboration with youth and families. This collaborative process can be accomplished through (1) providing tools and resources that foster knowledge and self-management skills (for example, resources on the *gottransition.org* website), and (2) providing opportunities (i.e. joint meetings among youth, families and healthcare providers before, during and after transition) for youth and families to actively engage and participate in planning their transition in order to ensure an individualized, patient- and family-oriented transition plan tailored to their goals and needs (Magill-Evans *et al.* 2005; Major *et al.* 2014). Collaboration among all stakeholder groups is documented and emphasized in the literature, suggesting that collaboration for service providers should extend beyond just the system itself, to include active collaboration with youth and parents (Barlow *et al.* 2002; Gorter *et al.* 2015; Miller *et al.* 2015). In particular, parents and healthcare providers must work together to gradually enable youth for self-management instead of meeting expectations for immediate and complete autonomy in adult services.

A key finding of this study suggests the need for healthcare providers to adopt a gradual, developmental perspective when working with transitioning youth and parents. It can be challenging, and sometimes unrealistic, for parents and youth to stop navigating the healthcare system together and for youth to assume full responsibility for their medical management at 18, the typical time of transition. It is advisable for adult healthcare providers to become more cognizant of any unrealistic expectations about the patients entering the adult health care system, the role of parents and medical self-management skills of youth. It is important for healthcare providers in both paediatric and adult services to recognize and take into account the complex and dynamic relationship between youth with chronic health conditions, their parents and the healthcare system. Typically developing adolescents and emerging adults without chronic health conditions are reported to continue to receive support from their parents up

to 25 years of age in life domains, such as finances and housing (Stewart *et al.* 2008; Gorter *et al.* 2011; Gorter *et al.* 2014).

As highlighted by the results, for many of the youth, self-management did not mean doing everything on their own. Rather, managing their healthcare needs was and continues to be a gradual process that occurs with a safety net of parents and provider support. Healthcare providers can collaborate with and enable parents and youth to move gradually towards adult healthcare and self-management together so that expectations and goals are met from everyone's perspectives (Fraser 2007). In that respect, transition readiness measures, such as the STARx Questionnaire and TRANSITION-Q (Klassen *et al.* 2014; Cohen *et al.* 2015), may be useful resources for healthcare providers. For example, the 14-item TRANSITION-Q, a self-management skills scale, can help set developmentally appropriate goals for self-management with youth and parents before, during and after transition as the items are organized in difficulty order: item 1 ('I answer a doctor's or nurse's questions') being the easiest, to item 14 ('I book my own doctor's appointments') being the hardest skill to achieve (Klassen *et al.* 2014). This approach will allow youth to take an active role in the planning of their transition while giving them an opportunity to voice their needs and goals.

Study limitations

The experiences of youth and parent participants involved in this study may not be representative of other transitioning youth as they had more opportunities for transition support available to them compared to most youth.

Areas for future research

Currently, there is limited research about self-management of transitioning youth systematically (Sattoe *et al.* 2015). In particular, we recommend research to learn more about the various factors that influence self-management (such as access to care, communication and enhancement of family resources to improve self-management) in order to identify effective strategies to support youth and families (Hsin *et al.* 2010; Modi *et al.* 2012). Through systematic, longitudinal studies, researchers and clinicians can gain knowledge of trajectories of self-management skills in youth with and without chronic illnesses, identify those who are at risk for unsuccessful transition outcomes and work towards enhancing existing tools or development of innovative, patient-oriented tools for self-management promotion. Furthermore, in current practice clinicians are not mandated to spend designated time to

promote self-management for transitioning youth because of challenges with time management and high volume of patient care loads. Thus, it is critical that policies are in place to enforce adequate funding, institutional support and accreditation incentives to allow for designated time for paediatric and adult healthcare providers to foster self-management skills in transitioning youth and parents.

Conclusions

The identified themes about the development of self-management add new insight about the interconnected and interdependent nature of the experiences of youth, parents and service providers. Results reveal that youth depend on their parents and healthcare providers for support with their needs for self-management while parents and healthcare providers depend on each other to guide and enable youth for self-management in transition to adult healthcare. Furthermore, these findings emphasize the importance of a gradual, developmental perspective when working with transitioning youth and parents. Active engagement and collaboration among youth, parents and healthcare providers are essential for empowerment of youth for self-management. Researchers and clinicians are encouraged to examine self-management systematically in order to enhance existing tools and solution-based interventions for health promotion, in particular in youth at risk for transition failures.

Key messages

- The identified themes about the development of self-management add new insight about how the experiences of youth, parents and service providers are interconnected and interdependent.
- Fostering strategies among youth, parents and healthcare providers to enable youth to work towards gradual self-management of their healthcare is in facilitating successful transitions.

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