

Qualitative Study of the Use, Utility and Impact of a Transition Coordinator and Youth KIT among Adolescents with Chronic Health Conditions

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INTRODUCTION

Youth with chronic health conditions face barriers that impact an effective transition from pediatric to adult healthcare systems. This difficult transition is often associated with poor health outcomes. Currently there is limited evidence regarding which service models or approaches are effective in delivering transition services.

The purpose of the pilot TRACE (Transition to Adulthood with Cyber guide Evaluation) study is to investigate the utilization, utility, and impact of a novel transition intervention. This intervention includes access to the TRACE online mentor email and instant messaging and Youth KIT© (Keeping It Together Youth Version) which is a workbook designed to promote self management.

METHODS

Design: phenomenological approach

Ethics approval: McMaster University REB

Recruitment: Participants were attending one of the study clinics at McMaster's Children's Hospital and were to be transferred to an adult clinic within one year of starting the study.

Exclusion Criteria: can not be fully dependent on adults in their daily functioning, self-care and communication.

Data Collection: 7 semi-structured interviews, 1 focus group, online chat transcripts and emails with TRACE. Raw data were transcribed to text for analysis.

Data analysis followed qualitative guidelines, which involved reviews of all transcripts, highlighting preliminary codes, then testing the coding scheme and comparing for agreement. A final coding scheme identified the emerging themes for the report.

Interview Demographics

Participant Total		7
Age range (years)		17-21
Gender	Male	2
	Female	5
Clinic	Developmental Disabilities	3
	Lipids	1
	Inflammatory Bowel	2
	Disease	J

5 Main Themes and Subthemes

Why People Like TRACE Mentor

'Kind of someone that knows what I am going through.'

Availability Impacts Use of TRACE Mentor 'I don't think I've been on in I don't know how long just because it doesn't fit into my schedule....I've just been so busy with school and stuff. But I was using it a bit more in the beginning...'

Different Feelings about Transitions
'I'm nervous. I've been away from my family before but it will be a bit different, going off to school, but I am excited and looking forward to it.'

Preparedness for Transition 'I kind of feel prepared but not fully prepared.'

General Transitions

Typical Developmental Transitions
'So I just finished all my applications for university next year...Um, and I have a part-time job. So right now I am working a lot.... And I do a lot of homework. That's about my life right now.'

Support and Mentoring

Areas TRACE Mentor gives Support 'I applied [for a scholarship] and the TRACE coordinator was... just being very, very supportive... I did end up getting the scholarship...I do give a lot of credit the TRACE coordinator for preparing me so well for the interview.'

"I Don't Know"

'I don't know if there's such a thing as a person who would sit down with you and, um, draw out like things that just need to be done. I can do that on my own but it's a little bit difficult when I don't have my foot in the other side of the door...'

"...it's not like just cutting the scissors at eighteen... It's a bit of a gradual transition."

Ease of Transition

myself but it's my mom

like the fact that I can

still have the option of

having my parents there.

really wants to be there...I

'I just didn't think that the medical transition was going to be my complete responsibility. I thought it was...going to be a lot more easy.'

Emotions Regarding Transition
'...there's more responsibility

put on myself, which I like better...I definitely feel like I have more of an input.

Healthcare Transition

'I'm just completely frustrated because I haven't been given a game plan...It's really scary.'

Parental Support 'I don't mind going by First Adult Clinic Experience 'He [adult doctor] was really

'He [adult doctor] was really friendly, and I met like a student who was working with him, and I met the nurse and everything. It was really good.'

Frequency of Use 'I used [the Youth KIT]

when it first started and I used it when I was with [name] and we filled out a couple questionnaires.

Utility of medical Section 'My mom started a huge binder when I got sick and everything. I just use that binder instead.'

The Youth KIT

Helpfulness

'I just like the questions that they ask because some of the questions are like you wouldn't think of it normally. Like what do you know about your financial system and that kind of thing. It's like "Oh. What do I actually know?".'

DISCUSSION

Participants were more focused on various general transitions that were typical for their developmental stage compared to the healthcare transition. It is possible that healthcare transitions are not as important to participants because this is not typically a concern for other youth at this age.

Participants reported that the Youth KIT was helpful for general transitions, such as school, but they were not using it for their healthcare transition. Participants may not feel the need to use this section because their parents were still involved in the management of their healthcare.

Participants acknowledged the support and mentoring they had received from TRACE in relation to concrete skills such as resume writing. Youth did not seem to be aware of the less tangible support that was being provided by the mentor through chats, such as guidance regarding social relationships and becoming more independent.

Regarding healthcare transitioning, some youth had not been given a clear 'game plan' and did not know what to expect. Therefore, they had difficulty identifying supports that they would need during their transition. Youth may need more concrete information about adult healthcare services and expectations to make more informed decisions.

RECOMMENDATIONS

These results suggest:

- There is an ongoing role for parents and healthcare to promote self-management during the transition to adulthood.
- They can do this by filling in the "I don't know" piece so that youth have a concrete idea of what to expect and by encouraging them to use the youth KIT in relation to their medical care.
- Healthcare providers need to put healthcare transition in context of other general transitions to make it meaningful.

References

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