

Presenters: Vanessa Matias & Mary Thurgood, MSc OT Candidates 2011, Supervisor: Deb Stewart MSc (OT)
 Research Team: Zubin Punthakee, MD, MSc; Jan Willem Gorter, MD, PhD; Herbert Brill, MD, MBA;
 Andrew Don-Wauchope, MB.BCh, BScMed(Hons), M.D.; Christina Grant, MD; Peter Rosenbaum, MD

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.

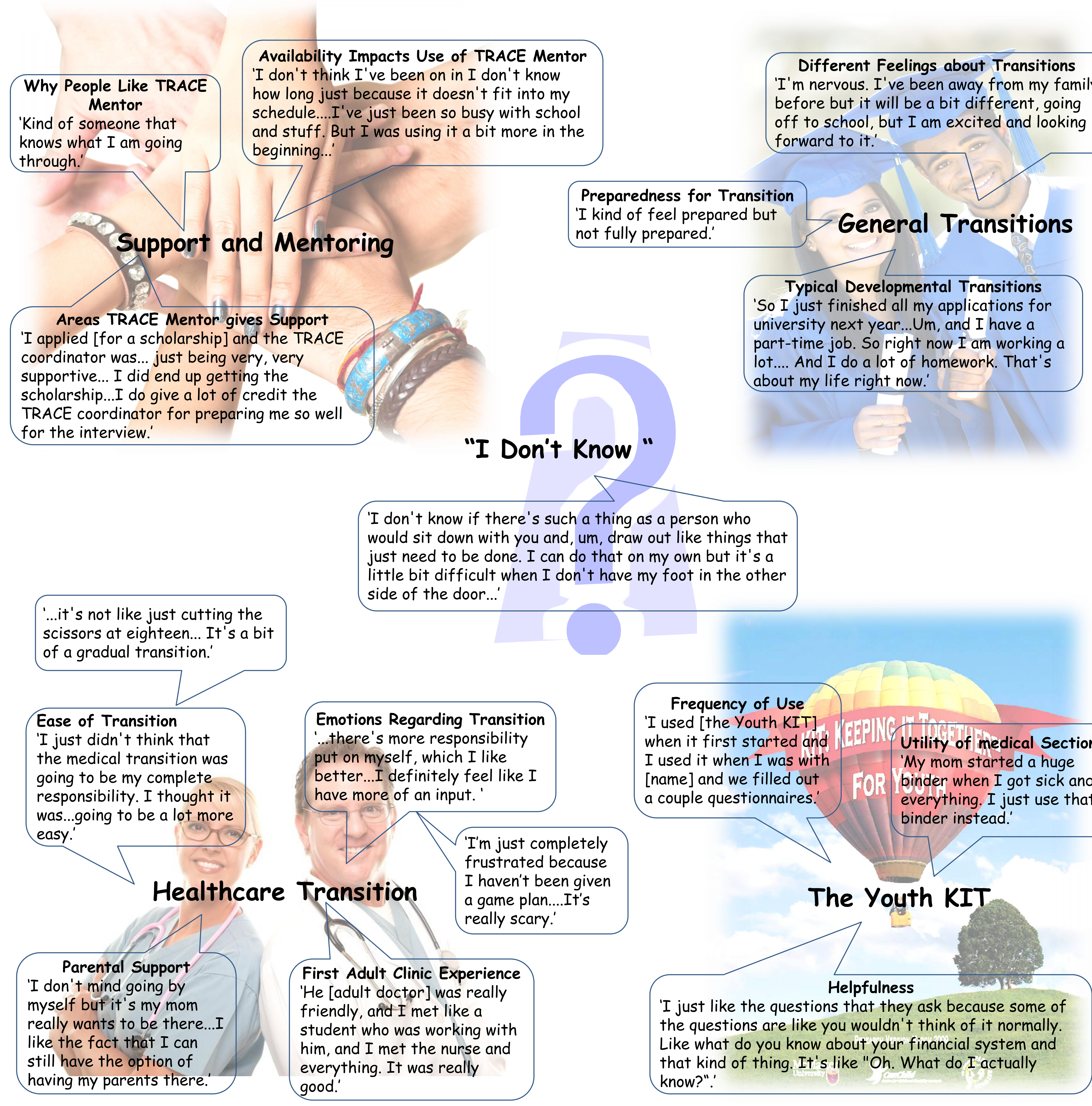
Data Collection: 7 semi-structured interviews, 1 focus group, online chat transcripts and emails with TRACE. Raw data were transcribed to text for analysis.

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 Disease | 3 |
| | | |

5 Main Themes and Subthemes



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.

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