

Emotional Challenges in Children and Young People with T1D: Piloting a Virtual Parent Workshop

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Introduction

- T1D can cause stress for the young person, the system and how the family functions. This stress can have an adverse affect on the young person's diabetic control and management.
- Fewer parents, children and young people have been engaging with groups offered by the Diabetes Teams across HHFT (Basingstoke and Winchester hospitals) since the pandemic. It is tentatively hypothesised that the increase in online content, social media platforms and accessibility to attend groups have contributed to this change.
- There has not been any history of diabetes workshops being delivered virtually within the Diabetes Teams in HHFT.
- The Paediatric Diabetes Psychology team within HHFT delivered two pilot virtual workshops for parents and carers of young people with T1 diabetes, focused on the emotional challenges presenting in these young people

Evidence base

Psychological impact of T1D on

A) Young people

B) Parents/carers

C) Family functioning

Impact of T1D on the wellbeing of young people & their parents/carers

- Children and young people with long-term health conditions such as diabetes are around <u>4 times</u> more likely to experience psychological distress than their healthy peers (Hysing et al., 2007)
- Young people with T1D may be up to two-three times more likely to experience mental health problems than the general population (Jaser, 2010)
- Diagnosable eating disorders in young people with T1D is twice as high as their peers without diabetes (Corbett & Smith, 2020)

Young People

Parents

Parents of children and adolescents with T1D may be more anxious and report less family cohesion compared to parents of healthy controls (Moreira, 2013)

Research into mothers of children aged 8 years and below with T1D showed increased levels of psychological distress (approximately 21% with clinical levels of anxiety and 24% with clinical levels of depression; Jaser, 2009).

Impact of T1D on the family and family functioning

- T1D can have a negative impact on family functioning (i.e. communication, affect management and family roles) (Piazza-Waggoner et al., 2008)
- Research has suggested that family functioning is linked to metabolic control (Lewin et al., 2006)
- The daily routine of young patients with T1D can become a source of family conflict, especially when young patients do not fully adhere to the testing and care protocols expected by their parents. Frustration can be felt on both sides, with communication and cooperation crucial in maintaining the patient's health (Zysberg & Lang, 2015)

With this knowledge, how can we as a Paediatric Diabetes Psychology team help support the wellbeing of our young people, parents and the family functioning generally?

Individual therapy

Systemic work with the family

Indirect work
(supervision,
consultation, MDT
discussions) with the
Diabetes team

Parent/carers workshops/groups

Work with the network around the child (i.e. school, social care)

OBJECTIVES FOR THE WORKSHOP

01

Introduce psychological theory behind emotional challenges for young people with T1 diabetes 02

Introduce strategies for parents/carers to use to help manage these emotional challenges alongside their young people 03

Offer a space for reflection for parents/carers

04

Offer opportunity to meet other parents/carers and connect through shared experience 05

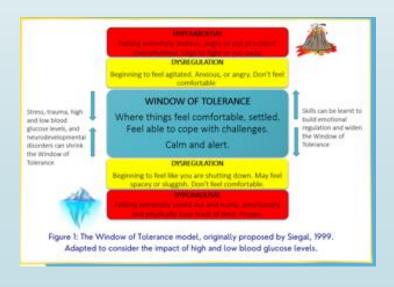
To understand the feasibility of delivering a virtual workshop for parents on emotional challenges.

Methodology

- ▶ Parents/carers of children and young people with Type 1 diabetes on the Winchester and Basingstoke caseloads (n=265 combined) were invited to the emotional challenges workshops
- ■The workshops were split into:
 - ■Pre-school & primary-school aged children
 - Secondary school & college-aged young people
- Workshops were delivered on Microsoft Teams by two senior clinical psychologists and a trainee Clinical Psychologist in June 2023
- ■The duration of each workshop was 1.5 hours
- Parents/carers were emailed afterwards with a feedback form to complete and return which included qualitative and quantitative questions

Workshop content

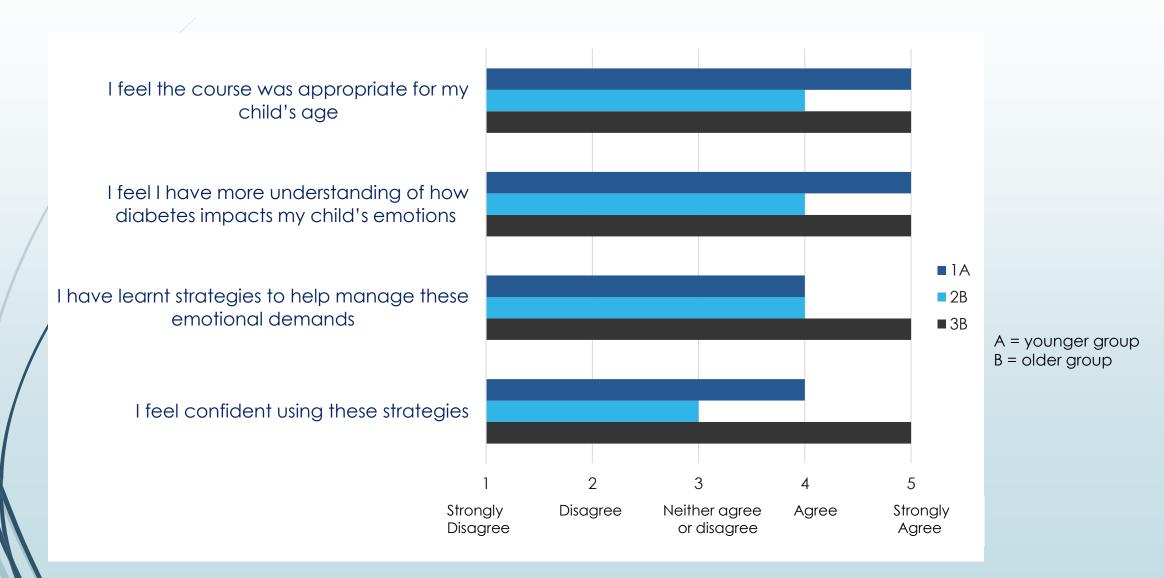
- ■Adapted from previous psychologist resources with the addition of the Window of Tolerance model and Diabetes Burnout
- Typical everyday emotions
- (adolescence: a developmental stage)
- The effect of having diabetes on emotions and behaviours
- Diabetes burnout
- Window of tolerance and coregulation
- The Hand Model: Dan Siegel
- Communicating during periods of dysregulation
- Relaxation & regulation strategies
- Improving self-esteem
- Resources
- Self-care for parents & carers



Attendance

- Preschool & primary-school aged n =5
- Secondary-school & college aged n= 14
 - 9 signed into Teams; 5 members were from a care team
- Other parents/carers who showed interest could not attend the dates and times offered and were added to a waiting list for future groups.
- Low return rate for feedback forms (n=3; 16%)

Quantitative Feedback (n=3)



Qualitative Feedback

What was most helpful about the group?

- "Hearing other parents' experiences, the explanations of impact of high and low BG on brain and emotions." (Parent 1A)
- "Meeting the members of the team, and understanding the brain development of teens and how this relates to those with T1D." (Parent 2B)
- "The charts that explain the emotions." (Carer 3B)

Qualitative Feedback

What was your experience of the group being held virtually?

- "This was excellent: very convenient and made it more accessible for me with a preschooler at home." (Parent 1A)
- "It was more convenient to attend but would have maybe been better split into two shorter sessions or with more breakout groups / discussion / quizzes to check understanding and break-up the passive listening.." (Parent 2B)
- "Perfect we are carers and there was five of us so space in face to face training is hard." (Carer 3B)

Qualitative Feedback

Additional comments/anything you would like more information on?

- Thank you for running this course. It was very a helpful and positive experience and easy to attend as virtual attendance possible." (Parent 1A)
- "Shorter sessions that are more interactive may break up passive listening/ aid understanding." (Parent 2B)
- "It would have been nice to hear more personal experiences, especially from those with older children than their own." (Parent 2B)
- "A fair bit of this course was also repeated in the Year 6 transition workshop which I attended only a week later and found overall more useful." Parent 2B)
- "We don't usually get invited or allowed to attend this type of training which leaves our children less supported, thank you so much." (Carer 3B)
- "Everything was perfect". (Carer 3B)

Observational feedback

- We noted that parents/carers particularly resonated with the Hand Model (Siegel, 2010), "that makes so much sense", "I really get it now".
- The younger age workshop facilitated more in depth discussion, possibly due to it being a small group.
- The older age workshop participants made more use of the Teams chat function and this generated a lot of useful discussion and support between parents/carers.

Discussion & Future Workshops

- Overall, parents engaged well in the workshops and found them accessible online.
- The virtual setup meant that more parents and carers could attend around other responsibilities and brought parents and carers together from a wider geographical area.
- The content of the sessions seemed well-received in both workshops.
- Findings of this pilot are limited due to the small sample size (n=3) for feedback.

Discussion & Future Workshops

In future workshops, we plan to:

- Create a QR code and ask that attendees complete the feedback form before leaving the session. This will enable us to collect additional feedback which will then help us to further alter content and delivery of sessions to best suit the audience.
- Consider the length of the session perhaps 2 hours with more breaks and discussion/reflection time.
- Redesign some aspects of the workshop to make them more interactive and engaging, and facilitate more discussion (i.e., the use of break-out rooms).
- Discuss the potential of asking a parent of an older child to share their experiences of navigating the teen years- with their own tips and helpful strategies.
- More carefully consider which parents will be attending other Diabetes Team workshops around the same time (i.e., the Year 6 transition workshop) as there may be some overlap in content regarding the development of the teenage brain.

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Thank you & Questions

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