
Remotely Delivered Behavioural Interventions for Children and Adolescents with Tourette Syndrome: Focus Group Insights

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Abstract

Evidence-based behavioural interventions for Tourette syndrome cannot foreseeably be delivered at sufficient scale in the U.K. National Health Service. This is due to a severe shortage of expert therapists and geographical constraints. The work in this paper examined the potential for young people to receive a remotely delivered, digital, mHealth intervention to help them manage their tics. Using a focus-group design, we provided young people and parents with a prototype mobile app containing psychoeducational content, therapeutic content and symptom tracking. Participants were enthusiastic about the app's potential. The opportunity to monitor symptoms was also well received. However, there were repeated requests for more "in the moment" features to help with anxiety management, which is a common comorbidity. Our findings support the development of digital technology for the treatment of Tourette's, but highlight the need for direct user involvement in the design of any intervention from young people with the disorder.

Author Keywords

Tourette Syndrome; mHealth; Intervention; Remote Monitoring; User-Design; Focus Groups.

Prevalence of Tourette Syndrome

Worldwide Prevalence [1]:

- 1-2% of the population
- Male to female ratio is 4.4/1
- Mean age-of-onset 6.4 years
- 50% of tics disappear by adulthood
- 51% have family history

UK Prevalence:

- 70,000 young people with Tourette's
- 11 therapists (4 private)
- Patient to therapist ratio is 10,000/1
- 50% receive medication
- 25% receive behavioural therapy

ACM Classification Keywords

Human Factors and Measurement

Introduction

Tourette Syndrome (TS) is a childhood-onset neuropsychiatric condition characterised by chronic motor and vocal tics. It is associated with high levels of comorbidity, significant distress, psychosocial impairment and reduced quality of life.

Evidence based interventions for the treatment of tics in young people with TS include both pharmacological treatment and behaviour therapy [1,2]. Habit reversal training (HRT) is an effective component of behavioural therapy for tics [3] and the comprehensive behavioural intervention for tics (CBIT) package based on HRT shows similar efficacy to medication [4]. European guidelines [3] and recent evidence synthesis [1] recommend that behavioural therapy should be offered first-line for tics in young people in a stepped-care approach.

The majority of young people surveyed with TS in the U.K. request greater access to behavioural interventions [5]. However, evidence-based behavioural interventions for tics cannot foreseeably be delivered at sufficient scale in the UK due to the low number of therapists, who rely on traditional face-to-face delivery or telemedicine, as well as the practical barriers in terms of time, cost and geographical location.

For example, within the U.K. there are 70,000 young people with TS. A national charity called Tourette's Acton hosts a list of chartered therapists trained in CBIT. This list has 11 therapists, seven of which are available through the National Health Service (NHS) while four can be accessed privately. For NHS patients this amounts to

10,000 young people per therapist. Furthermore, most therapists are located in London and the south east of England. Approximately 50% of young people will access medication but this can have severe side effects such as weight gain and sedation [5]

In light of these difficulties, efforts to increase access to evidence-based treatment is essential. Digital, online and mobile applications could offer patients greater access to information and services, enhance management of conditions and provide a means of early intervention [6]. There have been substantial efforts in the area of online or e-CBT (cognitive behavioural therapy) for young people's mental health but greater patient and clinician involvement in the design and evaluation of these interventions is required for efficacy [6].

Aims

The aim of the current work was to gather insight into the needs of young people with TS and their opinions towards a digital health intervention to help them manage their symptoms. We also aimed to obtain feedback from a prototype app and to have young people imagine their ideal app. The overall aim is to start an iterative process of designing and testing an app for young people with TS led by young people with the disorder.

Methods

We used a focus-group design to elicit discussions around needs, opinions and mobile app feedback. We had 5 young people with Tourette's (aged 12-18 years old, one female) and their parents attend focus groups, with a further 20 parents and their children surveyed online. During focus groups, we used the MoSCoW (Must



Figure 1: This image displays the symptom tracker for the tic app. The 10 segments of the motif represent different, relevant aspects of the patient's life that can be monitored. For example, we had "tic bother", concentration, worry, diet and school.

Have, Should Have, Could Have, Won't have) method to assist young people to prioritise features when imagining their ideal app for TS.

We used an existing mHealth application called uMotiff for the basis of our prototype app. uMotiff platform offers the opportunity to monitor symptoms through their tracking motif (Fig 1.) and presents customisable graphs to users for pattern monitoring. The platform also provides a means of hosting text, audio and videos. We generated videos of psychoeducational material about tics and directive material about managing tics, such as tic suppression, distraction and relaxation. The videos were developed with a trained CBIT therapist and included CBIT content. Young people were asked to use the app for two weeks prior to attending the focus groups.

Results

There were four main areas of feedback about the prototype app from young people: ratings and graphs, video content, app design and the use of digital.

1. Ratings and Graphs

The motif ratings were well received by all participants. This was the most used part of the app and was described as the part they found most helpful, providing insight into the relationship between their tics and behaviour. All participants appreciated that the ratings were inclusive of other aspects of their daily life, as opposed to specifically monitoring their tics.

Quotes: "Even from two weeks of data you can sort of see what makes a difference and what doesn't" (Male, 15 years old)

"That's interesting actually because when I'm usually thinking about tics or try to sort them out they get worse, just for like 15 minutes to an hour afterwards, because I'm thinking of them. Doing that [the rating] for some reason I don't". (Male, 14 years old)

2. Video Content

The collection of videos were watched, variably, by participants. Videos were watched in accordance with what the young person has used before, namely relaxation/breathing techniques. The quality of the video was recognized by everyone as being important. For example, sound quality and busy scenes were likely to distract and deter further watching. All participants highlighted their unmet need of managing their anxiety. They requested more "in the moment" or "on the spot" content to help with anxiety provoking situations and anxiety attacks.

3. App Design

Young people all agreed on having the ability to customize the app to suit their preferences (e.g. font size, colour, home screen layout). This would minimize nuances associated with TS, such as OCD tendencies or attentional and learning difficulties.

Quotes: "The biggest and most important thing is the options and the customization, so it bothers you as little as possible. So when you go to it to calm down it doesn't make you any worse"

4. Thoughts on Digital

MoSCoW Results for Ideal App

Must Have

Parent App; Ratings, Graphs, Videos; Offline ability; Different forms of content formats i.e. videos and text; Reminders for meds/exercises; Shared ratings with consultations (e.g. with parents); Customization of app (e.g. colour, font, layout); Links to clinics; Links to websites; Motivational input (virtual coach)

Should Have

Game story telling; Verbal note taking; Exercise Tracker; Age specific Content; Anonymous Forums; Stepped care access

Could Have

Peer Support (Forum); Rewards; Help button/tutorials; Live chat with clinic; Forums with nominated moderators

Won't Have

No Glitches; Appointment scheduler

All participants were receptive to the use of digital to help them monitor and improve their tics and mental health, more generally.

Quotes: "Everyone's on their phone all the time. That's the other great thing about this, is that it blends in, it's not obvious. If you're on your phone you just look normal." (Male, 12 years old)

"Instead of having to find something on the internet, it's all there already. It's quick; I can get to it before I'm even more stressed. It's all in one place." (Male, 14 years old)

Discussion

The young people involved all saw a role for digital in helping them monitor and self-manage their tics and mental health. They liked rating their tics alongside other aspects of their daily lives and found this information interesting and insightful when presented on graphs. For ease of use, engagement and enjoyment of the app the young people advocate for customization to suit individual needs and preferences. In terms of content, the young people would like access to more "in the moment" strategies to help them manage their tics and anxiety when they find themselves in anxiety provoking situations.

The study provides evidence for the receptiveness of a digital mental health tool for young people with TS. However, as the results show, we would encourage the development of any app for mental health to be developed in conjunction with the end user. This will insure that the app meets the needs of these individuals (e.g. tools to manage anxiety not just tic suppression)

clinically but also to ensure sustained engagement and adherence [6].

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