

Technology Based Interventions for Tourette's Syndrome- A Brief Review

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ABSTRACT

Individuals diagnosed with Tourette's syndrome (TS) often have a diminished quality of life and are prone to mental health challenges, which can affect them and their family members negatively. Unfortunately, accessing face-to-face support for tics can be challenging, thereby creating an opportunity for online interventions to help manage Tourette's symptoms. Relevant literature was identified through the use of specific search terms, including 'Tourette's Syndrome,' 'Technological interventions,' 'Online interventions,' and 'Assistive technology,' across several research databases. Twelve research papers investigating online interventions for Tourette's were identified and selected for the review. Findings showed that behavioral interventions, meditation, and support groups were the primary online interventions used for Tourette's management, for both children and adults with Tourette's. All of the aforementioned interventions have demonstrated favorable outcomes, such as decreased tic severity, improved symptom management, and enhanced well-being. Nevertheless, there is still much to learn about how technology can be optimally utilized in this regard.

Keywords: *Tourette's Syndrome, Tics disorder, Technological interventions, Online Interventions, Assistive Technology*

Tourette syndrome is an early childhood-onset neurodevelopmental disorder that is marked by the appearance of multiple involuntary movements and vocalizations (tics) (Paschou, 2013). It spans over a period of more than 1 year, and onset is before the age of 18 years and is not attributable to the physiological effects of a substance or another medical condition. The typical age of tic onset is 4 to 6 years old, with symptoms peaking around 10 to 12 years of age. Simple motor tics are typically diagnosed early, while more complex tics tend to develop later. Tics are defined as sudden, involuntary and repetitive movements characterized by premonitory urge, physical expression of the tic and sense of relief experienced afterward. There are several vocal tics, including: sniffing,

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grunting, humming, clicking, yelling words repeatedly (Jones et al., 2021). Tics usually begin in childhood and vary over time in number, frequency, and severity; without a consistent pattern (Lin et al., 2002). It is diagnosed in 1 percent of children all over the world (Robertson et al. 2009). It is often accompanied by other comorbid conditions like attention deficit hyperactivity disorder (ADHD), Autism spectrum disorder (ASD) and obsessive compulsive disorder (OCD). They also have a lower quality of life compared to those without Tourette's (Eapen et al., 2016). Children with Tourette's often face issues like delinquent behavior, low social competence, thought problems, attention problems and aggressive behavior (Zhu et al., 2006). Behavioral therapies like Cognitive Behavioral Therapy, Habit Reversal Training, and Comprehensive Behavioral Interventions have been used for all age groups, along with various pharmacological interventions which showed mixed results (Robertson. 2015). Since the last decade, technology in the mental healthcare field has been rapidly progressing (Hollis et al., 2015), despite this the literature on the use of such interventions for Tourette's is relatively scarce and limited. This review focuses on the technology-based interventions for children and adults with Tourette's. This was done by identifying relevant literature using the key words 'Tourette', 'Technological interventions', 'Online interventions' and 'Assistive technology', on several research databases.

REVIEW OF LITERATURE

Traditionally, the primary approach to treating severe tics has been through medication, specifically antipsychotics. Nonetheless, these medications can lead to unfavorable outcomes, including drowsiness and weight gain (Stroup & Gray, 2018). Behavioral interventions are considered a promising and effective alternative to pharmacotherapy for the treatment of tic disorders. However, the success of these interventions relies heavily on the patient's ability to devote significant time and effort to practicing demanding behavioral techniques, such as tic control or habit reversal. There are well-established benefits and effectiveness of behavioral therapies for tic disorders (McGuire et al., 2014; Whittington et al., 2016; Hollis et al., 2016), However accessing such treatments is a major challenge for patients due to the scarcity of trained therapists (Novotny et al., 2018). Using digital health interventions is an encouraging advancement in enhancing access to behavioral treatments (Hollis et al., 2017).

Behavior therapy

Exposure and response prevention (ERP)

ERP is a form of behavior therapy that's usually used for treatment of obsessive compulsive disorder. It involves allowing the individual to face their obsessional thoughts (exposure) and to make them resist actually performing the compulsions (response prevention), along with providing psychoeducation (Law & Boisseau, 2019).

An RCT was conducted to explore “online remote behavioral intervention for tics in children and adolescents (ORBIT)” which involved conducting ERP online, providing therapist support and parental assistance. The control group was given psychoeducation and results showed those who received ERP had a more significant decrease in tics than those receiving psychoeducation at 3 months (Hollis et. al., 2021). These results were maintained at 12 and 18 month follow up (Hollis et. al., 2023). Same conclusions were confirmed in another RCT with ERP and structured education as active control. It showed that ERP had more treatment responders and the treatment is also cost effective (Andr n et al., 2022).

Habit reversal training (HRT)

HRT is a multifaceted behavioral intervention that aims to lessen the manifestations of conditions that are habit-based. Habit reversal training has undergone simplification since it was first conceived. Through component analyses, it has been determined that awareness training, competing response training, and social support are the three most crucial therapeutic components (Woods & Miltenberger, 1995). A study by Himle et al. (2006) reviewed 16 researchers ranging from 1973 to 2006 investigating the effectiveness of habit reversal training for Tourette's and discovered that the effectiveness in reduction of tics was up to 99 percent in some and above 50 percent in most of the studies. HRT and ERP were combined in one RCT and while both interventions were rated as highly credible and satisfactory and resulted in reduced tic-related impairment, parent-rated tic severity, and improved quality of life, 75 percent of participants in the ERP group and 55 percent of participants in the HRT group were treatment responders. The therapeutic effects were maintained from 3 months to 12 months. Providing Habit Reversal Therapy (HRT) remotely may be more challenging, especially for vocal tics. This is because identifying an appropriate competing response for specific tics may require additional guidance from a therapist. In contrast, teaching patients to suppress all tics at once, as in Exposure and Response Prevention (ERP), may be simpler. HRT as a therapy, required considerably more content (videos, exercises etc) to deliver and thus may have been harder to grasp. Therefore, the findings do not suggest that ERP is superior in general. Moreover, the remote delivery of HRT required significantly less therapist support time than traditional face-to-face behavior therapy, which indicates its potential for being cost effective (Andr n et al., 2019).

Comprehensive Behavioral Intervention for Tics-

CBIT is an extension of habit reversal training (HRT), which includes tic awareness, competing-response training, and social support. Additionally, CBIT includes sessions of psychoeducation, function-based assessment and interventions, relaxation training, and relapse prevention plans (Woods, 2008). Himle et al. (2012) conducted a randomized pilot trial comparing the efficacy of videoconference versus face-to-face CBIT. The study found that both types of therapy were effective in reducing tic severity, with no significant differences between the two groups, which consisted of children aged 8 to 17. However, videoconferencing requires a technical expert at both ends and requires the participant to reach the nearest center that has the necessary equipment to receive treatment.

Building on this study, Ricketts et al., (2016) conducted CBIT on children through Voice-over internet protocol which is a web-based video conference that allows parties at both ends to conduct the intervention from any location and only requires basic equipment, hence reducing the technical complications. In both of these studies, approximately 30 percent reduction in Yale Global Tic Severity Scale tic severity was found. Furthermore, this study also conducted the assessment of tic severity online, and high interrater agreement was found with in-person assessment.

The next study included comorbidities like OCD and ADHD along with tourettes and was conducted by Rachamim et. al (2021a). The intervention was named ‘‘Internet-delivered, self-help comprehensive behavioral intervention for tics (ICBIT)’’ and was conducted on children and adolescents. Participants received either ICBIT or a waitlist control condition. Participants with ADHD and tourettes and OCD and tourettes showed reduced severity in tics, along with those with no comorbidities. However, it is important to note that people with OCD and tourettes benefited relatively less. Results were maintained upto 6 months. Hence, intervention was deemed feasible and effective. In the same year, a reanalysis of the

Technology Based Interventions for Tourette's Syndrome- A Brief Review

data confirmed the findings that this may be a useful intervention for those with comorbidities and that it may help decrease symptoms of inattention and impulsivity (Rachamim et. al 2021b).

Finally, Haas et al. (2022) investigated the effectiveness of an internet-delivered behavioral treatment (ONLINE-TICS) for patients with chronic tic disorders on a larger population of 161 adults in 5 different centers. Participants were either assigned to ICBIT, face to face CBIT, or placebo group. Improvements in the ICBIT group were significantly greater than in the placebo group at 3 and 6 months after the treatment ended. There wasn't much difference between improvement of ICBIT and face to face CBIT.

Mindfulness

"Mindfulness" refers to the non-judgmental observation of the ongoing stream of internal and external stimuli as they arise (Baer 2003). Due to the positive effects mindfulness has shown on psychological well-being (Brown & Ryan, 2003; Walach et al., 2006), its techniques have since been incorporated in various types of therapies (Kabat-Zinn, 1982; Linehan, 1993; Segal et al., 2002). Reese et al. (2021) conducted an online feasibility and acceptability study on a mindfulness-based intervention for adults with tic disorders. It is the first of its kind, as no online meditation-based intervention has previously been conducted. The intervention was conducted on a cohort of adults for 8 weeks. The researchers hypothesized that mindfulness intervention would help individuals cope with the discomfort of the urge to tic. The dropout rate was low and participants were highly satisfied with the intervention. After the study, 40 percent of the participants were considered treatment responders, and compared to the initial in-person pilot test (Reese et al., 2015), which had 58.8 percent treatment respondents, there was a significant improvement in tics severity. In the online study, the home practice adherence was much lower, which probably contributed to the lower improvement in the tics. A larger RCT would be required to make definite claims about the effectiveness of online meditation interventions, as this study had a very small sample size of 5 and was limited in gender and race. A qualitative analysis showed that the parts of the intervention that participants found helpful were increased calmness, tools for improvement, acceptance and kindness, group support and discussion, and an appreciation of specific practices that they preferred.

Online Support Communities

Online support communities have proven to provide huge benefits to those with other mental disorders. Only 2 researches were found exploring the effects of online social support on individuals with Tourette's. One study utilized inductive thematic analysis of posts on an online support community for Tourette's. It was found that these individuals felt that this was a place that helped them share and ask information about their condition, it gave them a place to vent their feelings, a place to interact with those with the same condition and freely share the individual realities of having tics (Soós, Coulson, & Davies, 2022). This method of research has its own drawbacks, such as not being aware of the demographics of the people making posts, or being unaware if the person is suffering from tics themselves or is a caregiver.

In another study, researchers utilized a survey to examine the effects of online support communities on individuals with Tourette's syndrome or their caretakers. Through thematic analysis, it was found that these communities were perceived as helpful due to the limited availability of offline support. Participants reported that being a part of such communities allowed them to gain more information about the disorder, experience a sense of

Technology Based Interventions for Tourette's Syndrome- A Brief Review

community, positively impact their wellbeing, and receive guidance on the management of tics (Perkins, Coulson, & Davies, 2020). However, it is important to note that these communities are not without criticism. Participants may receive unreliable information from others as everyone's experiences differ, and there may be conflicts within the group due to differing perspectives. In addition, conflicts arose between adults with Tourette's syndrome and parents of children with the disorder.

Therapeutic platforms and Assistive technology for individuals with Tourette's

A study by Conelia & Wellen (2017) reviewed the AI TicHelper.com, which is a self-help program available for young individuals between the ages of 8 and late adolescence who experience tics. It follows the structure of CBIT over the course of 8 weeks, including 30 to 60 minutes of time investment every day. The review states that although the effectiveness of CBIT is so well known, it is difficult to conduct and most people don't have access to the right professionals or have financial burden and time commitment issues; hence, platforms like these offer the help that they require at a low cost. The site forms individualized plans for the individuals, however, it would be difficult to achieve the same level of progress as they would with the involvement of a therapist. Besides, no research has been conducted using the site as an intervention. Similarly, there's a scarcity of research on any other such platform or assistive technology for TS. Although a wrist-worn device is an assistive technology that emits electrical impulses is currently being studied in a clinical trial to help reduce the frequency and intensity of tics in individuals with Tourette Syndrome (University of Nottingham, 2021).

Limitations and Research gaps

The findings of the reviewed research indicate an overall favorable trend towards the effectiveness of online interventions for tics. However, there are several challenges associated with conducting these interventions in an online format. Specifically, when using videoconferencing technology, access to advanced equipment and technical support can be a barrier, limiting the potential benefits of the intervention to a specific population. Similarly, web-based interventions are subject to the effectiveness of the internet connection and speed, and distractions and multitasking can interfere with the treatment, particularly when parental supervision is required for children.

Despite the proven efficacy of Habit Reversal Therapy (HRT), Exposure Response Prevention (ERP), and Comprehensive Behavioral Intervention for Tics (CBIT) in reducing tics, there are challenges to implementing these therapies online. Each study reviewed in this analysis addressed these challenges in different ways, including technical difficulties with the online platform or issues with content and its delivery. One study showed that ERP was more effective than HRT, although the authors noted that this may be due to the larger modules used in HRT and easier technique of ERP, rather than ERP being inherently superior.

Furthermore, it is important to note that most of the studies conducted in this area have been limited to small sample sizes, and participants did not have comorbid conditions or severe tics. The demographic characteristics of the sample too are not diverse enough, hence these research are inadequate to generalize the findings to the wider population. Additionally, one study that considered the comorbidity of Tourette's Syndrome (TS) with Attention Deficit Hyperactivity Disorder (ADHD) and Obsessive-Compulsive Disorder (OCD) found that the treatment was less effective for those with TS and OCD (Rachamim et. al., 2021a). While meditation has been shown to have positive effects on overall wellbeing, there is only one

Technology Based Interventions for Tourette's Syndrome- A Brief Review

online treatment for tics that incorporates it as intervention for tourette's (Reese et al., 2021). Similarly, research on the effectiveness of online support groups for TS is limited. The most significant research gap identified is the lack of studies on assistive devices, applications, and websites that can be used for the maintenance and treatment of TS.

Recommendations for future research

The current section involves recommendations for addressing the various limitations and gaps in the research highlighted in the previous section. Future studies may include exploring larger and more diverse sample sizes, investigating the use of assistive technology, and comparing the effectiveness of different technological interventions. Additionally, practical steps for clinicians could incorporate more meditation-based interventions, improving the content transfer of traditionally offline therapies, creating more user-friendly online platforms and apps that are age appropriate, while also researching the current platforms to make improvements. Based on the feedback given in the research, support group experiences can be further improved by keeping a separate space for adult individuals with tics and parents of children with tics. As observed, there is even a lack of literature on interventions for TS with comorbidities and severe tics. Development and adaptation of the current interventions will further benefit this area of literature. Finally, the literature review underscores the need for continued research to improve the accessibility and effectiveness of technological interventions for Tourette's.

CONCLUSIONS

Technology has the potential to assist individuals with Tourette's syndrome (TS) by providing tools and devices to help manage symptoms and improve quality of life from the comfort of their homes. It has significantly reduced the financial burden associated with various interventions, making them more affordable and accessible to a wider range of people. Some of the technology-based interventions discovered through this review for TS include computer-based behavioral therapy, online support groups, online meditation-based interventions, and wearable devices. Within behavior therapy, the three main techniques identified were habit reversal training, exposure response prevention, and comprehensive behavior intervention for tics. Some of these can be beneficial for individuals with TS to connect with others, track symptoms, access information and resources and improve overall well-being, but most importantly reduction in tics severity. Despite the potential benefits of technology-based interventions for TS, more research is needed on the above given suggestions to determine their effectiveness and feasibility in real-world settings. It is important to recognize that technology, as of yet, is not a substitute for comprehensive medical and behavioral interventions for TS, but can be used as a complementary aid to support treatment and self-management.

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Technology Based Interventions for Tourette's Syndrome- A Brief Review

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Technology Based Interventions for Tourette's Syndrome- A Brief Review

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Technology Based Interventions for Tourette's Syndrome- A Brief Review

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Conflict of Interest

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