The OCD Challenge: An online self-help program for obsessive compulsive disorder

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Abstract

Obsessive Compulsive Disorder (OCD) is characterized by unwanted thoughts and/or images followed by repetitive rituals. This debilitating disorder affects 2-3% of the population or about 5 million Americans; with nearly half suffering chronically throughout their lifetimes. Effective therapeutic modalities include medications, behavioural therapy and cognitive behavioural therapy utilizing exposure and response prevention. It is estimated that only 15-30% of sufferers receive adequate treatment. Technological advances create new ways to deliver more accessible interventions to individuals with limited options. This paper will explore how use of technology may extend OCD interventions, by offering a web based self-help approach.

Keywords: Obsessive-compulsive disorder, Self-help, Internet, Exposure and response-prevention.

Riassunto

OCD Challenge: un programma in rete di auto-aiuto per il disturbo ossessivo-compulsivo

Il disturbo ossessivo-compulsivo è caratterizzato dalla presenza di pensieri e/o immagini indesiderati ai quali seguono rituali ripetitivi. Questo disturbo invalidante colpisce il 2/3% della popolazione, circa 5 milioni di persone negli Stati Uniti; quasi la metà di questi individui ne soffre chronicamente per tutta la vita. Tra i trattamenti più efficaci si annoverano gli psicofarmaci, la terapia comportamentale, la terapia cognitivo-comportamentale in cui si utilizza l’esposizione con prevenzione della risposta. Si stima che solo il 15-30% degli individui che soffrono di disturbo ossessivo-compulsivo riceva un trattamento adeguato. Il progresso tecnologico può creare nuovi modi di erogare interventi più accessibili per persone che hanno possibilità di scelta limitate. In questo articolo si approfondisce in che modo l’uso della tecnologia può ampliare gli interventi per questo disturbo tramite un approccio di auto-aiuto basato su internet.

Parole chiave: Disturbo ossessivo-compulsivo, Auto-aiuto, Internet, Esposizione con prevenzione della risposta.
INTRODUCTION

Obsessive-compulsive disorder manifests in persistent and intrusive thoughts usually followed by ritualistic behaviours (National Institute of Mental Health, 2010). Obsessive compulsive disorder can manifest in various facets and, although no two individuals who suffer have identical experiences, they may be grouped into one or more of the following categories: counting and checking; contamination; scrupulosity; perfectionism and magical thinking (Besiroglu et al., 2007). If untreated, OCD can result in profound disability in which the compulsions occupy the entire day. About 15% of those with this illness show progressive deterioration in occupational and social functioning (DSM-IV-TR, 2000), making this disorder one that not only interferes with one’s major role obligations but impairs the ability to perform activities of daily living as well (Rocco, Slade & Andrews, 2005; Abramowitz, Taylor & McKay, 2009).

Affecting nearly 5 million Americans, obsessive compulsive disorder is the fourth most commonly diagnosed psychiatric condition in the U.S.; twice as prevalent as schizophrenia or bipolar disorder (Mascltis, Rector & Richter, 2003). Research has shown that prevalence rates for OCD are consistent across the world, affecting approximately 2% of the world population (Weissman et al., 1994; Sasson et al., 1997). The United States is a leader in medical research and technology, yet up to half of Americans suffering from OCD and other Axis I disorders (or specifically anxiety disorders) fail to receive treatment (Kessler et al., 1994; Shergold, 2007). These gaps in treatment exist not just in the U.S., but also around the world.

Up to 70% of patients with OCD are under-recognized by outpatient clinics (Wahl et al., 2009). The treatment gap for OCD is approximately 60%, making OCD one of the greatest mental health concerns universally (Khon et al., 2004). Internationally, OCD is recognized to be one of the most disabling disorders (e.g., Saxena et al., 2004) with increased prevalence of severe cases (Kessler et al., 2005). OCD does not only affect certain populations, obsessive compulsive disorder is gender-neutral and non-discriminating, appearing in all countries, cultures and affecting both genders and all ethnicities equally (Fontenelle, Mendlowics & Versiani, 2006; Zor et al., 2010).

Obsessive compulsive disorder is a considerable economic burden and is estimated to cost the U.S. economy upwards of $8 billion per year in lost productivity (Goodman, 2006) and without treatment, the chances of symptom remission are extremely low (Mascltis et al., 2003). Additionally, neuropsychiatric disorders, including OCD, account for nearly 21% of the total disease burden in the world (Eaton et al., 2008). Due to the inadequacy in assessment tools, knowledge dissemination of new evidence-based therapies, diagnosis and treatment can often be time-consuming and difficult. It is estimated that OCD sufferers spend an average of nine years seeking treatment before receiving a correct diagnosis (Jenike, 2004). An online self-help intervention, such as the OCD Challenge, can help close the gap among people with OCD and those who can access an evidence-based intervention.

TREATMENT

Two basic treatment options have been shown to be effective for OCD: cognitive behavioural therapy (CBT), and psychopharmacology, particularly serotonin reuptake
inhibitors (Jenike, 2010). The most widely studied psychological treatment for OCD is exposure with response prevention (ERP). Under the rubric of cognitive behavioural therapy ERP is used to systematically expose a patient to his or her fear, while encouraging the individual to prevent engaging in a ritual(s). The efficacy of ERP, for patients diagnosed with OCD, has been clearly established (Abramowitz, Franklin & Foa, 2002; Björgvinsson & Hart, 2007; Pignotti & Thyer, 2011; Whittal et al., 2008). Exposure with response prevention should be the first line of treatment and is the most adequate short and long term treatment for those diagnosed with OCD (Abramowitz, 2006). A number of meta-analyses and clinical significance analyses indicate that 60% to 80% of patients who complete treatment with ERP, particularly those who engage in treatment with compliance and motivation, get significantly better (e.g., Abramowitz, 1997; Fisher & Wells, 2005). The definition of significant improvement usually refers to a 35% or higher reduction in Yale-Brown Obsessive Compulsive Scale (YBOCS; Goodman et al., 1989) scores (see Pallanti & Quercioli, 2006), the most frequently used measure to gauge patients’ response to treatment.

ERP is initiated by creating a hierarchy of situations that trigger anxiety in relation to one’s OCD. The items on a hierarchy include both external cues (e.g., seeing or touching something dirty or leaving without checking if the stove is off) and internal cues (e.g., thoughts, images, or impulses that trigger distress). Effective ERP treatment includes assessment of the patient’s avoidances, safety behaviours, and covert neutralizations (mental rituals), which are then incorporated into the exposure hierarchy. The patient then gradually moves up the hierarchy; progress up the hierarchy takes place once successful habituation to the anxiety-provoking situation occurs without engaging in a ritual.

Habituation occurs as the patient learns that the distress generated by the exposure will gradually decrease spontaneously if the previously assumed necessary compulsion or avoidances behaviours are prevented (Bjorgvinsson & Hart, 2007). Frequent and repetitive ERP practice produces better outcomes than less practice with large gaps of time between. Gains are typically maintained for longer periods and generalize to a greater degree when treatment is intensive, for example having 90-minute ERP sessions 3 to 5 times per week for many weeks (Abramowitz, Foa & Franklin, 2003; Neziroglu, Henricksen & Yaryura-Tobias, 2006). However, twice weekly outpatient treatment utilizing ERP is an effective treatment option for OCD when provided by clinicians who have been trained in this modality (e.g., Foa et al., 2003).

A more recent development in the treatment of OCD is cognitive therapy (CT). CT addresses various core beliefs typically held by persons with OCD and has been shown to be effective in significantly reducing OCD symptoms (Clark, 2004; Frost & Steketee, 2002; van Oppen et al., 1995). It aims at identifying and correcting dysfunctional beliefs or faulty appraisals of obsessional stimuli. According to the cognitive model of OCD, these beliefs lead to obsessional fears and responses that are maladaptive, reinforce specific core beliefs, and maintain dysfunctional neutralization responses. Although the data clearly demonstrates that the most effective treatment for OCD is ERP, promising data is emerging about the efficacy of CT (Clark, 2004). Specifically, CT demonstrated efficacy
in reducing dropout rates among patients in treatment and in enhancing motivation (Kozak & Coles, 2005). Often, CBT is combined with medication; however, cognitive behavioural therapy with exposure and response prevention (ERP) is often preferred over medication alone (Jenike, 2004). Incorporating ERP into a technological medium can increase access to an evidence based intervention and help overcome barriers associated with the high cost typically associated with ERP.

**BARRIERS TO TREATMENT**

Obsessive compulsive disorder is a complicated illness, which is often difficult to treat. The cost of treatment can be prohibitive to some individuals and finding a trained therapist can be difficult due to the lack of availability and various logistical problems. It is estimated that nearly 66% of OCD patients are unable to seek treatment because of the high cost (Clark et al., 1998; Maltby & Tolin, 2005). Despite having been shown to be the most effective treatment for OCD (Jenike, 2004; Maltby & Tolin, 2005; e.g., Foa et al., 2002), ERP continues to be under-utilized by clinicians for various reasons, including a lack of adequate training opportunities and a deficit of information distribution regarding evidence-based treatment for obsessive compulsive disorder (Maltby & Tolin, 2005).

Maltby & Tolin (2005) report that fewer than 50% of therapists who identify as CBT practitioners use exposure with response prevention. In addition shame, embarrassment and stigma may interfere in seeking treatment (Marques et al., 2010). Furthermore, people living in rural areas have less access to mental health services than those living in urban areas (Safran et al., 2009; Hauenstein et al., 2006). Overall, the worldwide median untreated rate, or treatment gap for OCD was found to be 59.5% (e.g., Saxena et al., 2004). Given these barriers, the deficits that exist in OCD treatment delivery need to be diminished. Advances in technology can help improve access to mental health services for patients in need and decrease the costs associated with ERP. Technology can be utilized to help close the gap that exists between effective interventions and people with OCD.

**TECHNOLOGY AND ACCESS TO HEALTH SERVICES**

People are changing the way they access services, and as such, the medical community should adapt a service delivery to meet changing needs. The U.S. Census Bureau (2009) reports that nearly 70% of American households own a home computer with internet access. Nearly 80% of American internet users reported regularly accessing the internet to obtain information regarding specific health concerns (Pew Charitable Trust, 2011). Self-help websites increase accessibility of services, making intervention options available to more people who need them, regardless of geographical location or restrictions. Patients living in rural areas with no access to mental health providers can have access to an evidence-based intervention, which is offered via the internet by simply logging-on to the self-help website.
The accessibility of self-help websites may assist in diminishing many of the treatment barriers that sufferers encounter in seeking traditional help for obsessive compulsive disorder. When compared with face-to-face therapy, internet mediated services could offer an affordable alternative to traditional interventions. Websites are available 24-hours a day, 7-days a week and without an appointment. Increased accessibility may increase patient interaction with the program, maximizing the cost-effectiveness over traditional therapeutic modalities. Self-help websites can not only increase accessibility for individuals seeking an intervention but may also be a supplement to traditional clinical methods, by helping clinicians enhance and extend their services.

COMPUTERS, SELF-HELP, AND OCD

Currently, there are dozens of self-help books and workbooks available that offer help for OCD. It is estimated that 75% percent of individuals with OCD have read a least one self-help book (Moritz et al., 2011). In comparison with face-to-face therapy, books are low-cost, self-paced and highly accessible; however, they lack user-interaction. While there is evidence that self-help books are useful in the treatment of OCD (Fritzer, Hecker & Losee, 1997; Tolin et al., 2007), only a small amount of research has been done. An interactive website that includes psycho-education and individualized hierarchy planning may help increase motivation; however, research should be done to examine differences in motivation.

Self-help for OCD is not limited to books. Emerging technology can broaden the delivery for self-help programs and benefit people who cannot or have not utilized traditional approaches. Self-help websites currently exist for a variety of conditions such as depression, trichotillomania (stoppulling.com), skin picking (stoppicking.com) and other mental health disorders (depressionselfhelp.tripod.com; www.fearofflyinghelp.com; www.anxietybc.com).

One of the earliest uses of computer technology in the treatment of OCD was a case reported by Baer, Minichiello and Jenike in 1987. Clark et al. (1998) utilized a computer program that modelled exposure and response prevention for checking and washing rituals that produced significant reductions in symptoms. Greist and his colleagues (Greist et al., 1998) developed a computerized self-help program (BTsteps, now OCFighter, www.ocfighter.com), which is accessed remotely via telephone and utilizes interactive-voice-response technology. This program was shown to be effective across four studies including two randomized controlled trials (Bachofen et al., 1999; Kenwright et al., 2005). Greist et al. (2002) in a RCT allocated 218 OCD patients to the BT steps protocol, clinician-guided behaviour therapy, or systematic progressive muscle relaxation. After a 10-week trial, systematic progressive muscle relaxation proved to be ineffective, while those in the BT steps and the clinician-guided behaviour therapy groups showed significant improvement on a measure of OCD severity. Overall however, clinician-guided treatment showed greater gains than BT steps.

Cognitive behavioural therapy with exposure with response prevention has been shown to be the most effective treatment protocol for obsessive-compulsive disorder. It is crucial
that patients engage in self-directed exposures in order to maintain long-term success. If patients rely solely on therapist aided exposures it can be very difficult when they are triggered outside of the therapist’s office. Online self-help programs can help reinforce positive behaviours outside the clinical environment; patients can log their exposures and compliance with exposures in-between sessions and therefore expand services beyond the clinic walls. Additionally these factors may increase accountability and compliance for people using this website as a sole intervention.

**OCD CHALLENGE**

The OCD challenge is an interactive self-help website designed specifically for those diagnosed with obsessive compulsive disorder. This website was developed to help address the treatment gap that currently exists between those with OCD and those who are receiving an evidence-based intervention. The website is currently available only in the English language; however, it is undergoing translation to Spanish, Norwegian, Portuguese, Mandarin, Italian and other languages. This website was developed to serve in three specific areas of need: 1) as a sole-intervention where no other options exist; 2) as a clinician’s tool to supplement traditional therapy; and 3) as a relapse prevention tool. The OCD Challenge was developed by psychologists, researchers and professionals in the field (www.ocdchallenge.com). As a collaborative effort, this website is and will be continually evaluated and updated as needed in order to provide the highest level of support for users.

The OCD Challenge is a confidential and secure website that allows users to log-in and interact with the program through three modules, assessment, gaining awareness and intervention. Users are guided through stages ranging from psycho education, hierarchy development and the understanding and implementation of exposures. This site allows users to combat obsessive compulsive disorder by gradually taking them through the steps of exposure with response prevention (see figures 1, 2 and 3). The background graphics of the website portray a snow-peaked mountain. The developers chose this because they felt that the metaphor of climbing a mountain best describes what it feels like to have OCD. Professionals in the field serve as mountain-guides, explaining how the program works and the importance of ERP. Videos are available throughout the website in order to increase interaction with users.

The program is divided into three modules: Assessment, Gaining Awareness and Intervention. After creating an account, users are asked to enter basic demographic data, such as treatment history, age, gender and geographical location. All of this information is gathered for research purposes. After the demographic section is completed, users move onto the Assessment module. Here, users will complete several questionnaires to assess their OCD symptoms and severity. The OCD Challenge administers the Yale-Brown Obsessive-Compulsive Scale (YBOCS, Goodman et al., 1989); the Dimensional Obsessive-Compulsive Scale (DOCS, Abramowitz et al., 2010); the Depression, Anxiety and Stress Scale-21 (DASS-21, Lovibond & Lovibond, 1995); The Sheehan Disability
Scale (Sheehan, Sheehan & Raj, 1996); the Self-Compassion Scale-Short Form (SCS-12, Raes et al., 2011); the Motivation Scale (The Peace of Mind Foundation, 2011); and the Greater Purpose Statement (The Peace of Mind Foundation, 2011).

The Motivation Scale and the Greater Purpose Statement were developed based on classic elements of ERP treatment (Abramowitz, 2006) and adapted for use by psychologists and clinicians working with the OCD Challenge. The Motivation Scale asks users to choose statements that reflect how they feel about challenging their OCD versus keeping...
their OCD (see figure 4). This scale can be modified throughout the program to reflect the motivation levels of the user. The Greater Purpose Statement is a motivational statement that users create to capture the essence of what they may gain by challenging their OCD. This can be further personalized by adding a photograph or image, which will appear on the user’s homepage along with the Greater Purpose Statement. These two scales were
created for the program because some research has shown motivation to be a significant factor in beginning treatment and compliance throughout treatment (Abramowitz, 2006).

After completing the Assessment module, users enter the Gaining Awareness module. For ease of use, Gaining Awareness is sub-divided into three sections: Gaining Awareness 1; Gaining Awareness 2; and Gaining Awareness 3. When in Gaining Awareness 1, users view videos and read about the obsessional themes common to OCD, and will choose which may apply to them. By selecting specific themes, users are simultaneously selecting the challenge areas that will apply to them later in the program. For example, if a user answers «yes» to the question about having excessive worry about dirt and germs, the program will assign the contamination challenge, which will appear in the Intervention Module. In Gaining Awareness 2, users identify their OCD rituals, which correspond to the challenge areas selected in Gaining Awareness 1. During Gaining Awareness 3, users are asked to track and record their rituals and avoidance behaviours they engage in over a seven-day period. This process helps increase self-awareness of behaviours that may have previously been unnoticed and helps personalize the ERP exercises, which will appear in the Intervention module. Users who are more familiar with logging behaviours and hierarchy building, can «skip to intervention» by selecting a tab located in this section.

The Intervention Module is the final module of the OCD Challenge program. Like the previous module, Intervention is sub-divided into three sections. All users start this section with Intervention 1, where they are asked to complete re-assessments and view two videos explaining the importance of ERP for the reduction of OCD symptoms. Intervention 2 asks users to create a hierarchy, by rating their OCD triggers (logged during Gaining Awareness 3) on a scale of 0 to 10 (0 [least anxiety provoking]; 10 [most anxiety provoking]). For ease of use, anxiety levels are colour coded with green and blue corresponding to lower-level triggers, yellow to mid-level triggers, and orange and red corresponding to higher-level triggers. The final module is Intervention 3. In this module, users begin performing their ERP exercises and recording them in their personalized Intervention log. Each exercise is grouped by challenge area, with each challenge area appearing on the user’s homepage.

Users log by clicking on a challenge area (for example, contamination) and record the number of exposures performed (e.g., touching a door knob) and the number of rituals that followed (e.g., hand washing). For each task, users rate their compliance level, from highly compliant to highly non-compliant. The compliance level allows users to self-rate how compliant they were with each exposure; compliance levels are subjective and differ from user to user. As users progress through their exposure hierarchy and their compliance levels increase, messages appear next to the challenge areas encouraging users to continue their hard work and informing them when they are moving up to the next hierarchy levels. Also on this page, is a mountain depicted with a winding path to the summit. An avatar is shown at the bottom of the mountain. As users successfully progress through this phase, by performing their ERP exercises without ritualizing, the avatar advances up the mountain path, towards the summit. This metaphor corresponds with the overall theme of the website and adds to the interactive aspects of the website.

Self-help books and workbooks may present the same basis (cognitive behavioural therapy with exposure and response prevention) as the OCD Challenge but are often flat
in affect; as noted, this website utilizes technology to not only increase appeal but to be interactive with each user in a unique way. Furthermore, this program allows users the opportunity to utilize this self-help intervention at their own convenience, either as a sole intervention, in conjunction with another intervention (e.g., individual or group therapy), as a segue from residential treatment to outpatient, or as relapse prevention tool. It is the goal of the website developers to help reduce the barriers that exist in the utilization of ERP and to have a positive impact on the lives of those with obsessive compulsive disorder. The OCD Challenge helps increase accessibility to an evidence based intervention. It is available free of charge for anyone in the world with an internet connection.

**OCD Challenge research**

Current research is being conducted on the feasibility of the OCD Challenge as a self-help tool for reducing and managing OCD symptoms of the users of the program. There are currently over 250 users in over 10 different countries. As research is ongoing, the results have not yet been analysed to determine the feasibility of this program as a self-help tool for treating OCD. The data from this website will explore user characteristics and the feasibility of the website will be assessed. The OCD Challenge website allows for continuous data analysis and ongoing research. Future research implications include examining the use of this website as a sole self-help intervention, as a therapist guided intervention, analysing the feasibility of this website as a relapse prevention and maintenance tool for OCD, comparing the use of this application among users in different countries or geographical regions, and by comparing this website to other OCD interventions.

**CONCLUSION**

Obsessive compulsive disorder is a devastating illness that affects millions of people, worldwide. According to the World Health Organization, nearly 450 million individuals will suffer from a neuropsychiatric illness in their lifetime and obsessive compulsive disorder is one of the leading disorders (e.g., Saxena et al., 2004). The treatment gap that exists worldwide increases the rates of disability due to obsessive compulsive disorder. The most common barrier to treatment is accessibility, mainly cost of treatment and lack of services (e.g., Saxena et al., 2004). The OCD Challenge was developed to promote access to an evidence-based intervention that is both cost effective (free to users) and readily available (online 24-hours per day). This online self-help program is a novel approach based on a proven method (cognitive behavioural therapy with exposure and response prevention) and designed to help those with obsessive compulsive disorder gain awareness and learn techniques to help reduce OCD symptoms. It is the developers’ hope that this website will prove useful as a sole intervention, as a clinical tool to aid therapists in working with patients with OCD, and as a maintenance and relapse prevention tool for those individuals in the management phase of treatment.
REFERENCES


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