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Social Media Peer Support Groups for Obsessive-Compulsive and Related Disorders: Understanding the Predictors of Negative Experiences

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Abstract

Introduction: As social media platforms become commonplace in daily life, online peer support groups have become increasingly popular in populations with physical and mental health conditions. Although the benefits of using social media peer support groups have been well documented, there can be significant risks associated with them, which could result in negative experiences for users. **Method:** Using a mixed-methods approach, the aim of the current study was to identify the predictors of negative experiences among people who used social media peer support groups for obsessive-compulsive and related disorders. **Results:** Results indicated that barriers to treatment and quality of “offline” interpersonal support predicted users’ negative experiences with using social media peer support groups for obsessive-compulsive and related disorders. Thematic analysis suggested that the contributing factors towards participants’ negative experiences included: (1) confronting content; (2) misinformation; (3) preoccupation with symptoms; (4) social comparison; and (5) hopelessness about recovery prospects. **Discussion:** It was concluded that using social media peer support groups for obsessive-compulsive and related disorders, without adequate support structures in place, can pose users at the risk of negative experiences. Further research is necessary to gain a deeper understanding of how to enhance positive experiences and protect against the possible risks for users of unmoderated online peer support groups.

Keywords: online peer support group, social media, obsessive-compulsive and related disorders, risks, negative experience

Understanding the Predictors of Negative Experiences When Using Social Media Peer Support Groups for Obsessive-Compulsive and Related Disorders

Ever since the World Wide Web became widely available to the average person in the late 1990s, it has transformed the way information is consumed. More recently, the internet – and specifically, social media – has become a tool for people to form online communities around shared interests and experiences. The penetration of smartphones into people's everyday lives in the past decade has increased the demand for instantaneous delivery of information, including for health-related information (Mattsson, Olsson, Alfonsson, Johansson, & Carlsson, 2015). Since Facebook became popular in the late 2000s, it has drastically changed the way people communicate and interact with others. Today, internet users with mental health issues share their personal experiences and seek support from others on a wide variety of social media platforms, including but not limited to Twitter, Reddit, Facebook, and YouTube (Berry et al., 2017; De Choudhury & De, 2014; Naslund, Aschbrenner, Marsch, & Bartels, 2016).

While there are many moderated online support groups hosted by non-profit mental health organisations (e.g., Griffiths, Reynolds, & Vassallo, 2015; Kendal et al., 2015; McCosker, 2018; Smith-Merry et al., 2019), peer support groups hosted on social media platforms are unique in that they are typically created and managed by individuals with lived experience of a particular mental health issue for their peers with the same condition. Social media peer support groups (PSGs) are not commercial entities and their content is not moderated by trained volunteers, peer workers or healthcare professionals. Social media PSGs can be open to anyone browsing the internet, or they can be closed such that a group administrator must grant the user access before they can view member posts or post their own content. Unlike traditional face-to-face support groups, social media PSGs afford users anonymity and control over the type of information they share and receive (Naslund et al., 2016). Given that social media is highly accessible for most people, such groups appeal to those who face difficulties with engaging in "offline" support, either with peers, family and friends, or healthcare professionals.

Benefits and Risks of Participating in Social Media Peer Support Groups

Outcomes of using online PSGs have been documented in literature over the past 20 years for a range of health issues and populations, and literature has found evidence in support of both benefits and challenges (e.g., Ali, Farrer, Gulliver, & Griffiths, 2015; Eysenbach, Powell, Englesakia, Rizo & Stern, 2004; Hanley, Prescott, & Ujhelyi Gomez, 2019; Kingod, Cleal, Wahlberg, & Husted, 2016). Through content analysis of interviews conducted with 32 users of online PSGs for various health conditions, van Uden-Kraan et al. (2008) identified six different ways in which the participants had positive experiences. Participants reported: (1) being better informed of their health condition; (2) feeling more confident in navigating the health system and their social environment; (3) feeling more able to accept their health condition; (4) feeling more optimistic and in control of their situation; (5) increased self-esteem; and (6) acting to improve their situation. Indeed, similar benefits have been reported by more recent studies into the benefits of social media PSGs for mental health issues. For instance, across YouTube and Twitter, positive experiences reported by users included gaining increased sense of hope, social connectedness and feeling a sense of community, sharing strategies for coping with distress and other challenges associated with living with a mental health issue, seeking professional healthcare offline, raising mental health awareness, and combatting stigma (Berry et al., 2017; Naslund et al., 2014).

However, there are challenges associated with social media PSGs. Social media PSGs lack trained volunteers, peer workers or health professionals acting as moderators. Although lack of moderation may facilitate self-disclosure and allow users to share their experiences without fear of being censored (DeAndrea, 2015), it also exposes users to various risks since trained moderators are responsible for maintaining group rules, facilitating a shared understanding of those groups rules, and removing potentially harmful content. One risk is the increased level of distress that users can experience as a result of excessive expressions of fear and anxiety among their peers; this was evident in online PSGs for both physical and mental health issues (Salzer et al., 2010; Kaplan et al., 2011). Other risks can include privacy breaches, exposure to poor quality information (about medications or recovery prospects, for example), feeling disempowered when confronted by the negative aspects of one’s condition, and facing unhelpful comments made by users who are perceived as “complainers” (van Uden-Kraan et al., 2008, Naslund, Bondre, Torous, & Aschbrenner, 2020). Among social media PSGs that are open to public viewing by non-members, another risk to users is exposure to hostile or stigmatising comments from people with limited understanding about what it is like to live with mental health issues (Naslund et al., 2020). Surprisingly, as Naslund et al. (2020) point out, few studies have investigated the potential harms of social media use from the perspectives of those living with mental health issues.

Social Media Peer Support Groups for Obsessive-Compulsive and Related Disorders

There has been very little research on the experiences of using online PSGs catering to individuals living with obsessive-compulsive and related disorders (OCRDs). OCRDs include obsessive-compulsive disorder (OCD), hoarding disorder, body dysmorphic disorder (BDD), excoriation (skin picking) disorder, and hair pulling disorder (trichotillomania; American Psychiatric Association [APA], 2013). OCD is characterised by persistent intrusive thoughts (i.e., obsessions), and repetitive behaviours (i.e., compulsions) that are performed as a consequence of, or to neutralise, those thoughts (APA, 2013). Body-focussed repetitive behaviours (BFRBs) like skin picking and hair pulling, while currently classified as OCRDs, are considered to be quite distinct from OCD, as these behaviours are not elicited by obsessions; instead they often occur with limited awareness and are believed to serve a self-regulatory function (Phillips et al., 2010). Nevertheless, as a whole, OCRDs are highly stigmatised, trivialised, characterised by shame, and poorly understood by the public and health professionals alike, which is believed to facilitate delayed diagnosis and treatment seeking (Coles, Heimberg, & Weiss, 2013; Marcks, Wetterneck & Woods, 2006; Marques et al., 2010; Robinson, Turk, Jilka, & Cella, 2019; Weingarden & Renshaw, 2015). For example, one study found that only 25% of individuals with OCD seek help from specialists and that some delay treatment for as long as 14 years (Cullen et al., 2008).

Online PSGs are sometimes seen as an alternative to seeking “offline” mental healthcare, particularly when access to treatment is limited, or one’s mental health issues are a source of personal shame and embarrassment (Davison et al., 2000; DeAndrea, 2015; Jackson et al., 2012). A recent large-scale, nationally representative mental health survey in Singapore found that people living with OCD or major depressive disorder had the highest rates of online support group participation (Roystonn et al., 2020). Participation among these groups was significantly higher than among participants with diagnoses of bipolar disorder, dysthymia, generalised anxiety disorder, and alcohol use disorders (Roystonn et al., 2020). This could indicate a gap in awareness or availability of mental healthcare services for individuals with OCD and depression specifically or of their preferences to seek out other forms of support. For people living with BFRBs, whose repetitive behaviours result in unwanted hair loss and/or skin lesions, the desire to self-manage the condition and seek support from those with similar lived experience is highly valued (e.g., Slikboer, Rehm, Lam, Maloney, & Nedeljkovic, 2020). In a study investigating the risks and benefits of participating in online mailing lists for trichotillomania (Bruwer & Stein, 2005), participants reported “feeling supported” and “obtaining information” were the greatest benefits offered by this type of online peer support. Participants also thought that peer support helped them learn about treatment options from people who had reported success with various treatment methods. These benefits are similar to those reported by users of online PSGs for physical health and other types of mental health issues (e.g., Smith-Merry et al. 2019; van Uden-Kraan et al., 2008). The main risk identified by Bruwer and Stein (2005) was that users were actively promoting diets touted as being useful for reducing symptom severity despite the lack of any scientific evidence suggesting that specific diets could reduce hairpulling behaviour and/or stimulate new hair growth. Additionally, most of the participants were not receiving any professional treatment at the time, relying primarily on the mailing list for support and advice (Bruwer & Stein, 2005). Besides being exposed to such misinformation, it is not known if the negative experiences associated with using online PSGs, as discussed above, are relevant to people who use similar groups for other types of OCRDs.

Aims of the Current Study

To our knowledge, there has been no further investigation into the uses of online PSGs for OCRDs since the study by Bruwer and Stein (2005). This is of concern, given that: (1) online peer support now predominantly harnesses a diverse range of social media platforms (rather than mailing lists), and (2) our cursory search of Facebook groups using the terms "trichotillomania" and "support" in April of 2019 returned at least five peer-run groups with over 18,000 members in total. Based on the literature reviewed above, it is evident that an in-depth investigation of user's experiences with social media PSGs for OCRDs is needed to bridge the gap in our understanding of the challenges and potential risks that users face.

As such, the primary aim of the current study was to explore the predictors of negative experiences when using online PSGs for OCRDs – particularly those hosted on social media platforms without moderation by trained volunteers, peer workers or health professionals. The predictors of negative experiences that were examined included symptom severity, offline characteristics (including treatment barriers, internalised stigma, and offline sources of support), the nature of social media PSG use, and the quality of participants' online relationships. Further to this, by employing a parallel mixed-methods approach, the study also included a brief thematic analysis to gain an understanding of users' perceived sources of negative experiences.

Method

Participants

Institutional human research ethics committee approval for this study was granted on May 15th, 2019. The recruitment method used was similar to that applied by Lawlor and Kirakowski (2014), whereby online peer support groups were identified by entering a list of OCRD terms ("trichotillomania", "hair-pulling", "excoriation", "skin-picking", and "OCD") into social media search engines preceded by "support group". Social media peer support groups were included in the study based on four criteria: (1) a group must not be facilitated by a mental health professional or organisation; (2) the group must be active, with at least five new posts made to the group in the past day; (3) researchers must not be explicitly prohibited from advertising the study invitation to participant per the group's published rules; and (4) the group must not serve commercial interests. Permission to advertise the study was sought from the administrators of the identified social media PSGs. Study advertisements were posted only if permission was granted. Based on these criteria, participants were recruited from thirteen online peer support groups from Facebook (*n* = 10) and Reddit (*n* = 3). The groups catered to users who were experiencing trichotillomania (*n* = 3), skin picking disorder (*n* = 4), OCD (*n* = 4), BDD (*n* = 1), and one group focussed on both OCD and BDD. Study advertisements were also posted to the websites of the Anxiety Recovery Centre of Victoria (based in Australia) and the TLC Foundation for Body-Focused Repetitive Behaviours (based in the United States); both organisations provide advocacy, education, and professionally moderated peer support services (online and face-to-face) for OCRDs.

Participants were eligible if they were aged 18 years or older, had a self-reported experience or clinical diagnosis of one or more OCRD(s), and were willing to complete an online survey in their own time. One-hundred and twenty-seven individuals consented to participate. The final sample comprised 90 participants who completed more than half the survey. The majority of the participants were female (93.3%) and the average age was 27 years (range = 18.0 – 44.0, *SD* = 5.85). On average, participants first experienced OCRD symptoms at 11.1 years (range = 0.00 – 25.0, *SD* = 4.87). Demographic characteristics of the sample are summarised in Table 1 and mental health characteristics are summarised in Table 2.

Design

The current study employed a convergent parallel mixed-methods approach. Quantitative and qualitative questions were administered within the same survey and results from the two sections were analysed separately. The results were then integrated to achieve complementarity, with the results from the qualitative section providing clarification for the results from the quantitative section.

Measures

An online survey containing thirteen questionnaires and three open-ended questions was administered. Copies of questionnaires designed or adapted for the purposes of the current study can be requested from the authors.

Demographics and mental health questionnaire. This is a 13-item questionnaire designed by the researchers to enquire about participants' key demographic and mental health characteristics, including self-reported lifetime experience of OCRDs and access to professional and non-professional supports (as shown in Tables 1 and 2).

Massachusetts General Hospital Hairpulling Scale (MGHHPS; Keuthen et al., 1995). This is a validated seven-item self-report measure of the severity of hair pulling behaviours experienced over the past week. Items in this measure included, for example: "On an average day, how often did you feel the urge to pull your hair?" and "On an average day, how often did you actually pull your hair?" Each item was rated on a 5-point Likert scale ranging from 0 to 4, where higher scores indicated more severe hair pulling behaviours. The total score was calculated by summing the participant's responses to all items. Based on Keuthen et al.'s (2007) study sample of self-reported hair pullers, a cut-off score of 17 was used to identify problematic hair pulling. The MGHHPS has been reported as having good internal validity ($\alpha = .80$).

Skin Picking Scale – Revised (SPS-R; Snorrason et al., 2012). This is a validated eight-item self-report measure of the severity of skin picking behaviour experiences over the past week. Items in this measure included, for example: "How much time do you spend picking your skin each day?" and "How much does your skin picking interfere with your social, work or role functioning?" Each item was rated using a 5-point Likert scale ranging from 0 to 4, where higher scores indicated greater severe skin picking behaviours. The total score was calculated by summing the participant's responses to all items. The SPS-R has good internal validity ($\alpha = .83$) (Snorrason et al., 2012).

Obsessive Compulsive Inventory – Revised (OCI-R; Foa et al., 2002). This is a validated 18-item self-report measure of the severity of obsessive-compulsive behaviours experienced over the past month. Items in this measure included, for example: “I find it difficult to control my own thoughts” and “I frequently get nasty thoughts and have difficulty in getting rid of them.” Items were rated using a 5-point Likert scale ranging from 0 to 4, where higher scores indicated more severe obsessive-compulsive behaviours. The total score was calculated by summing the participant’s responses to all items. Based on Foa et al.’s (2002) study sample, the optimal cut-off score for distinguishing between patients with and without OCD is 21. The OCI-R has good internal validity (α = .90) (Foa et al., 2002).

Depression Anxiety Stress Scale (DASS-21; Antony et al., 1998; Lovibond & Lovibond, 1995). This is a commonly used, validated 21-item self-report measure of depression, anxiety, and stress symptoms over the past week. For this study, only the depression and anxiety subscales were administered (14 items in total). The items were rated on a 4-point Likert scale, ranging from 0 (*did not apply to me at all)* to 3 (*applied to me very much or most of the time*); here, higher subscale total scores indicated more severe symptoms. Cronbach’s alphas for the depression and anxiety subscales are .94 and .87, respectively (Antony et al., 1998).

Health Online Support Questionnaire (Mattsson et al., 2015). The researchers adapted the original scale by Mattson et al. (2015) for the purposes of the current study. This 18-item self-report measure featured two subscales (“reading” and “interactive behaviours”) that asked about participants’ reasons for engaging in online peer support groups. Items in the reading subscale included, for example: “I participate in online peer support groups for obsessive-compulsive and related problems to read about other people’s experience of their condition”. Items in the interactive subscale included, for example: “I participate in online peer support groups for obsessive-compulsive and related problems to share practical advice and suggestions regarding my condition”. Participants responded on a 6-point Likert scale (1 = *strongly disagree*, to 6 = *strongly agree*). The reading and interacting subscales had nine items each and were summed to produce separate subscale scores. Cronbach’s alphas for the reading and interacting subscales were calculated for the current sample and found to be .76 and .78, respectively.

Online Peer Support Group Use Scale. This eight-item questionnaire was developed by the researchers to evaluate the amount of time participants spent “actively” and “passively” engaging with online peer support groups, like those hosted on social media platforms. Participants were advised that active use involved "any form of direct interaction with the platform's features and functions. For example, posting a status update, sharing links or photos, and commenting on friends' posts, or sending instant messages". Passive use was defined as "any form of indirect use, like browsing, reading, viewing and 'liking' posts. For example, passive use is any time you have scrolled through other people's posts, or looked at someone's pages, pictures or status updates without commenting or posting something yourself". Participants were asked to estimate what percentage of their use of online PSGs for OCRDs was active (Active Use variable) and what percentage of their use was passive (Passive Use variable) during the past week. Participants' total use percentage had to equal 100%.

Online Peer Support Group Experiences Questionnaire. This 15-item questionnaire was developed by the researchers to evaluate a range of both positive and negative experiences with using online PSGs, like those hosted on social media platforms. Eight of the 15 items corresponded to negative experiences, specifically: (1) cyberbullying; (2) being removed, blocked, or banned from the group; (3) worsening of OCRD symptoms; (4) anxiety; (5) distress; (6) anger; (7) guilt; and (8) frustration. These eight items formed the Negative Experiences subscale. Participants rated their negative experiences using a 6-point Likert scale ranging 0 (*never*) to 5 (*very frequently*). A total score was calculated by summing the scores from each item and a higher overall score indicated more frequent negative experiences with using online PSGs. Cronbach's alpha in the current sample was .88, indicative of good internal validity. However, its reliability is limited as it has yet to be extensively tested with other samples. The remaining seven items asked participants about positive and other specific experiences when using online PSGs (specifically; validation, sense of belonging, relief, hope for recovery, receiving advice about diets, supplements or medications), and were included so as not to bias participants' responses towards negative experiences.

Quality of Online Relationships Inventory (Pierce et al., 1997). This ten-item self-report questionnaire was adapted by the researchers for the purposes of the current study and measured the quality of relationships developed though online PSGs like those hosted on social media platforms. Items in this measure included, for example: “How much do you depend on these relations that you have developed though online peer support groups?” and “How positive a role do people you have met though online peer support groups play in your life?” Responses were made on 5-point Likert scale ranging from 0 (*no relationship*) to 4 (*very much*). A total score was calculated by summing the scores from each item and a higher overall score indicated a higher level of support from relationships formed through online peer support groups. Cronbach’s alpha for the current sample was computed as .94 indicative of good internal validity.

Interpersonal Support Evaluation List-12 (ISEL-12; Cohen et al., 1985). This is a validated 12-item short-form of the original 40-item ISEL scale. It is a measure of the quality of offline relationships and responses were made on a 4-point Likert scale ranging from 1 (*definitely false*) to 4 (*definitely true*). Items in this measure included, for example: “If I were sick, I could easily find someone to help me with my daily chores” and “If a family crisis arose, it would be difficult to find someone who could give me good advice about how to handle it” (reverse scored item). Six items in this measure were reverse scored and participants were given an overall score by summing the scores from each item. A higher overall score indicated a higher level of perceived support from “offline” relationships. Cohen et al. (1985) found the scale to have good internal validity ($\alpha = .86$).

Treatment Barriers Questionnaire (TBQ; Marques et al., 2010). This is a 17-item self-report questionnaire which evaluated individuals’ perceived barriers to treatment. Items in this questionnaire included, for example: “Health insurance would not cover treatment” and “I felt ashamed of needing help for my problem”. Instead of asking participants to endorse questionnaire items which were applicable to them, responses were made on a 4-point Likert scale ranging from 1 (*strongly disagree*) to 4 (*strongly agree*) for the purposes of this study. A total score was calculated by summing the scores from each item and a higher overall score indicated greater perceived barriers to treatment. This questionnaire was determined to have adequate internal validity in the current sample ($\alpha = .71$).

Internalized Stigma of Mental Illness Inventory-10 (ISMII-10; Boyd et al., 2014). This is a validated 10-item self-report measure of self-stigma and each item was rated on a 4-point Likert scale ranging from 1 (*strongly disagree*) to 4 (*strongly agree*). Items in this measure included, for example: “Mentally ill people tend to be violent” and “I can have a good, fulfilling life, despite my mental illness” (reverse scored item). Two of the ten items were reverse scored, and participants were given an average score based on their answered items. Based on their average score, participants were considered to have minimal (average score between 1.00 and 2.00), mild (average score between 2.01 and 2.50), moderate (average score between 2.51 and 3.00), or severe (average score between 3.01 and 4.00) internalised stigma based on their average score (Lysaker et al., 2007). Boyd et al. (2014) reported this scale as having adequate internal validity ($\alpha = .75$).

Open-ended qualitative questions. This qualitative questionnaire consisted of three items which allowed participants to elaborate on their experience with using online peer-support groups for OCRDs. The questions in this section were: (1) “What information, advice, or strategies have you benefitted from as a result of accessing online peer support groups for obsessive-compulsive related disorders?”; (2) “What information, advice, or strategies have caused you negative consequences as a result of accessing the online peer support groups for obsessive-compulsive related disorders?”; and (3) “If there is anything else you would like us to know about your experiences with these online peer support groups, please tell us more”.

Procedure

The survey was hosted on Qualtrics and the survey link was posted alongside the study advertisement. Participants were invited to click on the link, which directed them to the participant consent form. Participants were then required to read an information sheet and provide consent before they could start the survey. The information sheet outlined the study’s purpose and the benefits and potential risks of participation. Participants were also informed that their participation was voluntary and that they could withdraw from the study at any time. After participants provided consent, the survey was completed in their own time and took approximately 75 minutes.

Statistical Analysis

Data were analysed using the Statistical Package for Social Sciences (SPSS 26). Some variables, namely Negative Experience, Passive Use, and Active Use scores were operationalised based on participants' responses to the Online Peer Support Group Use Scale and the Online Peer Support Group Experiences Questionnaire (see Measures section for details). Correlations and hierarchical regression analyses were conducted to determine the predictors of negative experiences of online peer support groups for OCRDs.

Results

Descriptive Analyses

Of 90 participants who completed more than half of the survey, 36 participants (40.0%) indicated that they had never been part of an online PSG, so their data were excluded from analyses. Users (*n* = 54) and non-users (*n* = 36) of online PSGs did not differ in terms of OCRD symptom severity (MGHHPS, SPS-R, OCI-R, DASS-21) or other characteristics (TBQ, ISEL-12, ISMII-10).

Table 3 summarises the symptom severity of 90 participants who completed a majority of the survey. Twenty-eight participants (31.1%) reported MGHHPS scores which suggest problematic hair pulling and 43 (47.8%) reported clinically significant obsessive-compulsive symptoms (OCI-R). The mean SPS-R scores (skin picking symptom severity) of this sample were lower than that of a similar sample in Snorrason et al.'s (2012) study (*M* = 15.48, *SD* = 4.92). Twelve participants (13.3%) had DASS-21 anxiety scores in the "severe" range and 27 (30.0%) had scores in the "extremely severe" range. Twelve participants (13.3%) indicated DASS-21 depression scores in the "severe" range and 25 (27.8%) had scores in the "extremely severe" range. Participants reported reasonably high levels of "offline" interpersonal support (*M* = 35.64, *SD* = 7.53) and moderate barriers to treatment (*M* = 41.78, *SD* = 8.72). Thirteen participants (14.4%) reported moderate internalised stigma and one participant (1.1%) reported severe internalised stigma.

Table 4 describes the characteristic use of, and satisfaction with, social media PSGs for OCRDs across those who had used PSGs (*n* = 54). The majority of users reported accessing their peer support group(s) once a day (*n* = 26, 48.1%) or not at all (*n* = 9, 16.7%). On average, participants estimated that 5.9% of the time they spent on social media PSGs per week was "active use" while 86.9% was "passive use". Indeed, most participants (*n* = 35, 64.8%) reported that they had not actively engaged with their social media PSGs in the past week.

As shown in Table 5, the three most common reasons for accessing social media PSGs were to: (1) read about other people's experience of a treatment (*n* = 52, 96.3%); (2) read about other people's experience of their condition (*n* = 51, 94.4%); and (3) search for information that could improve their condition (*n* = 49, 90.7%). Based on advice encountered while engaging in social media PSGs for OCRDs, 20 participants (37.2%) reported having made changes to their vitamin or supplement intake (*n* = 15, 27.8%), medication regimen (*n* = 5, 9.3%) and/or to their diet (*n* = 6, 11.1%), with six participants making changes to more than one of these three areas. Of the 15 participants who made changes to their vitamin or supplement intake, five participants had consulted a health professional before making these changes. Of the five participants who made changes to their medication regimen, four had consulted a medical professional, and only one of the six participants who had made changes to their diet had consulted a medical professional.

Correlations

Bivariate correlations were carried out to determine the variables that should be entered into the regression model. Descriptive statistics and correlations for Negative Experience, OCRD symptom severity (MGHHPS, SPS-R, OCI-R, DASS-Anxiety, DASS-Depression), offline characteristics (ISEL-12, TBQ, ISMII-10), nature of social media PSG use (HOSQ-Reading, HOSQ-Interacting, Active Use, Passive Use), and quality of online relationships (QRI) are summarised in Table 6.

Treatment barriers (TBQ) were positively and moderately significantly correlated with Negative Experience scores. That is, as treatment barriers increased, so too did reports of negative experiences with social media PSGs for OCRDs. Offline interpersonal support (ISEL-12) and Passive Use scores were also negatively and moderately significantly correlated with Negative Experience scores. That is, poorer perceived interpersonal support and increased passive use of social media PSGs for OCRDs were associated with increased reports of negative experiences in these groups.

Social media PSG use characteristics (HOSQ-Reading, HOSQ-Interactive, Active Use, Passive Use) were not significantly correlated with OCRD symptoms (MGHHPS, SPS-R, OCI-R), internalised stigma (ISMII-10), or quality of online relationships (QRI).

Hierarchical Regression

Based on findings from the bivariate correlations, a three-stage hierarchical regression was conducted with Negative Experience as the dependent variable and TBQ, ISEL-12, and Passive Use scores as predictor variables. Preliminary analyses were conducted to ensure that assumptions of normality, collinearity, and homoscedasticity were not violated.

TBQ scores were entered at step one, ISEL-12 scores at step two, and Passive Use at step three. The regression statistics are reported in Table 7. Step one of the regression indicated that treatment barriers explained 13% of the variance in Negative Experience, $F(1, 48) = 7.38$, $p < .01$. After entry of ISEL-12 scores in step two, the model explained an incremental 7.2% of the variance in Negative Experience, $F(1,47) = 4.27$, $p < .05$. Finally, in step three, the addition of Passive Use explained an additional 1.6% of the variance in Negative Experience, although this change was not significant, $F(1,46) = 0.97$, $p > .05$.

Qualitative Analysis

Thematic analysis was conducted in parallel with the quantitative analyses, in order to contrast meaningful information that emerged from the data. The total participant responses ($n = 40$) across these items were subjected to theme extraction, consistent with Braun and Clarke's (2006) approach. Themes were coded based on participant responses. While most participants (*n* = 38, 95%) mentioned at least some positive aspect to their experience with social media PSGs for OCRDs, 19 responses (47.5%) were initially found to be predominantly negative in tone. Due to the data-rich material of these responses, and their confirmatory nature with respect to the quantitative analyses, the contents of these responses were explored in more depth. Nine initial codes were collapsed into two main themes (external and internal factors) which contained a total of five sub-themes: (1) confronting content; (2) misinformation; (3) social comparison; (4) feelings of hopelessness; and (5) preoccupation with symptoms. The sub-themes are summarised in Figure 1.

External factors. The first two of the sub-themes involved external. A number of participants indicated that confronting content posted by other users directly influenced their experience and led to unpleasant emotions. Some expressed that "seeing pictures of bald spots or close up hair follicles can be triggering for me". Participants also mentioned that misinformation was posted in their online peer support group, causing them confusion. One participant in particular mentioned that "it's hard to sort through what is evidence based and what is homeopathic".

Internal factors. The remaining three sub-themes identified involved internal factors. One sub-theme was that participants sometimes spent more time thinking about their OCRDs after using online peer support groups; as one participant reported, "thinking about it makes it worse at times". Another participant also reported feeling upset if they became preoccupied with their symptoms. Feelings of hopelessness was also a sub-theme; for example, one participant reported that using online peer support groups "makes me feel discouraged about permanent progress or remission". Using social media PSGs also led some participants to engage in social comparison, which often had negative consequences. As one participant described, "for a while, I haven't sought help because others describing their experiences has made mine feel less severe". Another participant mentioned that "I maybe feel ashamed or embarrassed that I can relate to these people that have it worse than I do".

Discussion

Individuals living with OCRDs can experience numerous barriers to finding evidence-based, accessible treatments and support in the community (Coles et al., 2013; Marques et al., 2010). This situation is influenced, at least in part, by stigma, trivialisation, and poor understanding about OCRDs among the public and health professionals alike (Marcks et al., 2006; Robinson et al., 2019). Online PSGs, like those hosted on social media platforms, have the potential to offer highly desired information (e.g., about symptoms, treatments, self-management strategies) and social support (e.g., companionship, understanding, emotional support) that may otherwise be difficult for people living with OCRDs to find offline. Despite this positive potential, accessing social media PSGs can also present a host of unique risks (Naslund et al., 2020). An in-depth investigation of user's experiences and challenges with online PSGs for OCRDs is lacking. The current study aimed to help bridge this gap by exploring the predictors of negative experiences when using online PSGs for OCRDs, like those hosted on social media platforms without moderation by trained volunteers, peer workers or health professionals. The study also sought to investigate users' perceived sources of negative experiences through the use of a parallel mixed-methods approach.

Predictors of Negative Experiences with Social Media Peer Support Groups

Barriers to treatment were shown to positively predict negative experiences when using social media PSGs for OCRDs, while quality of offline interpersonal support was found to be a negative predictor of such experiences. Treatment barriers (as measured by the TBQ; Marques et al., 2010) included cost, insurance coverage limits, accessibility issues (e.g., location, time commitment, and availability of preferred health professionals), personal shame and social stigma about seeking treatment, and low confidence in the effectiveness of treatment. The results suggest that those who experienced more of the above treatment barriers were more likely to have negative experiences when using social media PSGs for OCRDs. The results also indicated that participants who had lower levels of offline interpersonal support were more likely to have negative experiences in social media PSGs; here, interpersonal support (as measured by the ISEL-12; Cohen et al., 1985) included perceived access to others in their everyday lives who can provide tangible (instrumental) assistance, advice or guidance to support decision-making, and emotional support such as empathy, acceptance and a sense of belonging. Additionally, although passive use of social media PSGs was significantly and negatively correlated with negative experiences, it was not a significant predictor of such experiences above and beyond barriers to treatment and quality of offline interpersonal support. Overall, the findings suggest that participants who experience greater barriers to seeking mental healthcare and poorer social support are more likely to endorse negative experiences, such as distress, anxiety, frustration, symptom exacerbation, and cyberbullying, when using social media PSGs for OCRDs; regardless of whether their participation in these forums tends to be more passive than it is active.

While research that examines user characteristics and predictors of engagement in online PSGs for both physical and mental health issues is emerging (e.g., DeAndrea, 2015; Griffiths, Carron-Arthur, Reynolds, Bennett, K., & Bennett, A., 2017; Plinsinga et al., 2019; Chung, 2014), research that has specifically explored the predictors of *negative experiences* in such groups remains scant. Grounded in the uses-and-gratifications theory of media usage (Rosengren, 1974; Whiting & Williams, 2013), Chung's (2014) research investigated how participants' motivations to engage in online PSGs for cancer and diabetes affected their use patterns, and how those use patterns in turn influenced their "appreciation" of such groups. Chung found that participants who were interested in socialising with others were likely to engage actively by posting photos, videos, blogs, and use "befriending" features of social media platforms, while those who were interested in information-seeking were more likely to engage passively by browsing discussion board posts. Moreover, use of each of these features was related to participants' perceptions that participating in online PSGs could indeed satisfy their needs for emotional and/or informational support. Overall, participants' needs and motivations for accessing online PSGs were concluded to have a significant influence over their appraisals of such groups (Chung, 2014).

The current findings can similarly be understood by applying the uses-and-gratifications theory; participants' top three reasons for using social media PSGs for OCRDs were to: (1) read about others' experiences of a specific treatment, (2) read about others' experiences of living with their condition(s), and (3) search for information that could help improve their condition. Eighty-seven percent of participants' time spent on social media PSGs for OCRDs in the preceding week was passive (associated with information-seeking per Chung's 2014 research). Participants in the current study were clearly motivated to seek information online to help them better understand and manage their OCRDs. It may be that, in the context of greater treatment barriers and poorer quality offline supports, participants may not have been satisfied with the informational support they were hoping to gain in their social media PSGs, leading to negative experiences in these groups. Indeed, participants' satisfaction with their social PSGs for OCRDs was mixed, with 53.7% reporting they were either "partly" or "not at all" satisfied. Alternatively, a lack of offline professional and social supports to help buffer against any negative experiences encountered in participants' social media PSGs, such as misinformation or confronting content, may account for our findings, consistent with the social buffering hypothesis (Cohen & Wills, 1985).

Perceived Sources of Negative Experiences and Other Challenges

Thematic analysis of participants' qualitative responses revealed five sub-themes relating to perceived sources of negative experiences in social media PSGs for OCRDs: (1) confronting content; (2) misinformation; (3) social comparison; (4) feelings of hopelessness; and (5) preoccupation with symptoms. Many of these experiences and concerns have been identified in other studies of online PSGs for both physical and mental health issues (e.g., Griffiths et al., 2015; Hanley et al., 2019; Holbrey & Coulson, 2013; Kaplan et al., 2011; Salzer et al., 2010; Takahashi et al., 2009; van Uden-Kraan et al., 2008).

Participants reported that misinformation, or difficulty determining the quality of information and advice shared on their social media PSGs, created feelings of confusion. Participants also reported finding themselves spending more time thinking about their OCRD symptoms, which led to significant distress. This is understandable in the context of the high rates of information-seeking endorsed by the sample, including specifically when feeling worried about their condition (77.8%) and to guide them in making well-informed decisions (87%). Repetitive reassurance-seeking is a type of compulsion common to many OCRDs. Online, reassurance-seeking could take the form of repeated checking or searching for content, extensive reading and re-reading of others' comments, and explicitly asking for repeated reassurance about one's symptoms, experiences, treatment, or decisions (Vismara et al., 2020). It may be that confronting, conflicting or otherwise unsatisfactory information encountered on social media PSGs has the potential to fuel the obsessional worry, uncertainty or symptom preoccupation that people with OCRDs are trying to neutralise by accessing their PSGs in the first instance. Indeed, Vismara et al. (2020) proposed that a range of cognitive biases known to maintain OCRD symptoms, like anxiety sensitivity, intolerance of uncertainty, and catastrophising, may also maintain excessive online reassurance-seeking behaviours ("cyberchondria"). Another potential pathway to symptom exacerbation for those living with trichotillomania or excoriation disorder, specifically, may be social contagion; at least one participant described seeing images of group members' hair loss or tissue damage as "triggering" (it is unclear if the participant meant these images elicited distress and/or BFRB urges, however). While BFRBs are not considered a form of non-suicidal self-injury (NSSI), social contagion risk is a critical reason why sharing NSSI methods and images are actively discouraged and removed by many social media and other media outlets (e.g., Robinson et al., 2018). Social contagion risk in relation to sharing BFRB imagery online ought to be further investigated as a matter of priority.

Related to issues of misinformation is the issue of medical advice that may be disseminated in social media PSGs by non-physicians. Between 9.3% and 37.2% of participants agreed that they had made changes to their medications, vitamin or supplement intake, or diet based on information they encountered in their social media PSGs for OCRDs. Positively, the majority of these participants reported consulting a health professional before making such changes, although only one of six participants who had made dietary changes on the basis of forums advice reported seeking a health professional's advice. Bruwer and Stein (2005) noted similar issues in their survey of online mailing lists for people with trichotillomania. N-acetylcysteine (NAC), an off-the-shelf supplement that has shown mixed evidence for its efficacy in treating OCRDs (Ooi, Green, & Pak, 2018), is discussed among users of social media PSGs for these conditions. Even with its limited side-effects profile, social media PSG users must be encouraged to seek advice from a health professional prior to taking NAC. Discussions about NAC with a suitably qualified health professional can support individuals to understand the limitations of its effectiveness, clarify the evidence-based dosage, and mitigate against possible medication interactions of which users may not be aware. The dissemination of misinformation, in its various forms, is a unique challenge in social media PSGs that are not moderated by people who would otherwise remove content that could be considered, or misconstrued, as medical advice.

Exposure to a community of people experiencing the same conditions, some of whom had experienced OCRDs for many years, also led some participants to feel less hopeful about the prospects of long-term recovery. Definitions of recovery are highly personal and multi-faceted (van Weeghel, van Zelst, Boertien, & Hasson-Ohayon, 2019). For some, recovery goals are primarily focused on permanently eradicating unwanted symptoms, while others aspire to learn to live a personally meaningful, satisfying and contributing life, even with the presence and persistence of unwanted symptoms; there are, of course, "shades of grey" between those dichotomous examples. The nature of social media engagement, and features of the platforms themselves (e.g., asynchronous text-based communication, character limits, algorithms that "promote" some content and not others), may not be conducive to nuanced discussions about personal definitions of recovery. While peer support has the positive potential to inspire hope for recovery through upwards social comparison (Collins, 1996), the current findings indicate that there can be a risk of creating hopelessness and distress when incompatible or different definitions of recovery to one's own are encountered in a community that was otherwise anticipated to bring comfort through shared experience (Smith-Merry et al., 2018; Ziebland & Wyke, 2012). Here again is where the role of moderation can be helpful to maintain balanced, respectful, and inclusive discussion.

Issues of self-stigma noted in online PSGs for other mental health issues (Merry-Smith et al., 2018; Lawlor & Kirakawski, 2014) may also be relevant to participants' social comparisons and feelings of hopelessness. Self-stigma is the internalisation of negative stereotypes that devalue people with mental health issues, including but not limited to, the belief that one is not deserving of treatment or support because people with mental health issues cannot recover or get better. Lawlor and Kirakawski (2014) found that, particularly for passive users, participation in online PSGs for mental health issues did not support a reduction in self-stigma as hypothesised; instead, the opposite was found. Further, compared with active users, passive users were less likely to be engaged in formal supports, like those provided by mental health professionals. In light of these findings, Lawlor and Kirakawski proposed that dependency upon online PSGs may be a form of offline social avoidance that presents a risk of reinforcing self-stigma and its deleterious effects, such as delayed treatment-seeking. While the current study did not find a correlation between self-stigma and active or passive use of social media PSGs to OCRDs, this may be due to methodological differences in operationalising usage characteristics.

Relatedly, the belief that one's symptoms or experiences are not as severe as those of others, and therefore do not warrant treatment, is consistent with Suls et al.'s (1997) proposal that social comparison influences an individual's decision to seek treatment. In relation to the current findings, online PSG users who face significant barriers to treatment and have low levels of offline interpersonal support are likely to lack references, external to their PSGs, for evaluating the severity and impact of their OCRDs; usually, such references could be provided by health professionals, family members, intimate partners, or friends. Without the perspective of others external to the group – particularly from people who care for, value, and know the individual, offline – participants reliant upon social media PSGs may be more likely to engage in social comparisons that go "unchecked", potentially leading to a decision not to seek treatment in the community. Of note, the rate of treatment participation was 50% in the current sample. DeAndrea's

(2015) study of a large, nationally representative U.S. sample of help-seeking adults, in which both logistical and social stigma barriers to traditional mental health treatment were significant predictors of using online PSGs. However, as we did not explicitly ask participants to evaluate the severity of their OCRDs relative to that of their social media PSG members, nor whether their group experiences dissuaded them from treatment seeking, this suggestion requires further study. Future research could focus on how social comparison processes influence users' experiences with social media PSGs, including their influence on professional treatment seeking.

Implications of the Findings

Collectively, the findings of this study suggest that people living with OCRDs may be particularly vulnerable to the risks and challenges associated with participating in online PSGs; particularly those hosted on social media platforms without adequate support structures in place, such as online moderation, and access to offline professional and interpersonal supports. As such, it is crucial for health professionals to understand the potential negative experiences their patients or clients may encounter when participating in social media PSGs. Mental health professionals are especially encouraged to ask their clients who experience OCRDs about the information they have read about their condition and its treatment online, including about their experiences in social media PSGs specifically. Knowing about these experiences can present an opportunity to explore, clarify, and sometimes correct, what users of social media PSGs have learned about the prognosis and treatment of OCRDs; the diverse nature of symptom experiences; and about personal definitions of, and goals for, recovery. Health professionals are also encouraged to ask if their clients or patients have considered making, or actually made, changes to their medications, diet, or vitamin or supplement intake on the basis of information encountered in social media PSGs and refer to a suitably qualified professional if necessary. Users of social media PSGs may also require support to limit their use of such groups if symptoms have become exacerbated, or if they have experienced distressing online interactions such as cyberbullying. Similarly, users may require support to block or report inappropriate content or other users. For clients whose online information-seeking has become excessive, psychoeducation and formulation-driven use of cognitive-behavioural therapies, as similarly used for reassurance-seeking compulsions, may be useful (Vismara et al., 2020).

Additionally, understanding the risks and challenges that people with a range of mental health issues, including OCRDs, might face when seeking information or support via social media can aid mental health professionals, researchers, organisations, policy-makers, and governments to advocate for social media platforms to update their policies and content moderation guidelines. Such advocacy efforts have facilitated the development of a suite of reporting and notification methods for supporting Facebook users who may be at risk of suicide (de Andrade, Pawson, Muriello, Donahue, & Guadagno, 2018), while Instagram have implemented content policies that restrict the promotion of weight loss and cosmetic surgery to support the wellbeing of young people who may be vulnerable to body image issues (The University of Sheffield, 2019). Collaboration with users of social media PSGs for OCRDs, as experts by lived experience, is also important to ensure policies, safeguard mechanisms, information campaigns, content moderation guidelines, and other resources are maximally useful and appropriate (e.g., Thorn et al., 2020). For instance, resources designed by, and for, people with lived experience of BFRBs to establish and facilitate their own face-to-face PSGs (Robertson & Raikes, 2018) may be adapted for use in social media contexts.

Peer support is central to recovery-oriented approaches to mental healthcare, which seeks to respect and empower people to identify their strengths, needs, and preferences for relating to, and coping with, their mental health issues (van Weeghel et al., 2019). As such, our position is not that social media PSGs should *not* be accessed by people living with OCRDs nor that such groups *must* be moderated by health professionals. Rather, the key is to ensure that users of social media PSGS are: (1) informed about the benefits, risks, and limitations of accessing peer support via these mediums, and (2) have access to efficient and effective mechanisms that can assist in safeguarding their own and others’ wellbeing when harmful content is encountered, or other negative experiences become apparent. Given that treatment barriers were found to be a significant predictor of negative experiences when using social media PSGs for OCRDs, there is an opportunity for mental health professionals, social media platforms, and social media PSG users to work together to ensure that users can access reliable information about evidence-based treatment and how to seek help from reputable healthcare providers, if and when these forms of support are desired.

Limitations of the Current Study

This study is not without limitations. Despite targeted recruitment via organisations and social media forums that offered peer support for OCRDs, 40% of the sample indicated that they had never participated in an online PSG so their data were excluded from analyses. While there were no differences between online PSG users and non-users, the treatment seeking experiences, interpersonal support, internet/computer literacy, clinical characteristics, and sociodemographic characteristics may systematically differ between those 54 participants whose data were analysed compared with the broader population of people living with OCRDs. Additionally, answering the qualitative questions were optional, meaning it is possible that those who volunteered responses had unique experiences in social media PSGs that they felt compelled to share. Furthermore, a large majority of the participants resided in the United States, which has a vastly different healthcare system as compared Australia and Canada, where most of the remaining participants resided. The overrepresentation of participants from one country makes it difficult to generalise the findings of this study across geographical regions. It is also important to note that several of the measures used were either adapted from previously validated measures or developed bespoke for the purposes of the study. While all novel measures had acceptable internal reliability in the current sample, they do require psychometric validation. The findings of the current study should therefore be considered preliminary and warrant further investigation. Finally, it was beyond the aims of the current study to investigate the unique benefits that people living with OCRDs encounter in their social media PSGs, and this should also be examined in future research.

Conclusions

The results of the current study demonstrate that, for people living with OCRDs, barriers to treatment and poor interpersonal support offline predict negative experiences in social media PSGs. These findings suggest that using social media PSGs for OCRDs without adequate support structures in place offline, such as a strong social support network and professional mental healthcare, may place users at greater risk of a range of negative experiences. Qualitatively, themes of confronting content, misinformation, social comparison, feelings of hopelessness, and preoccupation with symptoms were identified as important contributors to such negative experiences. Many of the findings of this study are consistent with those of previous studies, although, to our knowledge, the current study was the first to investigate predictors of negative experiences in social media PSGs that are accessed specifically by people living with OCRDs. Further research, and collaboration between multiple stakeholders, is necessary to develop resources, content moderation guidelines, and reporting mechanisms that may strike a balance between safeguarding participants' wellbeing and their right to autonomous access to preferred supports, which may leverage the positive potential of online peer support for OCRD recovery.

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Table 1

Demographic Characteristics of Participants (*n* = 90)

	N	%
<u>Country of residence</u>		
United States	52	57.8
Australia	13	14.4
Canada	12	13.3
Germany	2	2.2
Switzerland	2	2.2
United Kingdom	2	2.2
Denmark	1	1.1
New Zealand	1	1.1
Norway	1	1.1
Romania	1	1.1
Slovakia	1	1.1
Wales	1	1.1
Not specified	1	1.1
<u>Highest level of education</u>		
Secondary school	19	21.1
Apprenticeship/trade certificate	3	3.3
Diploma	13	14.4
Undergraduate degree	39	43.3
Postgraduate degree	16	17.8
<u>Employment</u>		

Employed Full Time	53	58.9
Employed Part-Time/Casually	9	10.0
Student	18	20.0
Home or caring duties	4	4.4
Disability Support (pension)	1	1.1
Unemployed	3	3.3
Unemployed and actively seeking work	2	2.2
Relationship status		
Married	23	25.6
Single	30	33.3
In a de facto relationship (i.e., living together)	26	28.9
In a relationship but not living together	11	12.2

Table 2

Mental Health Characteristics of Participants (*n* = 90)

	N	%
Self-reported lifetime experience of mental health condition		
Obsessive-compulsive disorder	37	41.1
Trichotillomania	49	54.4
Excoriation	58	64.4
Depressive disorder	56	62.2
Anxiety disorder	71	78.9
OCRD diagnosis status		
Never been diagnosed	52	57.8
Formal diagnosis by mental health professional	48	42.2
Current treatment status		
Not in treatment	45	50.0
Currently in treatment	45	50.0
Current health professionals engaged		
General practitioner	23	25.6
Psychologist	17	18.9
Psychiatrist	19	21.1
Counsellor	8	8.9
Social worker	3	3.3
Current augmentative supports engaged		
Peer support service or group	15	16.7
Internet-based counselling or self-help service	15	16.7
Smartphone app for mental health	16	17.8

Self-help book	9	10.0

Table 3

OCRD Symptom Severity (*n* = 90)

	Minimum	Maximum	*M*	*SD*
MGHHPS	0.00	26.00	9.03	8.92
SPS-R	0.00	26.00	12.03	8.19
OCI-R	2.00	60.00	22.54	13.54
DASS Depression	0.00	42.00	19.02	12.51
DASS Anxiety	0.00	38.00	13.71	9.74

Note. M = mean, *SD* = standard deviation.

Table 4

Online Peer Support Group Use Characteristics and Satisfaction (N = 54)

	Frequency	%
Length of online support group use		
Less than one month	12	22.2
Between one and six months	17	31.5
Between six months and one year	6	9.2
Between one and two years	12	22.2
More than two years	8	14.8
Usage time per week		
Less than 30 minutes	27	48.1
Between 30 and 60 minutes	17	31.5
Between 60 and 90 minutes	3	5.6
Between 90 and 120 minutes	4	7.4
Between 120 and 180 minutes	0	0.0
More than 180 minutes	3	5.6
Frequency of passive use per week		
None	2	3.7
One or two times	9	16.7
Three or four times	12	22.2
Five or six times	11	20.4
Seven or eight times	7	13.0
Nine or ten times	12	22.2
More than ten times	1	1.9
Satisfaction with online PSG experience		

Not at all satisfied	2	3.7
Partly satisfied	27	50.0
Satisfied	22	40.7
More than satisfied	2	3.7
Very satisfied	1	1.9

Table 5

Health Online Support Questionnaire (*N* = 54)

	Frequency	%
Reasons for accessing online PSGs as endorsed by participants[a]		
To search for information that can improve my condition.	49	90.7
To share information about a treatment that I've been through.	22	40.7
To share information about lifestyle changes that I've tried.	20	37.0
To read about other people's experience of their condition.	51	94.4
To read about other people's experience of a treatment.	52	96.3
To be able to make more well-informed decisions regarding my condition.	47	87.0
To share practical advice and suggestions regarding my condition.	29	53.7
To search for information that enables me to better understand treatment providers (e.g. GPs, psychologists, psychiatrists etc.).	33	61.1
To search for information/recommendations about treatment providers who are experienced in obsessive compulsive and related conditions.	29	53.7
To search for encouragement from others when I'm having difficulty with my condition.	44	81.5
To search for encouragement from others when I'm experiencing obsessions, compulsions, or in-the-moment urges to engage in compulsive/repetitive behaviour.	34	63.0
To express my opinion regarding health care.	15	27.8
To seek out others' compassion when I'm not feeling well.	23	42.6

To get feedback from others who have, or have had, the same condition as me.	35	64.8
To search for information when I feel worried.	42	77.8
To get feedback from other members of the online support group on how I’m handling my condition.	19	35.2
To search for the latest research regarding my condition.	40	74.1
To find out whether the symptoms that I’ve experienced or am experience are dangerous or not.	28	51.9

Note. [a]Participants were considered to have endorsed a reason for accessing online PSGs of they responded *slightly agree*, *agree* or *strongly agree* to a questionnaire item.

Table 6

Correlations for Study Measures

Measure	1.	2.	3.	4.	5.	6.	7.	8.	9.	10.	11.	12.	13.	14.
1. Negative experience	–	.08	-.08	.27	.23	.26	-.30*	.36*	.19	.04	.07	.16	.12	-.29*
2. MGHHPS		–	-.48**	.07	.02	-.03	.03	.90	.03	-.24	-.02	.03	-.17	.09
3. SPS-R			–	.03	.21	.24	-.02	-.12	.20	-.04	-.03	-.04	-.25	.06
4. OCI-R				–	.60**	.38**	-.23	.30*	.34*	.13	.07	.21	.17	.004
5. DASS-Anxiety					–	.60**	-.20	.34*	.46**	.34*	.38**	.51**	.17	-.14
6. DASS-Depression						–	-.30*	.45**	.59**	.19	.30*	.35*	.13	-.19
7. ISEL-12							–	-.12	-.23	.07	.09	.09	-.01	.34*
8. TBQ								–	.56**	.26	.27	.26	.23	-.24
9. ISMII-10									–	.19	.24	.30*	.06	-.13
10. QRI										–	.49**	.47**	.57**	-.20
11. HOSQ-Reading											–	.86**	.32*	-.24
12. HOSQ-Interacting												–	.27	-.24
13. Active use													–	-.31*
14. Passive use														–

Mean	14.55	7.92	12.08	22.85	12.15	18.22	35.67	42.69	2.00	5.52	36.51	35.02	5.87	86.91
SD	7.59	8.28	8.41	12.99	8.72	12.30	7.11	9.41	.51	7.75	8.05	8.04	11.96	26.88

**$p < .01$ (2-tailed), *$p < .05$ (2-tailed)

Table 7

Summary of Hierarchical Regression Analysis for Variables Predicting Negative Experience

	b	*SE b*	β
Step 1			
Constant	1.07	4.98	
TBQ	.31	.11	.36**
Step 2			
Constant	12.18	7.22	
TBQ	.28	.11	.33*
ISEL-12	-.28	.14	-.27*
Step 3			
Constant	14.78	7.69	
TBQ	.26	.11	.31*
ISEL-12	-.23	.14	-.23
Passive use	-.04	.04	-.14

Note. R^2 = .13 for Step 1: ΔR^2 = .07 for Step 2 (*ps* < .05). R^2 = .20 for Step 2: ΔR^2 = .02 for Step 3 (*ps* > .05),

$^{**}p < .01$, $^{*}p < .05$

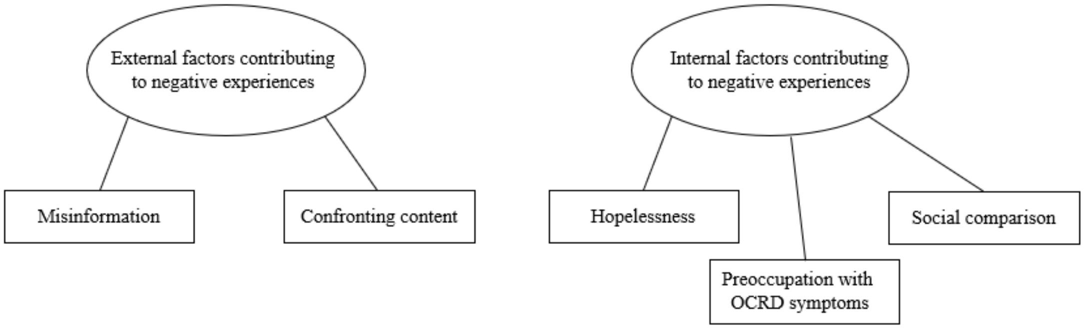

Figure 1. Thematic map of sources of negative experiences. Based on Braun and Clarke’s (2006) method of thematic analysis, two main themes and five sub-themes were identified from participants’ responses.