# "I'm so OCD!": A Qualitative Study Examining Disclosure of Obsessive-Compulsive Disorder

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# ABSTRACT

The following study explored how individuals with OCD communicate and disclose information surrounding the disorder. Twelve participants (ages 18-28) who self-identified as having OCD engaged in semi-structured interviews. Eleven interviews were conducted via WebEx and Zoom, and one interview was designed in a collaborative Google Document. All interview transcripts were analyzed using thematic analysis. Results from the study revealed that the stigmatization and misunderstanding of OCD had both a positive and negative influence on disclosure. For some, the misrepresentation of OCD encouraged individuals to educate the public and break the stereotype. Furthermore, the results provided consequences to not representing the reality of OCD. Individuals reported that the lack of correct OCD portrayals and messages in society subsequently led to an unawareness of self, avoidance of treatment, and concealment of the disorder. Additionally, the results were also explained using Communication Privacy Management (CPM) Theory. Individuals did not explicitly create boundaries before disclosing their OCD and they established privacy control by defining their OCD through labels and falsehoods. **Keywords:** Obsessive-Compulsive Disorder (OCD), stigma, privacy, mental health, disclosure

# INTRODUCTION

Due to misunderstandings of what Obsessive-Compulsive Disorder (OCD) is, it is often viewed as a "joke condition" (Fennell & Liberato, 2007, p. 317). This collective misconception is often expressed when individuals teasingly label themselves or others as OCD, with behaviors such as organizing or cleaning. Through this problematic societal discourse, the truth of the disorder has become more stigmatized and oftentimes, unknown. While individuals may poke fun when they notice an item is out of symmetry or that their excessive cleaning is due to their "OCD", this is not the full reality of the disorder. In actuality, OCD is categorized by obsessions, compulsions, and intrusive thoughts. According to the American Psychiatric Association (2013), "Obsessions are repetitive and persistent thoughts (e.g., of contamination), images (e.g., of violent or horrific scenes), or urges (e.g., to stab someone)" (p. 238). The obsessions are intrusive as they have the ability to create considerable mental discomfort. In response to the anxiety-inducing thoughts or urges, individuals will either suppress the obsessions or perform compulsions for relief. However, the American Psychiatric Association (2013) states that "these compulsions either are not connected in a realistic way to the feared event (e.g., arranging items symmetrically to prevent harm to a loved one) or are clearly excessive (e.g., showering for hours each day)" (p. 238).

In order to understand the misinterpretation and stigmatization surrounding OCD, further research is required to examine the discourse about it. Therefore, the purpose of this study is to understand why and how individuals choose to disclose their OCD, what factors inhibit interpersonal communication surrounding OCD, and the ways individuals choose to disclose their private information around the topic. By starting a conversation about the reality of OCD, this research will help project the truth about the disorder, as well as to improve dialogue about it. Those who suffer from OCD are well served to have reduced stigmatization and better understanding of it when discussing their mental health in interpersonal relationships. In order to support this goal, the following study utilized the communication privacy management (CPM) theory, developed by Petronio (2015), which served as a lens to understand how the stigmatization and misconception of OCD has challenged interpersonal conversations and as well as the effect it has on one's internal dialogue.

# LITERATURE REVIEW

Although there is a lack of research regarding communication about OCD, there is a large collection of previous findings involving the topic of mental health disclosure. Mental health research often refers to anxiety, depression, suicidal ideation, and PTSD. While this research is important and serves a purpose for the current study, Obsessive-Compulsive Disorder differs from other mental health disorders and needs further investigation.

Therefore, the literature here will define OCD, observe how the communication privacy management theory is effective in studying the topic, and how an individual may favor or be opposed to mental health disclosure.

## Obsessive-Compulsive Disorder (OCD)

OCD is characterized through heightened anxiety caused by intrusive thoughts or obsessions. Fennell and Liberato (2007) clarify that these unwanted thoughts are said to feel "somewhat alien, yet also feel real" (p. 315) and can include violent and sexual topics. The intrusive feelings can cause distress as those with OCD "wonder if the thoughts indicate some deep-felt urge, if they will act on their thoughts, and so on" (Fennell and Liberato, 2007, p. 315). While there are several different kinds of obsessions, common themes can include the recurring thoughts of harming oneself or others, a feeling of contamination, and precision concerns and/or hoarding (Stein, 2002).

In order to reduce anxiety developed from these obsessions, individuals perform repetitive actions, otherwise known as compulsions (Stein, 2002). According to the American Psychiatric Association (2013), compulsions are categorized as "repetitive behaviors (e.g., washing, checking) or mental acts (e.g., counting, repeating words silently) that the individual feels driven to perform in response to an obsession or according to rules that must be applied rigidly" (p. 238). Of these compulsions, contamination, constant checking, and the fear of harm to self or others are the most frequent symptoms of OCD (Stein, 2002).

While obsessions and compulsions regarding contamination and harm are more commonly known, there are several other subtypes of OCD as well. For example, Doron et al. (2013) discovered that those who experience Relationship Obsessive-Compulsive Disorder (ROCD) may have excessive doubts about their relationship and enact symptoms such as "repeated checking (e.g., of one's own feelings), comparisons (e.g., of partners' characteristics with those of other potential partners), neutralizing (e.g., visualizing being happy together) and reassurance seeking" (p. 169). Additionally, Zambaldi et al. (2009) conducted a study that focused on postpartum OCD and discovered that new mothers who had OCD were nine times more likely to experience aggressive obsessions than a mother who did not have OCD. Zambaldi et al. (2009) discussed the mother's fear of harming the newborn with thoughts such as "dropping the baby on the ground, putting them in the microwave oven, dropping the newborn in the water when crossing some bridge, throwing boiling water over the baby, or had violent horrific images of the baby dying from suffocation or falling down the stairs" (p. 505). Overall, while there are several types of OCD, all types include an underlying factor of fear or doubt that ignites the intrusive thoughts, and in turn, compulsions are performed in hope for alleviation.

While behaviors are executed to reduce the distressed feeling that comes from intrusive thoughts, the relief is brief, which causes the cycle of obsessions and compulsions to be ongoing and time-consuming for individuals. According to the National Institute of Mental Health (2019), those with OCD spend "at least one hour a day on these thoughts or behaviors" which may negatively impact their daily life. Generally, it can be frustrating and embarrassing for an individual with OCD to act on their compulsions because they are aware that their behaviors and thoughts are illogical.

The misinterpretation of the disorder may be traced to media representation, as oftentimes people rely on what the media displays for their understanding of OCD. Learning about OCD through media portrayals can provide benefits as well as consequences. On the constructive side, media viewers who have OCD may benefit by seeing actors who exhibit similar symptoms, and through this, the media acts as a learning tool (Fennell & Boyd, 2014). However, the stereotypical OCD behaviors shown in the media also have the ability to lead individuals to remain undiagnosed for years and ultimately further the misconception (Fennell & Boyd, 2014). In order to understand how OCD is often distorted in media and society, Fennell and Boyd (2014) performed qualitative research with participants who were either diagnosed with OCD, believed they had OCD, and/or hoarded, to discuss how TV shows and movies represent the disorder. The portrayals of individuals with OCD were "unpredictable, aggressive, and untrustworthy" (p. 683), and that there was more to the character than just those negative traits. The characters in the media with OCD were portrayed through humor, as they were often joked with or mocked by other characters. The participants in the Fennell and Boyd (2014) study were divided on their reactions. Some reported a neutral reaction, saying that the representation of OCD was presented as a joke to amuse viewers, while others did not agree with this portrayal and stated that the images do not display the truth about OCD and could further stigmatize the disorder.

Fennell and Boyd (2014) explained that even now "society views OCD as less serious and potentially less stigmatizing, or at least stigmatizing in a different way, from mental disorders in general" (p. 674). Robinson et al. (2017) discovered that the stigma surrounding OCD led to participants facing internal debate thinking of the consequences of possible disclosure. Emergent themes from this research included the fear of having OCD on a medical record, desire to shield one's family, and the dread of disclosing the disorder. The reluctance for disclosure

was often due to participants convincing themselves their OCD was manageable, that they did not "deserve treatment" (p. 202), and that they never thought of receiving help (Robinson et al., 2017).

This stigmatization is amplified through how characters with OCD in the media seek treatment. Fennell and Boyd (2014) revealed that in the media, characters with OCD did not seek treatment as they were "victimized by healthcare professionals" (p. 683). The portrayal of healthcare professionals being dangerous reinforces the perception that individuals with OCD do not need treatment, as well as making those with OCD fearful of seeking help. Overall, the study performed by Fennell and Boyd (2014) provides insight that while individuals recalled the benefit of utilizing media images for "self-diagnosis and informative purposes" (p. 683), others were "concerned that the media only shows a limited range of thoughts/behaviors as OCD, thereby stereotyping the disorder" (p. 675). Mediated messages about OCD can continue to stereotype that the disorder is not serious, and these false messages can be harmful to the viewer. However, it could be beneficial in the process of self-discovery as a source of information for viewers to understand their mental health. Overall, the stigmatization of OCD, as well as the portrayal, may lead to a lower likelihood of disclosure due to the general misunderstanding of the disorder. Thus, in order to understand how individuals, share their OCD and enact privacy boundaries, the communication privacy management theory is utilized as a framework.

### Communication Privacy Management Theory

The ways in which individuals control disclosure of private information was examined closely by Sandra Petronio, who developed the communication privacy management (CPM) theory (Petronio & Bantz, 1991). Hammonds (2015) explains the theory as a "systematic process that articulates how individuals obtain, control, negotiate, and manage their private information" (p. 592). The theory is summarized into four central characteristics.

First, Petronio (2015) articulates that the theory "assumes that regulating privacy access or protection is best explained as dialectical; that is, people need to be both social and autonomous simultaneously" (p. 2). This demonstrates that there is a choice of communicating with others while wanting to keep personal autonomy. Analyzing the desire to disclose, while also concealing, is relevant in the current research to understand how individuals with OCD create and maintain interpersonal boundary control.

Next, Petronio (2015) explains how the CPM theory encapsulates privacy regulation, stating "people believe they rightfully own their private information, even after they tell others or grant access to others" (p. 2). Hall (2020) discovered that within friendships, participants did not create explicit boundaries when disclosing their mental health. This was because friends did not perceive there to be any conflict once the private information was disclosed. Questions about interpersonal privacy regulation in the current study may support or contradict these findings. Additionally, since Hall (2020) did not specifically focus or mention OCD as a mental health disorder that was being disclosed between friends, it is valuable to study how OCD can change or confirm this previous research.

Third, Petronio (2015) describes how "the management of ownership and control over information is through the use of 'privacy rules'" (p. 2). Privacy rules are not rigid, as they can be flexible in order to support the required outcome of any interaction (Petronio, 2015). There are two types of criteria for privacy rules: core and catalyst. Braithwaite and Schrodt (2015) explain core criteria as "more durable, at times, functioning in the background and include criteria such as culture, gender, and privacy orientations" (p. 338). Catalyst criteria is when privacy rules are "responsive to needed change" (Braithwaite & Schrodt, 2015, p. 339). These adaptations can be due to risk-benefit fluctuations, changing situations that require different privacy rules, or when the motivations for disclosure or concealment is altered (Braithwaite & Schrodt, 2015). Overall, both core and catalyst criteria operate to understand how individuals utilize privacy rules to maintain boundaries within interpersonal relationships. Understanding privacy rules is important in the context of OCD disclosure in order to identify how individuals control their private information on a stigmatized topic.

Lastly, CPM theory states that individuals will create boundaries based on what is deemed private information. Petronio (2015) explains how the boundaries are labeled as "'thick' when people are less likely to reveal information or 'thin' when there is a higher possibility of people disclosing or allowing access" (p. 2). The boundaries, similar to privacy rules, are able to shift from allowing access to information to denying access, based on the degree of vulnerability of the discloser. Individuals may be more likely to share their story of OCD with certain people over others, which reveals information on how trust within an interpersonal relationship impacts disclosure.

The CPM theory is additionally defined through three axiomatic maxims (Braithwaite & Schrodt, 2015): privacy ownership, privacy control, and privacy turbulence. Privacy ownership, as Petronio (2015) explains, "regulates the parameters of the way people define their private information" (p. 2). Individuals make the personal decision to disclose or hold their information from others. When revealed, the receiver becomes a co-owner of the

disclosed information. Privacy control is when the owner of the information directs how the private information is being managed, likely through privacy rules. However, if those rules are unsuccessful, unclear, or unmet, turbulence may occur.

Privacy turbulence refers to a situation where disclosed information is repeated without permission (Braithwaite & Schrodt, 2015). Due to privacy rules being violated, the owner of the disclosed information may change privacy boundaries and rules toward the initial receiver, as perceived trust may be broken. Petronio (2015) states that, "If privacy turbulence occurs within a valued interpersonal relationship, the consequences grow to be more problematic because the level of trust the original owner assumed likely would be seen as misguided" (p. 6). Hall (2020) discovered that friendships often encountered confidant privacy dilemmas, which involves a situation where the receiver repeated the private shared information to get the assistance, *they* needed to handle the situation. Although some disclosers felt violated, some did not once they understood why another party was involved. Researching how privacy turbulence plays a part in the disclosure of OCD is valuable in informing how this disorder and disclosure impacts mental health, personal wellbeing, and relationships.

Since OCD is a stigmatized and silenced topic, it is beneficial to research the motivations and limitations individuals encounter when handling the aspects of privacy rules, boundaries, and ownership. Furthermore, to understand how individuals navigate privacy boundaries, the factors for and against disclosing information about mental health are explored.

#### Mental Health Disclosure

As previously described, interpersonal disclosure about OCD is often avoided due to the fear of anticipated stigmatization (Fennell & Liberato, 2007). Investigating how stigmatization affects one's social identity, Goffman (1963) wanted to understand the feelings of an individual who is perceived as odd in society. Overall, the research performed by Goffman (1963) provided an early awareness into additional OCD research. Goffman (1963) developed the term "passing" to describe the phenomenon where someone who is stigmatized hides their identity to blend in with others. However, passing can fail if a person does not appear natural in the environment. The inability to pass was displayed in the research findings conducted by Fennell and Liberato (2007), where participants recalled creating "alternative, less stigmatizing, explanations for their behavior" (p. 318). Many participants explained that if they needed to explain how their time is spent or what they were actually doing, the compulsions were covered with excuses. Some excuses seemed natural, as Fennell and Liberato (2007) explained how one participant said her "excessive hand washing is assumed to be natural for her job as a nurse" (p. 318).

According to Fennell and Liberato (2007), individuals with OCD may attempt to pass due to "fear of themselves (self-stigma) and fear of stigma from others" (p. 319). While participants recalled trying to fit in within public settings, they also recorded that, due to self-stigma, they would try to convince themselves that they do not have OCD and are like other "normal" people (Fennell & Liberato, 2007). One participant managed this act by avoiding information about OCD and resisting a diagnosis (Fennell & Liberato, 2007). Ultimately, while passing can be performed for the sake of commonality, to not upset a family member, or for fear of anticipated stigma, it also has the ability to harm the individual who would otherwise benefit from receiving support. By attempting to pass, individuals are conforming to what society expects for OCD, silencing voices even further. Understanding how self-image, as well as the anticipated stigmatization from others, impacts one's ability to pass is a point of interest for the current study.

In determining why an individual may disclose or hide their mental health, it is important to understand that there are influences from social, personal, and cultural factors. One influence is the quality of an interpersonal relationship. For instance, Fennell and Liberato (2007) discovered that there is more confidence to disclose information when there is assumed positive feedback. An assumed negative response from a trusted source can deter someone from disclosing information. Fennell and Liberato (2007) state that the Internet has become a place for self-discovery and provides positive feedback for individuals as there is an online OCD community that respondents saw as powerful since it provided "a sense of a shared identity" (p. 321) and was place to avoid stigma.

**Social Media and Mental Health Disclosure.** With different social media platforms rising in the digital age, individuals are able to anonymously interact and connect with others. Mickles and Weare (2020) measured how a pair of YouTube gamers are able to create a sense of community through self-disclosure by allowing subscribers to comment on their videos discussing the topic mental health. Mickles and Weare (2020) focused on the YouTubers "Game Grumps" and their video "Wind Waker HD: Fresh Air—Part 19—Game Grumps" where the creators explained their experience with their own mental health. The research demonstrated that by commenting anonymously, participants felt more at ease due to the reduced risk of discovery. Additionally, Mickles and Weare (2020) discovered that the disclosures in the comment section "led to the development of a community of peer-to-

peer support" (p. 240). This social support led many participants to explain how online anonymous interaction became a starting point for self-disclosure and to some, online anonymity was preferred over seeking professional medical help.

Yeo (2020) examined social media anonymity and mental health in Hong Kong. By studying how secondary students utilized a Facebook page named "School Secrets", Yeo (2020) was able to learn, through anonymous comments, how the students communicated to others about their reality through mental health disruption. From the findings, Yeo (2020) uncovered that the posts displayed themes of masking unhappiness and distress with a forced joyful demeanor. Yeo (2020) explained how the students "often frame their distress nondisclosure virtuously as not wanting to be a burden to their family members or make them worry" (p. 4). Similar to the findings that were conducted by Mickles and Weare (2020), Yeo (2020) revealed that personal narratives expressed a "lack of trust or rapport with professionals – social workers and doctors – who were often depicted as trivializing, dismissive, and disrespectful" (p. 5). Yeo (2020) also explained how the culture of mental health in Hong Kong varies from the United States as Chinese culture views suicide and self-harm as "irresponsible acts" (p. 5). Therefore, cultural expectations surrounding mental health in Chinese culture reinforces the importance of anonymous discussions among individuals. Although there may be a difference in cultural communication regarding mental health disclosure, the study conducted by Yeo (2020), as well as Mickles and Weare (2020), demonstrates that anonymous disclosure can be effective in understanding societal expectations surrounding mental health, connecting with others, and provide an intrapersonal perspective of mental health battles.

**Mental Health Disclosure to Family and Friends**. While online anonymous disclosure has the opportunity for building community, face-to-face interpersonal disclosure involves more risk. Hall (2020) investigated how individuals with mental health conditions managed privacy boundaries between friends. Participants reported several different mental health conditions, although OCD was not one of them. They reported that opening up to their friend about their mental health was not immediate (Hall, 2020). The study demonstrated how important friendship disclosure was to the participants as the individuals longed for "support seeking" (Hall, 2020, p. 29) and not information about their mental health. In fact, participants stated that if they did not receive support, and were instead told information surrounding their mental health situation, they were frustrated, as they understood what resources were available to them (Hall, 2020). Additionally, participants explained that life circumstances, as well as anticipated trust from the friend, were crucial to consider before disclosing any information (Hall, 2020).

Hall (2020) noted that "most of the participants did not explicitly create boundaries" (p. 32) when disclosing their mental health within friendships. The lack of privacy boundaries was not a dilemma since there was already inferred trust between the friends. Boundaries became turbulent within the friendship if the confidant would involve a third party for further support. As previously mentioned, this is an example of confidant privacy dilemmas, which is classified under the CPM theory. Hall (2020) described this phenomenon as where "...the confidant, or receiver of the information, is unsure how to handle the situation, and the confidant may need further assistance outside of their abilities in handling the disclosure" (p. 32). While some participants recorded feeling primarily upset over the privacy dilemma, the discloser became overall satisfied with the confidant's actions after understanding why another party was involved. Overall, the study by Hall (2020) indicates that friendship disclosure is important, as relief was the first emotion felt by participants after unveiling their private information.

Regarding familial disclosure, Fennell and Liberato (2007) analyzed participant's personal stories after revealing their OCD to their family. One participant recorded that when he was living at home, his family would be frustrated with the amount of time he spent in the bathroom. However, "5 years after leaving home, he gave his family information about OCD and the family have been somewhat more understanding" (Fennell & Liberato, 2007, p. 316). In order to understand why young adults keep private information from their parents, Hammonds (2015) discovered three prominent motivations which were "(a) family relational culture, (b) quality of relationship, and (c) relational risk" (p. 607). The research also discovered that if there was a strong perceived degree of open communication within the family, there was more of a chance for personal disclosure (Hammonds, 2015). However, a better-quality parent-child relationship may stray the child from disclosure as to not endanger their strong relationship (Hammonds, 2015). This information is valuable as it questions the likelihood of disclosure within strong familial relationships. Overall, with the data from Hammonds (2015) and Fennell and Liberato (2007), it is important to understand why individuals with OCD struggle to disclose their disorder to their family in order to destigmatize and optimistically have valuable conversations within the familial environment.

## **METHODS**

To provide a deeper understanding of OCD disclosure, the study applied the interpretivist paradigm through qualitative interviews. Conducting interviews allowed for detailed and clear explanation of one's personal experience with OCD. Keyton (2011) states that "qualitative research provides an intimate view of human communication" (p. 69). Unlike quantitative research, which measures data with numerical analysis to form generalizations, the qualitative method of interviewing allows for rich data that has the ability for distinctiveness (Alsaawi, 2014). In order to create this individuality within the data, open-ended questions were asked and in a semi-structured form to allow participants to elaborate and describe personal experiences (Alsaawi, 2014). The semi-structured interview questions allowed participants to provide detailed responses about their disclosure of OCD. In short, the interviews revealed information to better understand how CPM theory is reflected in an individual's disclosure of OCD through personal, lived experiences.

### Method of Archive Selection

Twelve individuals participated in the study. The identified gender of the participants included 6 males, 5 females, and 1 non-binary. Ages ranged from 18 and 28 with the average age being 21. Out of twelve interviews, eleven participants described themselves as having OCD. One participant did not identify as having OCD but was asked questions regarding OCD portrayal. Interviews continued until data saturation was reached. Data saturation is when repeated information occurs, with no new data (Alsaawi, 2014).

## Method of Analysis

The researcher received IRB approval and began recruiting participants. The researcher recruited through social media, personal connections, and snowball sampling. After each interview, the researcher asked if the participant had suggestions for other eligible individuals. Recruitment on social media included the use of Instagram and TikTok. For TikTok, participants who have OCD would receive a video on their page explaining the study. Hashtags such as #ocdtiktok, #ocd, #intrusivethoughts were utilized to reach out to Tik Tok audience members who interact with these topics. The researcher also reached out to users on Instagram OCD advocacy pages.

Participants engaged in semi-structured interviews conducted online through Cisco WebEx Meetings and Zoom. Two interviews were created in a questionnaire format for easier convenience to the participant. However, one participant received a follow up interview via Zoom for brief clarification. Before each interview, participants either signed a virtual consent form or verbally consented during the interview. To ensure confidentiality, names were changed into pseudonyms for the written report. The interviews lasted between one to two hours and were visually recorded. Once data saturation was achieved, the interviews were transcribed, and the data was analyzed to find reoccurring and significant themes.

# **RESEARCH QUESTIONS**

Researchers Mickles and Weare (2020), as well as Yeo (2020), analyzed how, through the rise of the digital age, social media anonymity surrounding mental health topics has created a sense of community and individual wellbeing. Additionally, while interpersonal disclosure about mental health is preferred, it is oftentimes feared due to the anticipated response (Fennell & Liberato, 2007). Due to the stigmatization and misunderstanding of OCD, the first research question is raised about disclosure:

RQ1: What relational factors facilitate disclosure of OCD?

Hammonds (2015) discovered how motivations, such as family relational culture, quality of relationship, and relational risk, affects the probability of disclosure within familial environments. This finding, along with the research conducted by Fennell and Boyd (2014) regarding OCD media portrayals, express the need to understand the following:

RQ2: What relational factors inhibit disclosure of OCD?

According to the CPM theory, in order to avoid turbulence after disclosing information, rules and boundaries are set (Petronio, 2015). Hall (2020) analyzed how mental health is discussed between friends for the desire of support and oftentimes, boundaries were not communicated. In order to comprehend how individuals with OCD determine privacy management within their relationships, the third research question is posed:

RQ3: When disclosing OCD, how do individuals enact privacy ownership and control?

# RESULTS

After analyzing the data, twelve overarching themes emerged. The themes for RQ1 were Comfortability with Self, Navigating the Relationship, Humanizing OCD, Setting the Record Straight, and Sense of Community.

The themes for RQ2 included Lack of Diagnosis, OCD Portrayal, Anticipated Responses, and the Battle of Stigma. Two subthemes emerged for Anticipated Responses: In the Workplace and Disbelief/Misunderstanding. The themes that emerged for RQ3 were Privacy Boundaries, Familial Environments, and Labelling. These themes are discussed below.

RQ1: What relational factors facilitate disclosure of OCD?

The purpose of RQ1 was to understand how and why individuals disclose their OCD with others. Four themes emerged.

## Comfortability of Self

This theme represents how participants who accepted their OCD as a part of their identity were more likely to disclose to others. While the majority of participants stated that while it was difficult to admit OCD was a part of them, it was something that they had lived with for years and had to learn to acknowledge. Sarah details that since it is part of her daily routine, OCD "is just who I am." Alex recognized that his OCD is different and recalled that it "kind of makes it mine in my eyes." Additionally, by seeing the disorder from an optimistic perspective, Luke described how this helps him overcome the hardships of OCD:

In a sense, I found it as a blessing because it taught me a lot of life lessons. And so, I will never say that it's not a part of me. In fact, I kind of enjoy saying it's a part of me, because it's part of my life story and it made me who I am today. And I'm proud to be who I am today and so, yeah, I'll count it as part of my identity for sure.

Because participants established their OCD, they also reported a higher likelihood of disclosure. After stating that he saw his OCD as a part of him, Luke described how he began to speak publicly about his OCD at his church. He did so because he had a feeling other people struggled with "anxieties or depression and maybe even it was OCD." Other participants, such as Jason, detailed how the acceptance of his OCD led to a nonchalant approach to disclosure. He stated, "At this point I don't really care. You can go ahead and tell anyone; I don't really care. It doesn't bug me."

While many participants reported a more accepting tone regarding how they viewed their own OCD, they also did not see their OCD as the most important factor of their identity. Janet emphasized that "this is not me, this is a part of who I am." Additionally, while participants stated they were open to disclosure, it often came with an undesirable anticipation that they would have to explain it. As explained by Sarah, "I wouldn't be ashamed telling people that I have it. I just have to explain what it actually is." Another participant, Sophia, resonated with Sarah's stance as she described how she was scared to tell people about her OCD because she did not want people to mistake her for her intrusive thoughts. She explained that her intrusive thoughts did not define who she was, and she did not believe that many people understood that OCD is "ego dystonic" meaning that her OCD does not follow her individual beliefs and values. Despite this, she did not "care about it being secret," explaining:

I just don't want people to misunderstand it, but at the same time...why does it matter? I don't care enough about people that are uneducated about it to go out of my way. But at the same time when it's a close friend and I'm asking for reassurance about it, that's a different story. But when I'm in a logical state of mind...I don't really care who knows that I have OCD. And if there's someone that I barely know that someone told and they said, "Oh, she's weird." I would just be like, "Okay, whatever. Screw them." I don't care. While participants reported that the internalized identification of their OCD increased the likelihood of

disclosure, another important theme that arose was regarding the relationship between the discloser and listener.

## Navigating the relationship

This theme represents how the relationship between the discloser and listener mattered in order for valuable conversations to occur. Individuals reported that the reason for disclosure was often for support from others. Most participants described how their OCD led them to excessively divulge information about their OCD for reassurance that they were not "bad" humans. Spencer explained their "confessing compulsion," which led them to explain their obsessions for fear of what people will think. Spencer states this internal dialogue often sounds like, "They (people around me) don't know how terrible of a person I am, so I have to tell them because they'll leave if they find out." Similarly, Luke explained how he could not get rid of any thought that produced guilt unless he told his mom about it. Luke described that the thoughts would range from "calling a kid stupid as a joke in a joke setting, to having just a thought that was about hurting myself." Thus, in order to feel reassured, Luke excessively told his mom every intrusive thought he had. He described:

I had a cell phone at school, so I would text her. There were some days I think I texted her 15 times a day of just these different thoughts, and just having her say, "Luke, these are just worries-(We would call them

worries to kind of minimize the harm of it)-These are just worries. These are just worries." And I just remember hearing that probably a million times in my life like, "This is just a worry, it's not you, this is your OCD." And so, I would probably text her 15-20 times a day. I would go down to the office and pretend I was sick so I could call her and tell her everything.

Luke described how when he talked to his mother openly about his anxiety surrounding OCD, he felt as though someone truly cared. The affirmations he received were beneficial to his mental health; however, he also described how he knew his actions were illogical and he did not want to tell his mother everything. Nonetheless, despite questioning his behavior and knowing it did not make sense, the affirmations helped him. He quotes, "That was the only way I could justify it, and that's so, that's what I did." Sophia also related to Luke's story as she stated:

Without that reassurance, I just feel incomplete, and I can't nove on to do anything else, before I get 100% proof that what I'm worrying about, I don't need to be worrying about. The reassurance never works because if you get one affirmation, you want more and more and more and you're never going to be fulfilled with it. That's why we kind of have to sit with the uncertainty.

Although participants described disclosing for reassurance and support from others, it was often due to the nature of the relationship with whom they disclosed. When asked why Luke chose his mother as someone to seek affirmations from, Luke stated that his mother "handled everything so well and so strong. There is just something about her mentality that she just doesn't let things phase her." Luke explained that his mother's fierce nature and words of encouragement drew him to disclose to her as she reassured him that he was not "crazy" and that there was "hope for him."

The understanding from the other party was extremely important to participants as they described who they told about their OCD. Janet explained how she would text her husband at work when she was having extreme anxiety and she described that he does not minimize her OCD, but he does not "glamorize it either." Penelope was similar to Janet as she discussed how supportive her boyfriend is with her OCD:

He never belittles anything, even though I feel like sometimes his issues and problems are much greater than mine. He never once has been like, "That's ridiculous, why are you freaking out about this?" Sometimes my parents would say that, like "Everyone goes through this, people go through way worse things than you." Just super invalidating. But he's always very much taken it seriously. It's a supernatural connection.

Overall, individuals reported the importance to disclose to someone who would be supportive and understanding. The quality of the relationship also mattered as it led individuals to be drawn to a specific confidant. Lastly, many participants stated the need for receiving affirmations and reassurance which was temporarily effective in the process of battling the cycle of obsessions, compulsions, and reoccurring intrusive thoughts.

## Humanizing OCD

Participants described how, when looking through the Internet for answers about their OCD, they often were faced with medical reports that had a serious tone about the types of OCD and how to seek treatment. Individuals stated that the medical reports panicked them or were avoided altogether. This was due to formality, absence of human representation, and lack of community. Sophia explained:

Yeah, there are good articles but a lot of them can make you feel even more shame because you don't see the other people who are dealing with the same things. You don't see the comments that are like, "Oh my God that's me." You don't see the likes and the engagement with it. You just see an article and your OCD brain is immediately going to try to twist it and be like, "You're the only one dealing with this. You're on some weird article that you found on the Internet."

Because articles do not often provide a space for connection and support, participants reported turning to Instagram account pages dedicated for OCD advocacy. Instagram pages and comment sections were praised among participants as there was no longer a sense of isolation in experiencing OCD. Sophia stated that Instagram helped her to see that she was "not alone in this." While also offering a sense of community, OCD advocacy accounts additionally fought to break the stigma and stereotypes around the disorder. The transparency of OCD advocates was valuable to individuals as some participants learned more about themselves through the public disclosure. This was shown by Alex as he began to understand himself better through Instagram OCD advocacy accounts. He stated:

There's been so many times where I've seen a couple of Instagram posts where I'm like, "Yes, that is me. I see myself there." And then there are other parts where I am like, "Wow, I've never experienced that at all." But people with different types of OCD do. Which is really helpful.

By following these accounts, participants reported a sense of contentment as they finally began to see OCD represented and could relate to content surrounding the disorder Unlike news or medical articles about OCD, Instagram pages provided a sense of humanization to the disorder as participants were able to see the faces behind

the people who experience it like they do. The empowerment from OCD advocacy pages also inspired some participants to disclose on their personal social media accounts. Penelope explained:

It just really makes me think like "Oh, I could do that too." And I just really, really appreciate the people who like just bare it all because that's really scary and that's not something that I've dipped my toes into. But you know my Instagram account does not revolve around that, and so people who do take that effort and that step to do it, it is just so amazing and there is so many people who go through it as well. And that's revolutionary in itself.

Therefore, the empowerment displayed from OCD pages allowed for virtual disclosure. Spencer stated that, "Because I'm open about my struggles on social media, they've definitely seen the posts I've made about it, but, again, they don't know the extent of it." While Spencer recalled that followers may not understand the full extent of their OCD, they would at least know that Spencer had OCD. This open display of disclosure was also echoed by both Penelope and Sophia, who explained that those who follow them on Instagram should know they have OCD as they post about OCD awareness. Sophia explained, "I'm pretty sure everyone I am friends with knows I have it unless they never looked at my account."

There was a valued connection between participants and Instagram advocacy pages as individuals could relate to the advocate who is posting about their own battle with OCD. This empowered participants and led to a disclosure on their own social media accounts. Like the Instagram advocates, participants reported the desire to break down the stigma of OCD when posting or discussing about it with others which is described in the following theme.

## Setting the record straight

This theme represents how the misrepresentation of OCD motivated individuals to inform the public about of the reality of OCD. Individuals explained how they felt sometimes it was "up to them" to educate others in their network and break the stigma. A recurring theme throughout this education was patience. While many participants reported feeling annoyed with phrases such as "I am so OCD", they also felt that the person just needed more information on why these terms reinforce the stereotype of OCD in society. Penelope described how the more she has gotten older, the more tools she had to talk about OCD with clinical language for others to understand. She stated that, "At the same time, I have more patience with people who don't know what it is, and I don't feel as defensive. It's just like this what it is and it's something that I have and that's that." Spencer had a similar opinion and stated:

I used to get so upset when I would hear people say, "I'm so OCD" and stuff like that. It wasn't until I gently corrected my boss when he made a similar joke about it. I was very open about what my average day looked like, and how much it hurt that people trivialized it. He was very understanding and apologetic about it but said something that stuck with me: "I guess that saying is so ingrained into society that it's hard for people to differentiate it for what it really is" (note: not the actual quote, just summarizing). That really changed how I look at it. People are so used to hearing it thrown around like that, that they don't actually know what it's truly like. It's not on us to educate people, and sometimes I don't have the spoons for it, but if I can try and correct someone on it, then maybe it'll save the next person they could've hurt.

Many participants reported the joy in contributing to research that could benefit others. Janet, who is more silent about her OCD, stated, "This is educational and if I can share my story and help with research then it's worth it." In addition to contributing to this study, the participants reported talking about their OCD with the hopes to inform those around them. Sophia described how she performed two speeches for her public speaking class at her university about her story of OCD and the stigma surrounding it. When asked how this public disclosure went, she stated, "I feel good educating people on that, because I care so much about it and I want people to know that OCD isn't cleaning." Overall, although participants explained the benefits of informing those around them, they also acknowledged the exhaustion from debunking OCD stereotypes. Spencer explained, "I have my good days and bad days on it. It sometimes drives me to tears, how misunderstood it is. Sometimes it makes me feel good, thinking I might be helping someone else. In the end, it's usually just a little frustrating."

Overall, while many participants stated that the misunderstanding of OCD was discouraging, there was also a motivation to change the narrative. Furthermore, participants were extremely patient in correcting and educating those around them. Ultimately, individuals wanted to break the stereotype of OCD and prevent others from being affected by insensitive language.

## Sense of community

This theme represents the sense of comfort and a higher likelihood of disclosure if participants knew someone who had OCD or experienced mental health battles. Overall, relationships that were open about mental

health were beneficial to participants as they reported feeling understood and accepted. Even if a confidant did not have OCD, participants explained that it was still extremely beneficial to relate to someone else who experienced mental health struggles. Janet shared a story about her friend, stating "They were navigating similar mental health concerns and they shared with me that they were experiencing significant mental health issues. So, I was like, 'Oh hey me too.' So, we were able to have that shared experience together."

While having someone in their life who also struggles with their mental health was valuable, many participants stated how different OCD disclosure was to those who also experienced OCD. Spencer explained, "It's easier to share with someone who has gone through it than someone who hasn't." However, not many participants knew someone who had OCD. In fact, when asked if they knew other people to interview for the study, only two participants could give names.

When asked how the participants felt discussing their OCD with a researcher who also had OCD, there was a sense of comfort, even if the OCD was not identical. Alex stated that, "Even though our experiences with OCD aren't, it sounds like exactly the same, being able to still have that kind of mutual understanding and connection about it, makes it feel easier to kind of talk about and talk through." The OCD relatability led participants to state that the interview felt more like a conversation than a research interview.

Because both the researcher and participant had OCD, this allowed individuals to disclose personal information they had never told to anyone else. In fact, many participants reported that the interviews were the first time they truly discussed their OCD in such detail. As explained by Jason, "Yeah, my wife knows about it. I don't think I've shared as much as I have with you just now...this is probably the most I've talked about it." The open disclosure without judgement was appreciated by many participants. In the interview with Penelope, she stopped mid-sentence as she was talking about her experience with OCD to say, "I am just baring my soul to you. It's really cathartic." One participant, Spencer, reported that talking to a researcher who also had OCD felt "clinical" but in a good way.

Since many participants reported that they had never discussed their OCD with someone who also experienced OCD, this led participants to feel satisfied and inspired to hear experiences similar to their own. Luke stated, "It's kind of crazy talking to somebody else that kind of understands how I am feeling. Yeah, it is encouraging to feel like I am not the only one." Additionally, several participants learned a lot about themselves during the interviews since they had not been as open about this topic before. After the interview was over, Alex stated:

I want to thank you also for giving an environment where I feel comfortable talking about all of this... to be entirely honest, I learned through these conversations a lot about myself because it's not something that I do talk about a whole lot with people.

While many participants did not know several other individuals with OCD, talking to others who had different mental health battles was still appreciated. However, individuals explained how discussing their OCD with a researcher who also had OCD was comforting and rewarding. Overall, while participants described how talking to someone who did not have OCD was valuable, it was different talking to someone who had similar experiences as there was an even higher level of understanding and relatability.

#### *RQ2*: What relational factors inhibit disclosure of OCD?

Through discovering the factors that encouraged disclosure, the purpose of RQ2 was to understand why individuals concealed their OCD. Therefore, the purpose of RQ2 was to examine what hindered OCD disclosure. Four themes and two subthemes emerged.

## Lack of Diagnosis

This theme represents how the lack of diagnosis in the participants impacted the likelihood of disclosure. While the study recruited individuals with OCD, not all participants were diagnosed. However, the participants classified themselves as self-diagnosed. Ultimately, regardless of seeing themselves as having OCD, participants with a self-diagnosis did not feel "qualified" to talk about their experience with the disorder compared to those who had a medical or clinical diagnosis. Alex explained how he does not talk about his personal experience with OCD in conversations because, "I don't always know the comfort level with talking about it without the official diagnosis." Sarah also described how if she was diagnosed, she would be a lot more comfortable. She stated that if she had a medical diagnosis, she would "not have a problem just saying 'Hey, I have OCD'", but it was due to her selfdiagnosis that she believed she could not say such a statement.

Ultimately, those who self-diagnosed their OCD, lacked the confidence of disclosing their OCD or labelling the disorder. Despite knowing that their experiences were considered OCD, participants did not feel comfortable describing it as such due to the lack of clinical help. Janet, whose therapist told her she exhibits OCD

behaviors and is on an OCD spectrum, is not "officially" diagnosed. Due to this lack of diagnosis, Janet questioned her eligibility for the study. Upon talking to Janet, she explained how she continuously puts herself down due to the lack of diagnosis stating, "I also gaslight myself too. I have done it in this conversation... like even when volunteering to be asked for this."

Participants said that if they tried to explain they had OCD to others, there was a fear that they would not be believed because of their self-diagnosis. Sarah details this further stating, "I feel if I was diagnosed, I'd be more comfortable telling people that I have it, but I'm not going to be like, 'Yeah, I have OCD, but I self-diagnosed myself' cause then people are like, 'Oh, you don't actually have it.' But if I did get diagnosed, I feel it would be different." Overall, unlike participants who were open about their OCD and had clinical or medical diagnoses, participants who were self-diagnosed did not feel qualified to speak out due to the lack of external confirmation.

Additionally, two participants reported having more of a high functioning OCD, which was presented as taking on excessive workloads, worrying about failure in life/school, and having a rigid routine. These participants explained that they did not see their OCD as a significant issue as it led them to be productive. This was demonstrated in Sam who stated, "I feel like my OCD is helping me more than it is hurting me." Furthermore, Sam and Emily reported feeling as though they did not have the "stereotypical" form of OCD, which deterred them from seeking treatment. Emily explained, "I feel there's this picture of what someone with OCD has and I don't really fit that but I'm at the same time I know what I do and the things I go through also aren't normal." Alex and Emily explained that, since their OCD was more praised and accepted in society, they did not feel the need to receive help. Nonetheless, despite a lack of diagnosis and feeling as though their OCD was different, both participants would describe their behavior as OCD to others and educate those around them about their personal experiences.

Overall, while participants self-identified as having OCD, the lack of an official diagnosis hindered the probability of disclosure. Participants who did not have an official diagnosis explained that they often did not see their type of OCD in the media which led them to feel as though they did not have the authority to disclose. The consequences from the misrepresentation of OCD are explained further in the following theme.

#### OCD Portrayal

Another theme that arose was the effects of OCD portrayal in the media; this theme represents how participants talked about these portrayals. Many participants explained that due to the lack of accurate messages they received about the disorder, they did not even know they had OCD. Alex recalled how the stereotypes of OCD affected him stating, "It made me for a while think that it was something I could ever experience, because for so long, I did just really think that it was the need to be organized." Other participants, such as Spencer, echoed this feeling stating:

It took me a long time to realize what my compulsions were. The stereotypical portrayal we see in the media is washing your hands and such, so when I found my diagnosis of OCD, it was confusing. *My room is dirty, so obviously I can't have OCD.* 

Sarah explained how the representation of OCD has an impact on people's beliefs surrounding the disorder. She described how this bothered her:

Growing up and seeing Howie Mandel, a lot of people talked about him being a huge germaphobe and you'd always see him fist bump people instead of shaking hands with them. And there is a lot of other things that I've seen in the media, but I don't remember anything going into what I was going through, because I would've remembered that. Like, "Oh, this is what I do." I think for me, it's just that is what everybody sees OCD is because it is portrayed only as that in the media. So, if I tell people I have OCD and explain it my way, they're gonna be, "Oh, that's not what it actually is." But I'm going to be like, "Yeah, it is. You just you just don't know because they don't tell you that."

Overall, the misrepresentation of OCD in the media led participants to feel frustrated. Spencer detailed how the societal understanding of OCD only discusses the "most basic and well-known obsessions, which are the ones surrounding cleanliness (particularly hand-washing)." While Spencer clarifies that those obsessions are "completely valid," it also leads to a common misunderstanding of other types of OCD. Spencer said, "I haven't seen anyone have sexual and/or harmful intrusive thoughts within the media, and I doubt I ever will, because nobody wants to see someone have something as dark and taboo as that." Due to the lack of OCD representation in the media, participants described how this would lead to consequences both individually and societally. Sarah explained how, if she had seen more OCD representation growing up, she would most likely not be in the place where she was now, stating:

I grew up thinking you have to have things organized with colors or the closet is color coordinated or something that. But that's not what I had. So, I was just like, "This isn't what it is." I guess I just never thought that I did have it.

Sophia aligned with Sarah's mentality, addressing how this misrepresentation could lead to serious consequences. Sophia explained:

And I think that there's probably a lot of people who are dealing with it, that we don't realize are or they don't realize. There are probably people that are in the same grocery store as you that are dealing with the same thing as you, but maybe they don't know what it is. And it is kind of sad because these people might not have access to Instagram accounts or things like that that give them that release of shame. They might just never get help because they are so unaware of what OCD really is. People are like, "Oh, I am not organized, I can't have OCD," and then they like never get help. And that's why it's so harmful to be like, "Oh, I am so OCD, I love to clean." And I think people think that we are over-reacting when we say, "Hey don't say that." I don't think they're maliciously trying to hurt people, but it is harmful. It's not just that I'm offended by it...there are people who are literally not seeking help and then that not seeking help can lead to suicide. It's serious. And I just wish that there was more awareness on it.

In society, Spencer describes how if "there isn't a more accurate representation of the others (types of OCD), they won't get talked about, and it means that less and less people won't really get what's going on when we try and explain what we go through, and the stigma will continue to fester." Ultimately, many participants described how they wished there was more representation to not only break the stigma surrounding OCD, but to benefit others who may be struggling with OCD.

#### Anticipated Responses

This theme represents how individuals would avoid or were hesitant to disclose due to the responses they expected to hear. The anticipated responses were categorized into two subthemes: In the Workplace and Disbelief/Misunderstanding.

In the Workplace. Individuals discussed how they wanted to hide their OCD for fear that their place of employment would start to treat them differently. Jason, a member of the military, mentioned that while he was okay with everyone else knowing about his OCD, he was strict on not wanting the government to know because "then they have problems and there's a lot of paperwork for me." Janet expressed her concerns with disclosing to her workplace as she does not want her co-workers to start looking out for her OCD. She stated, "Yeah, that I will need certain accommodations or something. Just assumptions because of what is seen as disabled; what is seen as OCD. They come into my office and it's a disaster like, 'Did you lie on the application?'" Matt expressed parallel concerns. Matt explained that he works at a golf course and if his employers knew about his OCD, they may view him differently regarding job competency. Matt explained:

If they knew that every little mess I make, I had to go back and fix it until it's perfect, they might not give me those precise jobs because they want me to keep moving and get through the holes instead of going back and fixing every little detail.

In order to keep her OCD hidden from her employer, Janet stated that when her job asked her to document any disabilities, she did not disclose her OCD. She explained, "I don't know if this is going to get me in trouble...but when you fill out applications and stuff, you are supposed to indicate if you have a disability. And OCD is listed as a disability. I never mark the box." When asked why Janet does not disclose OCD as a disability to her employer, she stated:

I've never been diagnosed clinically, you know? My therapist has told me, but does she have the authority to do that? I don't know. I justify a million different things and I don't want my employer to know. I don't want to be put into a group of that.

**Disbelief and/or Misunderstanding.** In addition to avoiding telling the workplace, individuals also indicated that they did not want to disclose their OCD for fear of not being understood or believed. Matt described how he was nervous people would say: "No you don't have it; you are just mocking people." Emily had a similar standpoint and explained, "If I use the term, 'Oh yeah, I have OCD,' people would say, 'Oh how do you know? When did you find out?' Ask all these questions about it. Or ask, "Do you actually? Or do you just say that?""

Many of the participants feel they would not be believed due to the misunderstanding the public holds surrounding the disorder. Sarah explained that if she were to tell someone she had OCD, people would not believe her because she is not organized or clean. However, if she fully described her OCD to people and how it was not about cleaning, she thought people would judge her and say, "I don't see that." For Sarah, she did not want to disclose because people do not know enough about OCD and "having to explain it to them would just be annoying for me." Sarah was not alone in this belief, as many participants described the frustration of people who do not understand the reality of the disorder. Jason stated that if his wife points out his compulsions and asks him to stop, it

makes him mad because he does not want to stop a compulsion. He explains, "Yeah, I've got a problem with not stopping. I feel like I know better." But to him, it feels right, and he is not sure his wife understands that he needs to do his compulsions. "Yeah, I just try not to make a big deal of it and then keep doing it."

Overall, the misconception surrounding OCD made it hard for participants to disclose and feel understood. As Alex stated, "How do I even talk about this when people just don't get it?" Jason agreed with Alex as he explained:

It's hard to explain unless you have it, I mean, it's not going to make sense to someone why the number 4 is cool and why it is the right number for me. It's like explaining what it's like being an introvert to an extrovert or a Black person telling a white person what it is like to be Black. You know? Unless you are that, it's hard to tell and it's hard to say.

Sophia described how the misunderstanding affects communication because she worried that people would mistake her OCD for something that it was not. She explained how after disclosing her OCD to people, she would ask for reassurance and this would catastrophize to her thinking, "Oh my God they're going to report me!" While many participants understood that their OCD was not considered "normal" to others, Alex described how, if someone gave him a "that's weird" reaction after disclosing, it reinforced in his mind that his OCD was not something that "other people experience."

Participants also described that the public does not necessarily understand the full extent of the disorder. Matt described that "people who don't go through it, they don't really understand exactly what it's like." He explained how his parents will often tell him, "Don't worry about it. That's nothing. You don't have to worry about that. You're probably just going through a stressful time right now. So just don't worry about it." This response bothered Matt as he said, "People just tend to not really understand to the extent, I guess." Luke related to Matt's frustration as he expressed:

I think people think they know about OCD, but they don't really know the effects that it plays. It kind of bothers me. When I've told people, that they'll make comments like "Well, yeah, I leave my volume at 22." It's just like, "All right does it bother you for the rest of- does it change the way you live?" And they'll be like, "Oh, no, it's just I like it at 22." And it's like, okay, then that's not OCD, I am sorry to break it to you. I don't think people understand the severity of it and how it plays an impact on people's lives.

Due to the misrepresentation of OCD, participants described how they did not want others to think they were lying about having the disorder. The anticipated responses of being misunderstood led to some individuals to avoid and/or dread disclosure. Overall, anticipated responses were often viewed as negative and were dreaded by participants.

#### The Battle of Stigma

Overall, almost every participant described how the stigma surrounding OCD had significant impact on the likelihood of disclosure. Jason described the stigma further stating, "I mean, I guess that's a reason to keep it hidden. It means you're imperfect, right? I mean, you've got something wrong with you. It's not always in the positive light that's for sure. It is rarely in a positive light."

Participants described that OCD is regarded as a quirk and not taken seriously within society. Many individuals in the study were annoyed at this representation, as Luke explained, "Yeah, and I hate it. I don't like that stigma at all because it's like I said earlier, it's something that shouldn't really be joked about or downplayed." Additionally, participants described how OCD is represented less than other disorders. Alex described how he thought this lack of representation surrounding OCD led to a higher stigmatization because "you get less exposure to seeing what else it might actually be." Janet explained:

I feel like we are working to destigmatize mental health and we have gotten to this space [where] we can talk more about depression and anxiety, but I feel like there is this other class of mental health issues like personality disorder and OCD is included in this other type. Like, these are normalized but if you have these, you're crazy. So that is really harmful.

In order to avoid potential stigma in public settings, participants reported that they would conceal their behavior to appear "normal." Penelope described how her OCD "became something that I had to hide" and that she would only "stop a compulsion if someone saw me." However, she explained the compulsion would not just stop immediately. Penelope described that she would think, "Oh shoot, I'm going to come back and do this later." Matt was similar in his approach as he explained that he would say something along the lines of, "Oh, I forgot something" to avoid the public setting and perform a compulsion in private. He described:

And I would start walking back and say, "Oh, wait, I actually have it now. I forgot, it's actually in my backpack." And that kind of masked it a little bit as to why I had to go backwards and redo something

because they thought I forgot something, but actually, I didn't forget it, I just had to go backwards [to perform compulsion].

Overall, individuals described how the stigma, misrepresentation, and misunderstanding of OCD led to a lower likelihood of disclosure. Participants explained that oftentimes these themes influenced how they discussed their OCD. Thus, the following research question was created to examine how individuals created privacy control when disclosing their OCD.

RQ3: When disclosing OCD, how do individuals enact privacy ownership and control?

In order to understand how individuals communicate about their OCD using privacy boundaries and control, the CPM theory was utilized as a framework for RQ3. Three themes emerged.

## Privacy Boundaries

This theme represents the explicitness of privacy boundaries and the certain circumstances in which boundary breakage was allowed. Individuals reported that if their information about their OCD was told to someone else other than the original discloser, it was acceptable if the intent was informative. Matt explained:

If you want to talk to your parents about it, because you think it's maybe something you're going through, if you want to bring that up like, 'Hey, Matt was sharing this story with me and I'm kind of struggling with it too. I think I might have it as well.' Then I'd be okay with that, but ask me first, make sure I am okay with it. But besides that, just don't tell anyone please.

The potential for relatability deemed boundary breakage as acceptable for participants. Penelope described how it would not make her uncomfortable if her parents talked to other parents about her OCD, if the parents who were being told "had a kid who is dealing with the same thing." Alex related to both Matt and Penelope's opinions surrounding external communication as he stated:

I don't do the whole explanation of, "Hey, don't tell other people that it's me who's talked about this, but you can still talk about this as an example in the future." But that's kind of what I hope for sometimes when I am talking with people about it... is that they'll be able to still go and share my experience later on, but just not necessarily use my name, or something like that.

Janet described how it was okay if her husband or friend told others about her OCD because she understood how they may need further support to manage such information. She explained how she knew "how hard it is to be a caretaker and not have anyone to dump that." Therefore, to Janet, boundary breakage was seen as acceptable because she trusted they were not "speaking ill of me…but just processing for themselves." In fact, she wished her husband would talk to additional resources because "he doesn't know what it is like to have OCD or have panic attacks so if he can find that support, cool."

In addition to privacy rules, participants also stated that privacy boundaries were mainly implied. Individuals recalled that opening up about their OCD was not prefaced with explicit boundaries on how the information should be handled. Luke detailed how his comfort with his OCD played a role, stating "In college I said, 'I don't care who knows anymore.' I just felt comfortable. So, I even prefaced it with like, 'You can tell anybody. If they want to talk to me, please direct them my way.'" However, most participants did not preface disclosure with privacy boundaries because of the strong relationship built between discloser and listener.

If participants did explicitly state privacy boundaries before disclosing their OCD, many reported that it was in the form of confirmation, reassurance, and/or respect. Spencer described how they disclosed because they wanted to know "if I was going insane or not." They detailed, "I remember saying, 'I think I have OCD,' and she said, 'If you think it, then you probably do.' It wasn't so much of a 'Don't tell anyone," more so a "Please tell *me*." Penelope related to Spencer as she explained that sometimes she would preface the conversation by saying, "I hope it is okay to tell you…" Penelope described how she was "more worried about their perception, than them telling someone." Additionally, while Janet did not explicitly state privacy boundaries, she detailed how disclosure with her friend was created in a considerate manner:

She also is really great about texting me things like, "Can I emotionally dump on you?" and I can say yes or no. And I have done both and she has too. She texted me the other night and was like, "Can we call?" and I asked if we could text because I had a stressful event happen and she was like, "Damn!" So, we can set those boundaries in a way that is respected and appreciated.

Overall, privacy boundary breakage was viewed as acceptable if it were to help the confidant or another person who may be also dealing with OCD. While boundaries were not explicit, they were often used in the form of reassurance. When discussing privacy boundaries and control, participants also described the aspect of family which is examined further.

#### Familial Environments

This theme represents how a strong familial relationship allowed for participants to disclose and for privacy to be maintained. Sarah explained how she did not set any privacy boundaries before disclosing her OCD because she trusted her mom was not going to post about it on Facebook. Luke, who solely confided in his mom for reassurance, echoed Sarah, stating that his mom "made it clear to my dad, especially my dad and brother, to better not say anything. So, they were really good with privacy." The trust within the family allowed for participants to state that privacy boundaries were implied when there was disclosure.

Additionally, participants reported that extended families enacted privacy boundaries in different ways. Penelope described how her mom most likely talked about her OCD to the extended family when she was younger because everyone "came to each other for parenting advice. So, I'm sure they told them before they even knew what it was." However, Penelope was not bothered by these external conversations. She stated how, "It's kind of beautiful that my extended family has been with me through all of that." Luke offered a different stance as he stated that he told his extended family on his own. Similar to Penelope, Luke also appreciated that his extended family knew about his OCD as he then had a sense of comfortability surrounding mental health topics. He described how he learned about other members who struggled with their mental health and he could hear their "tips and tricks." He explained that the understanding he received from his family members made him wish he would have disclosed "earlier."

Participants such as Luke and Alex described how their parents often asked if the private information could be shared. Luke described how his mother would ask him it if was okay to tell his uncle about his mental health. He stated, "And there was a time I said no right away, but I started to feel a little bit more comfortable with it and I told her it was all good." Alex shared a similar story stating that his mother asked if she could tell Alex's grandma. Alex stated that he appreciated that he did not have to tell his extended family. He explained, "I want them to know, but I don't know how comfortable I feel with going and telling them that."

Overall, participants explained that the trust within their families led to non-explicit privacy boundaries within the immediate family. Regarding the knowledge of the extended family, immediate family members often asked for the participant's approval before disclosing. However, participants also reported disclosing to their extended family personally. Nonetheless, participants were satisfied with the extent that the extended family knew regarding their OCD.

#### Labelling

This theme represents how participants would not reveal the entire extent of their OCD when disclosing. Sophia explained that while her friends knew she had OCD and "scary thoughts", she did not want them to know that the thoughts were violent or sexually intrusive. Spencer related to Sophia as they stated:

I do share my struggles with OCD publicly because I do want to break down the stigma whenever possible, but don't go into the depths of my obsessions. Usually, I just say I have Harm OCD, and leave it at that. It's too taboo to me, personally, and again, there's that fear that everyone will think I'm horrible.

Not sharing the severity of their OCD was apparent from Luke as well, who explained how he would downplay the disorder and how it affected him. He illustrated this phenomenon by saying:

It would be more of, "These thoughts aren't really that bad and they're not as they're not as big of a deal." So, they would ask, "So what are these types of thoughts?" And I would never tell them any of the severe ones. I'll just say, "Sometimes I just think of how I did bad in school and I just can't stop thinking about it for a little while, but it goes away." And so, I would kind of lie about it and make it seem like it's really not bad. And people then would just think, "Oh, that's it's just a little minor thing." And then they would kind of go away and they wouldn't ask me about it anymore.

Although participants wanted to inform the public, they also created their own form of privacy control by informing people less of the truth. Penelope described that when her health class watched a video explaining OCD, the students did not understand what a compulsion was. Thus, she decided to speak up and talk about her experience with OCD. She described:

I just kind of raised my hand and I was like, "Yeah I have that, and I do this this... it is just like we just watched in that video." But then I would kind of preface it by saying, "Oh, but I saw a doctor and it's totally fine now and I don't have anymore," even though that's not the case.

In addition to participants creating privacy control through what they wanted others to believe about their OCD, some participants also described how they would not use the label of "OCD" to describe their behavior. Janet used terms such as "panic symptoms" and "anxiety" to explain herself to family, even though her therapist said she was on the OCD scale. She described, "I have tried to call my, not call them panic attacks but in this context, they are 100% compulsions, but I call them more like panic symptoms. And this is just what I've made up."

Emily and Alex echoed Janet in saying that they often do not use the term OCD. Emily explained that if was talking to people about her behavior, she would often say, "This is how I am." And while Emily believed that everyone knew she had OCD, she did not go into depth about it. Similarly, Alex described how he would share in the sense of "This is something I do" instead of "I have OCD, so I do this."

Individuals described that labelling occurred within their families as well. A few participants stated that their parents did not know the full extent of their OCD. Jason provided an example of this. While his parents know about his behavior, he explained, "I still haven't told them to the full extent of what I was doing, and I swore up and down I wasn't doing what I was doing." Penelope described how her parents did not use the label OCD. She stated that her parents would just label it as "she" and this led to Penelope not understanding her OCD at the time. And while Luke's parents knew that he had OCD, his mother often used the word "worries" to help ease his anxiety.

Even though participants did not tell the full extent of their OCD or use the label of OCD to describe their behavior and thoughts, this was not always a negative aspect to some. Janet explained how she felt she was "being more honest than I ever was when I was hiding it." By describing her OCD as anxiety, she feels people are more understanding. She states, "So, I may not be fully transparent but it's like what do they need to know? Who cares? They don't have to know that."

Overall, participants described how they would often use more societally accepted terms to describe their OCD and did not give the full extent of the disorder. This form of privacy control allowed individuals to create their narrative of their OCD that would be considered appropriate in society.

# DISCUSSION

The purpose of this study was to understand why and how individuals choose to disclose their OCD, what factors inhibit interpersonal communication surrounding OCD, and the ways individuals choose to disclose their private information around the topic. Communication Privacy Management (CPM) Theory helps shed light on the results. The following section interprets the meaning behind the emergent themes.

*RQ1*: What relational factors facilitate disclosure of OCD?

The five central themes that developed from the first research question included Comfortability of Self, Navigating the Relationship, Humanizing OCD, Setting the Record Straight, and Sense of Community. These themes demonstrate that while OCD is stigmatized within society, participants emphasized the importance of disclosure.

Participants described how disclosure was often used for the return of reassurance or encouragement. This finding is consistent with Hall (2020), who stated that individuals disclosed in friendships solely for support. Hall (2020) explained that individuals who disclosed their mental health did not want advice or additional information from the friend. Participants supported Hall (2020) as they explained support or reassurance was the desired feedback. Additionally, participants explained that the relationship of those who they disclosed to, mattered. There was a higher likelihood of disclosure if the anticipated response was non-judgement and supportive. This aligns with the findings from Fennell and Liberato (2007), who stated that individuals are more likely to disclose if they predict positive feedback.

Additionally, the findings here extended upon the study performed by Fennell and Liberato (2007), which found that the online connection of those who have OCD provides a space to avoid stigma and create a shared community. From the findings of this study, participants reported that medical articles did not provide comfort or humanize OCD. Therefore, social media advocacy accounts, specifically Instagram, were utilized. Individuals said that these advocacy pages represented their OCD more accurately than societal messages and they allowed them to connect with others who had OCD. Making these connections allowed participants to disclose and feel accepted for their OCD. Furthermore, several accounts supported the findings from Fennell and Liberato (2007), who explained that the Internet has become a place for self-discovery. Individuals also described how learning about the different types of OCD helped to better understand the disorder.

The study is largely consistent with the research conducted by Mickles and Weare (2020), who showed how anonymous disclosures led to community support and this validation was preferred over seeking professional medical help. Instagram does not have anonymous comment sections, but participants reported that hearing other people's experience with OCD on Instagram was beneficial. Therefore, the element of support through comment sections aligns with the findings from Mickles and Weare (2020).

Lastly, participants reported that they did not want their OCD to be the only part of their identity. Spencer explained this stating, "I'm more than my OCD." While many participants recognized OCD as part of their identity, they still wanted the truth of the disorder to be shared amongst the stigma and misunderstanding. Thus, this desire for shedding light on OCD, and frustration of OCD misrepresentation, increased the likelihood for participants to disclose.

RQ2: What relational factors inhibit disclosure of OCD?

The four emergent themes from the second research question included elements such as the Lack of Diagnoses, OCD Portrayal, Anticipated Responses, and the Battle of Stigma. Anticipated responses contained two subthemes: In the Workplace and Disbelief/Misunderstanding. These themes illustrate how the stigmatization of OCD negatively impacted the likelihood of disclosure.

Participants who did not have a medical or clinical diagnosis of OCD often downplayed the severity of their OCD. This finding is consistent with that of Robinson et al. (2017), who found that individuals were hesitant with disclosure as they were convinced their OCD was manageable and that they did not "deserve treatment" (p. 202). Additionally, participants who reported having high functioning OCD explained that their OCD was not a significant issue as it led to more productivity. High functioning OCD was presented as taking on an excessive workload, worrying about failure in life/school, and having a rigid routine. These participants reported feeling as though they did not have the "stereotypical" form of OCD, which deterred them from seeking treatment.

Societal and mediated portrayals of OCD was reported on negatively by the participants. Their perceptions were affected by underrepresented portrayals and responses to OCD. Some said that this influenced them to avoid seeking treatment or to not fully understand the disorder. Many individuals recorded that, due to the stereotypical representation, they did not know they had OCD. This finding is consistent with the data collected by Fennell and Boyd (2014), who described that stereotypical OCD behaviors in the media can lead to individuals being undiagnosed for years. Fennell and Boyd (2014) additionally stated that individuals were divided on media reactions to OCD representation. Some participants saw it as humor to amuse viewers and others said the portrayal was completely stigmatizing. These results contradicted the current study, as participants did not view OCD representation as humorous and found that it needed to be corrected. Individuals felt that accurate portrayals would have been beneficial for their early understanding of self and OCD.

Participants described that the stigma surrounding OCD inhibited disclosure, which endorses the findings from Fennell and Liberato (2007) and Robinson et al. (2017). Individuals explained that the stigma caused by OCD was often from misrepresentation. This finding correlates with the study performed by Fennell and Boyd (2014) who explained that society stigmatizes OCD in a different way than other mental health disorders. In addition, many participants reported masking their OCD behaviors in public settings, which upholds Goffman's (1963) term of "passing." Furthermore, individuals recalled making excuses for their OCD behavior, which aligns with the findings from Fennell and Liberato (2007). They stated that individuals created excuses in order to appear natural in an environment. If participants were unable to pass in the moment, they explained how they would think about how to complete their compulsions once they were alone. Ultimately, the misunderstanding of OCD reinforces the societal expectations for individuals to conceal such a stigmatized disorder. Without portraying OCD correctly, the stigma surrounding OCD will continue, further silencing the voices of those with the disorder as they hide behind misunderstood explanations for their behavior.

Lastly, inaccurate portrayals of OCD create a false reality of what it is, which can lead to public misunderstanding. This was demonstrated by Earl, who volunteered for the study with an incorrect perspective on OCD. Earl stated, "I like my stuff neat, but I don't feel like it has to be a certain way. I just don't like messes and stuff." Later on in the interview, Earl explained that he did not believe he had OCD, but also only understood the stereotypical display of the disorder, which was organization. Earl's inaccurate comprehension of OCD is ultimately due to media and societal messages he received. After explaining aspects of OCD to Earl, he stated that the messages he received did not revolve around "a fear of something happening" but rather "making sure everything's right and in order." Thus, not only does OCD misrepresentation and stereotypes impact individuals with OCD, but it also provides a perception to the public that they have OCD as well. Due to Earl never receiving credible and accurate representations of OCD, this led to him perceiving himself as someone with OCD, which furthers the stereotype.

RQ3: When disclosing OCD, how do individuals enact privacy ownership and control?

The purpose of RQ3 was to uncover how the data from individuals with OCD would reflect the components of CPM theory when disclosing private information about the disorder. Three overarching themes that emerged from RQ3 included Privacy Boundaries, Familial Environments, and Labelling. These themes showcase the importance of applying the framework of CPM theory to understand how individuals maintain privacy boundaries and control.

When setting privacy boundaries, participants explained that the boundaries were mainly implied. This supports the findings of Hall (2020). Just as Hall (2020) explained, participants did not create boundaries within friendships due to inferred trust. Similar to the theme from RQ1 regarding how participants desired support when disclosing with friends, reassurance and confirmation were used in privacy boundaries as well. Individuals explained how, before disclosing their OCD, they would often ask if it was permissible to tell their private information to the

listener beforehand. By enacting this strategy, participants were demonstrating the importance of the private information before disclosing. This finding supports Petronio's (2015) notion of thick boundaries within the CPM theory, as participants strategized who had access to their private information. Overall, by asking for permission to disclose or not explicating stating boundaries, participants demonstrated implicit privacy control strategies for the importance of wanting to maintain the relationship's trust.

The theme of familial environments partially supported the results from Hammonds (2015). The finding that aligned with Hammond (2015) is that the strong perceived degree of open communication in the family led to a higher likelihood of disclosure. However, participants also described that a better quality, parent-child relationship increased the likelihood of disclosure, which contradicts Hammonds (2015). This finding demonstrates that participants valued the strong parent-child relationship, and many individuals considered their parents to be strong confidants. Individuals reported that if their families were supportive and understanding, this ultimately benefited the participant and their relationship with family members.

Participants explained that they expected their private information to stay between the relationship. Furthermore, some individuals stated that if the confidant involved a third party, it was permissible if the confidant needed support. As mentioned in RQ1, participants stated that it was acceptable if a confidant talked about their OCD for educational purposes. In addition, the findings also supported the study performed by Hall (2020) which stated that participants accepted if a confidant disclosed to others for personal assistance on the topic. This is an example of confidant privacy dilemmas, which is classified under CPM theory. Overall, while participants did not want their OCD to be shared without their permission, if a confidant needed to find personal support through the situation and talk to others, this was approved.

Finally, participants explained that, due to the stigmatization of OCD, they often did not give the full extent of their disorder in disclosure. Additionally, some participants explained how they would label their OCD under different names or not use the term "OCD" entirely. This finding aligns with the CPM theory as Petronio (2015) stated that individuals have a choice to communicate their private information while maintaining personal autonomy. Thus, by concealing their OCD in disclosure, participants fundamentally maintained privacy boundaries and control. Overall, the stigmatization of the disorder impacted how participants disclosed about their OCD as individuals did not want to be misunderstood or viewed differently which was demonstrated through the use of labelling.

# CONCLUSION

Overall, the study analyzed the factors that facilitate and inhibit OCD disclosure as well as how individuals with OCD establish privacy management. The themes that emerged demonstrated that the stigmatization of OCD had both constructive and destructive impacts on individuals. In order to create change, participants who were more comfortable identifying with their OCD, were motivated to set the record straight and break the stereotype surrounding OCD. They had patience to explain to others how certain phrases could be harmful and had the courage to share their story with OCD in front of large groups or online. Furthermore, the formality of OCD medical articles on the Internet encouraged participants to find support through Instagram OCD advocacy pages where they embraced seeing others who experienced similar obsessions, compulsions, and/or intrusive thoughts. The sense of community, both online and with a researcher who has OCD, was valued as the participants found a place of comfort and shared true vulnerability that society does not endorse. However, the stigmatization of OCD also led individuals to be afraid of disclosure due to negative anticipated responses. Participants reported not wanting to be misunderstood or viewed differently. Additionally, due to the misrepresentation of OCD in the media and society, several participants stated that this impacted their understanding of their own OCD. Ultimately, this led to some individuals having a lack of a diagnosis which was harmful in how participants saw their opportunities to seek help or disclose.

When disclosing, the quality of the relationship was crucial. Participants reported disclosing to confidants who were non-judgmental, supportive, and trustworthy and oftentimes, privacy boundaries were implied due to the nature of the relationship. Lastly, the stigmatization of OCD also impacted how individuals communicated about their OCD as many participants reported labelling their OCD under a more societally accepted term and did not disclose the full extent of their OCD or its severity. In conclusion, participants in this study illustrated the desire for more of an understanding of OCD in society as it could benefit those who are being impacted and lead to proper awareness. However, despite the societal stereotypes that are being reinforced, individuals are using their voices to speak out and deconstruct the misunderstanding. While participants tell their story to educate others about OCD, this is not where change solely begins. As a reader, you now have the knowledge and understanding to correct those around you and tell the stories of these participants who wanted to make a difference. Let us join together to break

the stigma and vow to never use the phrase "I am so OCD" without knowing the harm this can cause both on a societal level but an individual one as well.

# LIMITATIONS AND FUTURE DIRECTIONS FOR RESEARCH

There were several limitations in the study. First, the study did not require participants to have a professional diagnosis of OCD. This allowed for comparison between participants who were self-diagnosed versus individuals who had a clinical diagnosis. However, to allow for more consistency between participants and increased concentration, future researchers could perform studies focusing on those two variables. Second, the study had a total of 12 participants which limited the total scope of the research. Additionally, race was not a documented variable in the study. Thus, in order to analyze how the stigmatization of OCD impacts those in the minority, further research is required. Lastly, the average age of the participants was 21 years old. This younger age range fails to account for the vast majority of individuals who have OCD. In order to improve accuracy, additional studies should focus on aiming toward a wider range of each of the four total variables: age of individuals, OCD diagnoses, race, and an increased count of participants.

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# REFERENCES

- American Psychiatric Association. (2013). Diagnostic and statistical manual of mental disorders (5<sup>th</sup> ed.). <u>https://doi.org/10.1176/appi.books.9780890425596</u>
- Braithwaite, D. O., & Schrodt, P. (2015). *Engaging theories in interpersonal communication: Multiple perspectives* (2nd ed.). Sage Publications, Inc.
- Doron, G., Derby, D. S., Szepsenwol, O. (2013). Relationship obsessive-compulsive disorder (ROCD): A conceptual framework. *Journal of Obsessive-Compulsive and Related Disorders, 3*(2), 169-180. https://doi.org/10.1016/j.jocrd.2013.12.005
- Fennell, D., & Boyd, M. (2014). Obsessive-compulsive disorder in the media. *Deviant Behavior*, 35(9), 669–686. https://doi.org/10.1080/01639625.2013.872526
- Fennell, D., & Liberato, A. S. (2007). Learning to live with OCD: Labeling, the self, and stigma, deviant behavior. Journal of Deviant Behavior, 28(4), 305-331. <u>https://doi.org/10.1080/01639620701233274</u>
- Goffman, E (1963). Stigma: Notes on the management of spoiled identity. Simon and Schuster Inc.
- Hall, R. (2020). Between friends, an "implicit trust": Exploring the (non)disclosure of private mental health-related information in friendships. *Ohio Communication Journal*, (58), 26-39.
  <u>https://www.researchgate.net/publication/339274814\_Between\_friends\_an\_implicit\_trust\_Exploring\_the\_n</u> ondisclosure of private mental health-related information in friendships
- Hammonds, J. R. (2015). A model of privacy control: Examining the criteria that predict emerging adults' likelihood to reveal private information to their parents. *Western Journal of Communication*, 79(5), 593-613. <u>https://doi.org.libweb.uwlax.edu/10.1080/10570314.2015.1083117</u>
- Mickles, M. S., & Weare, A. M. (2020). Trying to save the game(r): Understanding the self-disclosure of YouTube subscribers surrounding mental health in video-game comments. *Southern Communication Journal*, 85(4), 231-243. <u>https://doi-org.libweb.uwlax.edu/10.1080/1041794X.2020.1798494</u>
- National Institute of Mental Health. (2019). *Obsessive-Compulsive Disorder*. <u>https://www.nimh.nih.gov/health/topics/obsessive-compulsive-disorder-ocd/index.shtml</u>
- Petronio, S., & Bantz, C. (1991). Research note: Controlling the ramifications of disclosure: `Don't tell anybody but...' *Journal of Language and Social Psychology*, 10(4), 263-269. https://doi.org/10.1177/0261927X91104003
- Petronio, S. (2015). Communication privacy management theory. *International Encyclopedia of Interpersonal Communication*. <u>https://doi.org/10.1002/9781118540190.wbeic132</u>
- Robinson, K. J., Rose, D., & Salkovskis P. M. (2017). Seeking help for obsessive-compulsive disorder (OCD): A qualitative study of the enablers and barriers conducted by a researcher with personal experience of OCD. *The British Psychological Society*, 90, 193-211. https://doi.org/10.1111/papt.12090
- Stein, D. A. (2002). Obsessive-compulsive disorder. *The Lancet*, *360*(9330), 397-405. https://doi.org/10.1016/S0140-6736(02)09620-4
- Wilson, S. R., Hintz, E. A., MacDermind Wadsworth, S. M., Topp, D. B., Southwell, K. H., & Spoont, M. (2019). Female U.S. military veterans' (non)disclosure of mental health issues with family and friends: Privacy rules and boundary management. *Health Communication*, 36(4), 1-12. <u>https://doi.org/10.1080/10410236.2019.1693128</u>
- Yeo, T. E. (2020). "Do you know how much I suffer?": How young people negotiate the tellability of their mental health disruption in anonymous distress narratives on social media. *Health Communication*, 1-10 <u>https://doi.org/10.1080/10410236.2020.1775447</u>
- Zambaldi, C. F., Cantilino, A., Montenegro. A. C., Paes J. A., de Albuquerque, T. L. C., & Sougey, E. B. (2009). Postpartum obsessive-compulsive disorder: Prevalence and clinical characteristics. *Comprehensive Psychiatry*, 50(6), 503-509. <u>https://doi.org/10.1016/j.comppsych.2008.11.014</u>