Exploring the Lived Experience of Individuals with Primarily Obsessional Obsessive-Compulsive Disorder (OCD): A Qualitative Study Focusing on Relationships and Help-Seeking

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Abstract

There has been little research focused specifically on individuals experiencing primarily obsessional obsessive-compulsive disorder (OCD). Primarily obsessional OCD is typically characterised by unwanted thoughts of a sexual, violent, or blasphemous nature with covert compulsions such as mental rituals (e.g., repeating phrases), or reassurance-seeking. Individuals with primarily obsessional OCD can experience shame and may fear seeking professional help. Furthermore, research suggests that the themes of intrusive thoughts in primarily obsessional OCD can be stigmatised by the public and misinterpreted by mental health professionals. The aim of the present study was to gain a broad understanding of how individuals with primarily obsessional OCD experience their relationships and help-seeking in the context of their lives. Online qualitative surveys were used to collect data from 70 participants aged between 18– 68 years, who either self-identified as, or had received a formal diagnosis of primarily obsessional OCD. Surveys served as one recruitment tool among others to identify participants willing to take part in an online or telephone interview. Four participants took part in the interview. The survey data and interview transcriptions were analysed using reflexive thematic analysis informed by a critical realist perspective. The thematic analysis led to the development of four overarching themes. These were 1. "*The Social Isolation of OCD: Physically and Psychologically Distancing and Disconnecting from Close Relationships*", 2. "*Hidden in Plain Sight: The Predicament of Disclosure*", 3. "*Perceived Misunderstanding and Misinterpretation of OCD in Personal and Professional*

Contexts” and 4. “*Support Outside the Therapy Room – Help or Hinderance?*”. Each theme reported on different challenges that participants faced in managing their OCD in the context of their interpersonal lives, as well as issues arising when they attempted to seek support within professional therapeutic contexts. The findings suggested that individuals with primarily obsessional OCD can struggle to feel supported both within their interpersonal relationships and within a professional help seeking context. This suggests that counselling psychologists and other mental health professionals need to consider the interpersonal difficulties these individuals face that could be adding to their distress and consider involving family or partners in their therapy. Furthermore, they need to support individuals’ understanding of their experience and to respect and work with their perspective and how they choose to define their experience.

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Introduction

The National Institute for Health and Care Excellence (NICE) (2005), report that between 1-2% of the population of the UK are thought to live with obsessive compulsive disorder (OCD). However, these figures likely underestimate the number of people living with OCD, given the complex and heterogeneous nature of the condition, delays in receiving a diagnosis and barriers to professional help-seeking. In this introduction I provide an overview of how OCD is defined and the heterogeneity between different presentations. The differentiation in OCD characteristics have been grouped into clusters forming dimensions which will be broadly highlighted. I will then define and elaborate upon the dimension that is the focus of the present research, referred to herein as primarily obsessional OCD. I provide an overview of the different therapeutic approaches employed by counselling psychologists (CoP), and other mental health professionals when working with individuals with OCD to provide further context. I highlight pertinent issues in the general OCD literature regarding conceptualisations of self, interpersonal problems, and help-seeking that have not been explored directly in relation to primarily obsessional OCD specifically. I will also review the limited literature that qualitatively explores lived experiences of OCD in general. Due to the limited literature specifically on primarily obsessional OCD, I will consider what might be learnt from this in relation to primarily obsessional OCD.

Due to the limited reference to OCD within the counselling psychology literature, I will draw upon the ethos and values of counselling psychology and how my approach to the research is situated within them. Key considerations that demonstrate the study’s grounding in counselling psychology will be: i) a critical approach to medicalised definitions of OCD; ii) a central focus on the relevance of OCD in the context of people’s lives and lived experiences; iii) the value of knowledge derived from subjective experiences;, and iv) the importance of giving voice to marginalised groups. Finally, I will present my aim and research questions that have guided the current study. While the study takes a non-pathologising stance grounded within the ethos and values of counselling psychology, more medicalised and diagnostic terminology will be used within the literature review to reflect the predominant stance taken in the existing literature.

Obsessive-Compulsive Disorder

Living with obsessive-compulsive disorder (OCD), is understood to be a potentially debilitating experience. Researchers have estimated that 1.5% of women and 1.0% of men worldwide will experience OCD in their lifetime (Fawcett et al., 2020; Torres et al., 2006). OCD is characterised by obsessions and compulsions (American Psychiatric Association, 2013). Obsessions are persistent unwanted thoughts, images, and urges such as thoughts that one is contaminated or inappropriate sexual thoughts. Approximately 55% of those with OCD may experience obsessions without compulsions but others experience both obsessions and compulsions (Torres et al., 2006). Compulsions, which some with OCD feel compelled to perform in response to obsessions, are described as repetitive behaviours or mental acts such as excessive cleaning, checking, or counting (APA, 2013). It is suggested that individuals with OCD who perform compulsions do so to avoid or relieve the distress arising from their obsessions, and in attempt to prevent harm to themselves or others (APA, 2013; Rachman, & De Silva, 2009). However, although engaging in compulsions might offer short-term relief, in the long term they can exacerbate obsessional thinking (Salkovskis, 1999; Wegner, 1994).

Researchers have attempted to categorise OCD symptoms into dimensions based upon the characteristics of obsessional thinking. In a recent meta-analysis, Bloch et al. (2008), created four symptom dimensions of OCD obsessions and associated compulsions:

i) symmetry obsessions which could relate to compulsive counting, ordering, and repeating.

ii) contamination obsessions linked to cleaning compulsions

iii) hoarding obsessions related to behavioural hoarding compulsions, and

iv) a forbidden thoughts dimension related to sexual, aggressive, religious, and somatic obsessions linked to checking compulsions (Bloch et al., 2008).

Grouping obsessive-compulsive phenomena into dimensions does not imply there is no overlap across dimensions but that certain obsessions and/or compulsions may be more dominant than others in severity (Mataix-Cols et al., 2005). Although some with OCD might experience symptoms solely within a specific dimension, some research suggest that OCD symptom constellations may change over time (Besiroglu et al., 2007; Rettew et al., 1992). However, other research suggests that symptom dimensions typically remain temporally consistent (Fullana et al., 2009). This along with other research highlights the diversity of presentations of OCD and further exemplifies the heterogeneity of the disorder (McKay et al., 2004). Few studies have explored dimension-specific experiences of OCD; hence the differing presentations of OCD have been overlooked revealing a gap in the literature the current project will contribute to (Bhattacharya, & Singh, 2015; Brooks, 2011).

Forbidden/Unacceptable Thoughts and Primarily Obsessional OCD

It has been estimated that obsessions involving “forbidden thoughts”, are experienced by 25% of individuals with OCD (Bloch et al., 2008; Frost & Steketee, 2002; Moulding et al., 2014). These can be characterised by sexual (e.g., sexually abusing children), aggressive (e.g., murdering a loved one), or blasphemous (e.g., committing adultery) themes (Moulding et al., 2014). Obsessions of this nature are thought to be a defining characteristic of a dimension of OCD referred to as “forbidden thoughts” (Bloch et al., 2008). This presentation of OCD has also been defined as “unacceptable thoughts" and "taboo thoughts" (Abramowitz et al., 2003; Pinto et al. 2008). This terminology reflects the idea that the content of these thoughts can be seen as shameful and morally challenging to individuals experiencing them.

The forbidden/unacceptable thoughts dimension of OCD will be referred to in the present study as primarily obsessional OCD (Bloch et al., 2008). Primarily obsessional OCD was historically labelled 'pure obsessional’ or “Pure O” because it was believed that it was not associated with compulsions, but rather only with obsessional thoughts (Baer, 1994; Bloch et al., 2008; Clark & Guyitt, 2007; Rachman, 1971). However, researchers have identified that those with obsessional thoughts do sometimes experience associated covert compulsions such as mental rituals (e.g., praying), reassurance seeking (e.g., telling others about obsessions to try to alleviate anxiety), checking (e.g., checking bodily responses to thoughts), and avoidance (e.g., avoiding places or people associated with thoughts) (Rachman, 2003; Williams et al. 2011). Due to this association with covert compulsions and the suggestion that “Pure O" may be a misnomer, the terms have changed within the literature (Clark & Guyitt, 2007). It was originally decided that the term “Pure O” would be used in the current study because it is still commonly used on websites, forums, media and books related to OCD (e.g., Cartwright, 2019), and reflects how those experiencing the related characteristics refer to their OCD. However, following data collection, progression feedback and personal deliberation, I have chosen to use the term primarily obsessional OCD to avoid using a potentially misleading term. Though, the term Pure O was drawn on initially for example in recruitment materials, as this may still be meaningful for many. The terms used by authors of previous literature (e.g., unacceptable thoughts, repugnant obsessions), will be drawn upon when discussing their research, but the term primarily obsessional OCD will be used in the current project to refer to individuals who experience unacceptable intrusive thoughts. This term will be used to concisely capture the largely covert nature of this type of OCD but not exclude the idea that individuals can also engage in compulsions.

Research looking at specific OCD dimensions has predominantly focused on contamination, cleaning, and checking symptoms, but unacceptable thoughts have not received as much attention (Ball et al., 1996; Sookman et al., 2005). Research suggests that mental rituals are significantly more prevalent within the unacceptable thoughts dimension, than other OCD dimensions, and those experiencing them can encounter greater symptom severity and long-term effects of OCD than those who do not (Abramowitz et al., 2003; Sibrava et al., 2011). This suggests that although the characteristics of primarily obsessional OCD are not necessarily observable by others, the associated covert compulsions can have a significant impact on people's lives.

Themes of ‘Unacceptable’ Obsessions and Implications for Primarily Obsessional OCD

Although there is limited literature focusing on primarily obsessional OCD, as I will highlight below, each of the obsessional themes typically associated with this dimension have been considered to a certain extent within the literature. Of note, is how the presence of these types of thoughts can present personal challenges for the individual experiencing them but also for therapists who may misunderstand these obsessions in a professional help-seeking context. As discussed, unacceptable thoughts typically involve intrusive thoughts related to religion or blasphemy, sexual, or aggressive themes (Moulding et al., 2014). Research on each theme will now be reviewed and implications for those with primarily obsessional OCD will be drawn out.

Religious Obsessions

Individuals who have been taught, or have learnt, to attach values to thoughts such as through religious teachings may be more vulnerable to obsessive thinking (Rachman, 1997). The term 'scrupulosity' is used to describe a phenomenon in OCD, where an individual fears that their thoughts or actions are immoral and represent them acting against their religious or moral values (Huppert & Siev, 2010). Religious obsessions typically involve blasphemous thoughts or images, fears around sinning, or behaviour incongruent with religious rules and fear of punishment from a divine power (Buchholz et al.,2019). Although religious scrupulosity can be found in different types of OCD, there is a strong association with unacceptable thoughts (Buchholz et al., 2019). OCD with religious themes can be a sensitive area to address for mental health professionals (Huppert & Siev, 2010). This sensitivity could be due to the possibility that religious communities might reinforce and reiterate these obsessions through the commendation of ritualistic practices and provide reassurance to those inclined toward excessive confession (Huppert & Siev, 2010). It is important to consider religious affiliation and cultural norms in the assessment of OCD to avoid the misinterpretation of religious beliefs or practices as indicators of OCD. For example, highly religious individuals without OCD may be more inclined to associate thinking or writing about aversive thoughts with immorality, compared to non-religious individuals (Berman et al., 2010). This highlights the complexity in assessing individuals who present with religious obsessions in ways that seek to relieve distress, but without pathologising religious and cultural values and practices (BPS, 2005).

Association has also been found between scrupulosity and unacceptable thoughts in individuals without religious affiliation (Buchholz et al., 2019). This suggests that counselling psychologists and other mental health professionals should endeavour to have a strong understanding of the types of moral values that individuals with primarily obsessional OCD might hold; the significance of those values to the individuals; and how their wider social and cultural context may impact their perception of intrusive thoughts. This research further suggests that scrupulosity can also be associated with individuals who have rigid moral values that are not necessarily a product of religious teaching. The relationship between self-concept, including one's values and standards seem to be an important factor in the experience of obsessional thinking and potentially the personal significance of primarily obsessional OCD.

Sexual Obsessions

As noted more broadly, intrusive thoughts may be common in the general population, but it is the interpretation of these thoughts that is critical in relation to OCD. This includes in relation to sexual intrusive thoughts (Julien et al., 2007; Real et al., 2013), whereby distress associated with sexual intrusive thoughts is also thought to be attributable to the personal significance individuals attach to them (Wetterneck et al., 2011). Intrusive sexual thoughts are ego-dystonic meaning that they are incongruent with the individual's perception of themselves (Aardema et al., 2013; Colman, 2015; Lee & Kwon, 2003). Intrusive sexual thoughts can include themes such as pedophilia, incest, aggressive sexual acts, or doubts about one’s sexual orientation (Real et al., 2013). The frequency of sexual intrusive thoughts is thought to relate to beliefs about sexual desire, those who perceive sexual desire as threatening can experience a higher frequency of sexual intrusive thoughts (Wetterneck et al., 2011). Sexual orientation obsessions can involve intrusive thoughts that are incongruous with one's sexuality or characterised by a fear that others might misinterpret one's sexuality (e.g., a heterosexual man experiencing intrusive thoughts about being attracted to a male friend), (Goldberg, 1984; Williams, 2008; Williams et al. 2015). Sexual orientation obsessions may be misconstrued by professionals who may interpret clients as distressed by difficulties in accepting their sexual identity which can inadvertently make the problem worse by reinforcing the individual's fears (Williams, 2008). This suggests that sexual obsessions in relation to OCD can be poorly understood and further research is needed to add to the current understanding about how these obsessions are experienced. As sexual intrusive thoughts can be one of the defining characteristics of primarily obsessional OCD, individuals with this OCD dimension may be particularly prone to misunderstandings from others about these obsessions.

Aggressive Obsessions

Aggressive obsessions can be very troubling for individuals with OCD and often involve thoughts about harming loved ones and the fear of acting upon such thoughts (Moulding et al. 2014). For example, mothers may fear that they might sexually abuse their children or harm their baby (Fairbrother & Woody 2008; O'Connor & Aardema, 2011). Although these thoughts can feel highly distressing and emotionally significant, the distress occurs due to the strongly held values (e.g., benevolence and non-violence) that are in opposition to the content of such thoughts (Rowa et al., 2005). Therefore, preoccupation with violent or aggressive thoughts in primarily obsessional OCD is not indicative of risk, nor intent, but rather the opposite; an intense fear of acting against a benevolent value system. Clinicians may fail to recognise the association between violent intrusive thoughts and OCD which can in turn lead to an overestimation of risk in this population (Booth et al., 2014). It can be difficult for psychologists to make judgments around risk, but this goes to show the need for additional learning around the recognition of violent obsessions as a feature of OCD rather than a risk (BPS, 2017).

Influence of Diversity and Context

A potentially influential factor in how individuals experience primarily obsessional OCD is their socio-cultural context. There is a paucity of research comparing OCD experiences cross-culturally, limiting our understanding of contextual influences (Nicolini et al., 2018). However, the literature that exists indicates that experiences of intrusive thoughts can vary across cultural and religious context (Williams et al., 2017). For example, it has been noted that sexual orientation obsessions have been detected within western culture but not in other culture settings (Williams et al., 2017; Williams & Farris, 2011). Despite limited literature to explain this difference, it has been speculated that societal perceptions in the West of 'non-heterosexual' sexualities may hold some influence (Williams et al., 2017, p.58). Furthermore, religious affiliation such as western Christianity may influence beliefs associated with the maintenance of OCD such as the importance and need to control thoughts (Abramowitz et al., 2004; Williams et al., 2017). As discussed previously, religious rules may be relevant. For example, higher rates of thought-action fusion (TAF) and need to control thoughts has been observed in western Christians, and it is thought that biblical assertions regarding sinfulness of thoughts may explain this (Abramowitz et al., 2004; Williams et al., 2013).

The existing OCD literature has typically been conducted within a western context, representing individuals with OCD with white ethnic backgrounds. Therefore, little is known about how diverse ethnicities experience OCD

(Fernández de la Cruz et al., 2015). Research looking into perceptions relating to OCD among parents with diverse ethnicities in the UK indicates that ethnicity may influence illness perceptions, knowledge, and views on help -seeking (Fernández de la Cruz et al., 2015). For example, differences around social support showed that ‘ethnic minorities’ were more likely to seek support from religious communities than white British participants (Fernández de la Cruz et al., 2015, p. 455). The OCD literature suggests that broad themes of OCD characteristics may be observed across most cultures that share similar cultural attitudes, but there is also variation in the specifics of such characteristics relating to specific cultural practices (Ghassemzadeh et al., 2002). For example, in an Islamic cultural context, religious influences and cultural taboo may be associated with a greater concern with sexual obsessions than other cultures (Karadağ et al., 2006). Considering the insights discussed, it may be that the tendency for OCD research to represents predominantly white western populations may miss important ethnic, cultural and religious contextual nuances. The minimal diversity seen across samples in the existing literature may present a picture of how primarily obsessional OCD may manifest within western culture but may not be indicative of important nuances associated with diverse ethnicities, cultures and religions.

Personal Significance and Perceptions of Self in Primarily Obsessional OCD

The Role of Personal Significance in OCD

Although people without OCD may experience intrusive thoughts, it is the personal significance attributed to them that distinguishes obsessive thinking in OCD from what are deemed 'normal' experiences of intrusive thoughts (Rachman, 1997). Cognitive-behavioural theorists suggest that intrusive thoughts can be interpreted by individuals with OCD as having the same moral significance as acting out the thought, which has been termed TAF (Rachman, 1993; Shafran et al., 1996). Individuals would therefore perceive the occurrence of thoughts as a transgression of their moral principles, despite the absence of any associated action. Individuals with strong values may be more likely to become distressed by thoughts that are incongruous with those values (Rachman, 1998). This indicates that the unacceptability of thoughts for individuals with primarily obsessional OCD and the distress they cause will be dependent upon the personal significance of the thoughts and the threat presented to their individual value system.

Negative Self Perceptions and Shame

Unacceptable thoughts may be more ego-dystonic than other types of obsessions, meaning they are incongruent with the individual's perception of themselves (Aardema et al., 2013; Colman, 2015; Lee & Kwon, 2003). Lee and Kwon (2003) proposed that unacceptable thoughts are autogenous, whereby they are generated internally, rather than through environmental influence (e.g., a thought of murdering someone occurring without any reason rather than being prompted by a particular stimulus). Perhaps unsurprisingly, these are often perceived by the individual as threatening. Not only are unacceptable thoughts unwanted, but so too are they associated with individuals' shame and self-doubt, leading to negative self-perceptions of being "unsafe" to others or "on the verge of going crazy" (Rachman, 2003, p. 6; Weingarden & Renshaw, 2015). Those affected can begin believing that the thoughts indicate that they are a "bad person" (Sookman & Pinard, 1999). Individuals with OCD may make greater negative inferences about the self and conceptualise a "feared self" that is deemed to be insane or immoral (Ferrier & Brewin, 2005). Individuals can therefore keep their intrusive thoughts a secret due to associated shame and to avoid revealing this feared identity to others (Rachman, 2003; Williams & Wetterneck, 2019). Experiences of shame may also affect how much OCD impacts on individuals lives as it has also been found that OCD related shame is negatively correlated with quality of life (Singh et al., 2016). These insights suggest that individuals with primarily obsessional OCD may perceive themselves in a negative light, experience shame related to their intrusive thoughts and question their sense of morality.

Different Theories to Explain Self-Concept in OCD

Numerous explanatory models have been developed to understand the relationship between self-concept and OCD (Ahern & Kyrios, 2016). Although it is beyond the scope of this thesis to discuss every model, two examples will be given. First, I will outline the psychoanalytic perspective that is underpinned by traditional theory of unconscious conflicts. Second, I will illustrate how attachment theory is utilised to explain a possible association between early relational experiences, the development of self-concept and OCD.

Psychoanalytic Perspective of Self-Concept in those with OCD

Psychoanalytic approaches have also offered some insights into self-concept through explanations of the psychic processes that may underlie concerns around the self for those with OCD. Traditional psychoanalytic theory suggested that OCD arises because of an unconscious conflict between the id and a rigid superego. The id is defined as an unconscious part of the personality which is believed to encompass our primitive (sexual and aggressive), impulses and the rigid superego is the part of personality that encompasses our conscience and the social and moral rules for appropriate behaviour (King, 2017). This traditional perspective suggests that individuals' personalities can develop in opposition to these underlying sexual and aggressive impulses (Freud, 1926,1959; Kempke & Luyten, 2007). In other words, individuals with OCD may have developed highly conscientious personalities as a defensive process to deter the threat of aggressive impulses coming into fruition.

Attachment Theory, Self-Concept, and OCD

More recent literature has suggested that the quality of early attachment with caregivers should be taken into consideration to understand beliefs about the self and others and behaviours associated with OCD (Van Leeuwen et al., 2020). Broadly, attachment theory suggests that the quality of early relationships with caregivers gives rise to internalised conceptualisations of the self, and expectations of how others may respond to our needs (Bowlby, 1973, 1980, 1982). Insufficient, overwhelming or abusive responses from early caregivers are thought to lead to the development of insecure attachment styles (patterns of relating to oneself and others) that affect how individuals behave within the context of their relationships, and how they learn to regulate their emotions (Mikulincer & Shaver, 2007). Insecure attachment styles such as anxious/ambivalent and avoidant attachment styles developed in childhood and that later manifest in adulthood may be relevant to understanding the characteristics of OCD (Bartholomew & Horowitz, 1991; Bartholomew, 1997; Brennan et al., 1998; Kempke & Luyten, 2007; Van Leeuwen et al., 2020). An anxious/ambivalent attachment style is thought to be the consequence of contradictory communications of warmth and rejection from caregivers in early life. These are understood to leave the child – and later the adult -unsure whether they are likely to be loved and accepted or unloved and rejected by others (Guidano, 1987; Guidano & Liotti, 1983; Kempke & Luyten, 2007). An ambivalent attachment style may help to explain individuals with OCD's uncertainty about whether they are a good or bad person (Guidano, 1987; Guidano & Liotti, 1983; Kempke & Luyten, 2007). This experience leads the child to attempt to resolve this uncertainty by imposing high moral standards on themselves to lean into positive ideas about the self and in attempt to eliminate negative aspects (Guidano & Liotti, 1983). The pursuit of certainty about the acceptability of the self may also be consistent with literature indicating that anxiously attached adults tend to excessively seek reassurance from others in anxiety evoking situations (Mikulincer et al., 2003; Van Leeuwen et al., 2020). This suggests that individuals with primarily obsessional OCD may feel unsure about who they really are, have highly moralistic expectations of themselves, have a desire to achieve certainty about the nature of their character and attempt to achieve this by seeking reassurance from others. Having explored different theories of self-concept, I turn now to explore the different forms of therapeutic support that those with OCD might encounter should they seek advice from CoPs and mental health professionals.

Therapeutic Support

There is an array of therapeutic approaches to support individuals with OCD. The counselling psychology literature describes the use of functional analytic psychotherapy (FAP), an approach that utilises the therapeutic relationship as a vehicle for behavioural change (Kohlenberg & Tsai, 1987; 1991: Vandenberghe, 2007). This involves working with obsessive-compulsive phenomena within the context of the therapeutic relationship (Vandenberghe, 2007). Vandenberghe (2007), exemplifies this with a clinical vignette of a client with compulsive reassurance-seeking. The therapist withholds reassurance in the therapeutic encounter and instead shares how it makes them feel to be asked and coerced to give reassurance by the client. On one hand, this enables the client to understand how others might feel outside of the therapeutic relationship when reassurance is asked for, but also as the therapist withholds the reassurance the client learns to tolerate the occurrence of an obsession without being able to fulfil the compulsive response (Vandenberghe, 2007). Research has suggested that FAP may be an efficacious transdiagnostic approach (Kanter et al., 2017). However, it has been indicated that further research is needed to support FAP's efficacy for different psychological problems (Kanter et al., 2017; López-Bermúdez et al., 2021).

Furthermore, the literature also refers to the use of psychodynamic therapy for OCD which involves exploring and interpreting unconscious mechanisms and meaning associated with obsessions and compulsions (Chlebowski & Gregory, 2009; Lang, 1997). There is limited research to support the efficacy of psychodynamic therapy for OCD and this approach is not recommended by the NICE guidelines (Gibbons et al., 2008; King, 2017; NICE, 2005). Some have argued this is due to the lack of research to support the effectiveness of psychodynamic therapy and the difficulty in testing the efficacy using randomised control trials (King, 2017; Leichsenring, 2005). However, some have argued that a psychoanalytically informed approach can be helpful for those with OCD to help them to understand the interpersonal meaning behind obsessions and compulsions and the dynamics of how OCD is managed within families (Gabbard, 2001; King, 2017). This suggests that a psychoanalytically informed approach may consider the social context and the meaning individuals connect to unacceptable thoughts which may be helpful for those with primarily obsessional OCD.

Cognitive-Behavioural Approaches

Despite the existence of alternative approaches to help those with OCD, the NICE guidelines recommend cognitive behavioural therapy (CBT), with exposure and response prevention (ERP) (NICE, 2005). Research published before these guidelines indicates that this was already the most common type of therapy (NICE, 2005; Roth & Fonagy, 2004). CBT is usually a time-limited therapy that focuses on here-and-now processes. When applied to OCD, CBT usually involves the identification and modification of irrational interpretations of obsessional thoughts (Salkovskis, 1999). It is these thoughts that evoke anxiety and can lead some to engage in compulsions (Salkovskis, 1999).

An array of cognitive-behavioural models have been developed to conceptualise OCD (Shafran, 2005). These models suggest that OCD occurs when normally occurring intrusive thoughts are misinterpreted and subjected to cognitive biases that lead individuals to perceive them as threatening (Purdon & Clark, 1999; Rachman, 1997; Salkovskis, 1985). It is thought that unhelpful beliefs and biases that individuals attribute to intrusive thoughts lead to anxiety and compulsions that keep OCD going (Shafran et al., 1996; McKay et al., 2015; Moulding et al., 2007). One example of a cognitive bias is over emphasising the importance of thoughts such as in TAF where it is believed that to think of an action increases the likelihood it will occur and that thoughts hold the same moral significance as actions (Rachman, 1993; Shafran et al., 1996). CBT therapists work with clients to identify and modify unhelpful appraisals of their intrusive thoughts (Salkovskis, 1999). There is an array of cognitive strategies that can be implemented. Cognitive techniques can include normalising intrusive thoughts (e.g., discussing their commonality in the population) and challenging unhelpful beliefs (e.g., disputing the belief that thoughts are important by asking the client to notice the frequency of unimportant thoughts they have that would usually go unnoticed) (Freeston et al., 2001; Salkovskis 1999; Salkovskis & Harrison, 1984). Cognitive exercises can also be used to highlight counterproductive coping mechanisms (e.g., demonstrating the futility of thought suppression by asking the client to not think about a particular object or animal) (Freeston et al., 2001; Salkovskis 1999). Cognitive strategies typically precede behavioral experiments to test the validity or usefulness of unhelpful beliefs and compulsions (e.g., challenging TAF by asking client to have thought about something happening over and over again and observe whether or not the thought comes into fruition) followed by further discussion to reflect on the outcome and learning from these experiments (Freeston et al., 2001; Salkovskis 1999).

It is thought that CBT can be used effectively on its own and in conjunction with ERP (Freeston et al., 2001). ERP is a structured behavioural intervention used in addition to CBT that involves asking the client to resist engaging in compulsions in response to anxiety provoking situations. For example, asking the client to resist washing their hands after touching a door handle that they believe is contaminated (Kennerley et al., 2016). CBT with ERP typically involves guiding clients to discover alternative interpretations of their obsessive thoughts and disprove irrational beliefs about the need to carry out compulsions (Salkovskis, 1999). In a meta-analysis of studies testing the efficacy of CBT to reduce OCD symptoms using the Yale-Brown Obsessive-Compulsive Scale as an outcome measure, symptom reduction was found in 50% of those that have this type of therapy (Goodman et al., 1989; Öst et al., 2015; Roth & Fonagy, 2004). This suggests that CBT may be successful in helping those with OCD.

Another form of CBT that is increasing popular and used to support those with OCD is acceptance and commitment therapy (ACT) (Hayes et al., 2011; Soondrum et al., 2022). ACT uses several techniques drawing from mindfulness and behaviourism to encourage clients to remain connected to the present moment without becoming intertwined, wrestling with, or trying to eliminate thoughts and emotions (Abramowitz et al., 2018). For OCD this may involve techniques to detach from unwanted thoughts and urges to engage in compulsions and rather identify and engage in meaningful behaviours (Abramowitz et al., 2018). While research on the efficacy of ACT for OCD is minimal as the approach is relatively recent, some research does suggest that it could be effective (Twohig et al. 2010).

Treatment Issues and Barriers to Help-Seeking

Despite the above research supporting the efficacy of cognitive-behavioural approaches, some researchers have drawn attention to potential treatment issues for those with OCD. Individuals experiencing unacceptable thoughts may be less responsive to treatment than other OCD presentations (Grant et al., 2006; Mataix-Cols et al., 2002; Rufer et al., 2006). Therefore, it may be that treatment needs to be more specialised to fit the variety of symptoms seen across dimensions and to improve treatment outcomes for those with primarily obsessional OCD (Williams et al., 2013). Furthermore, in research focusing on OCD in general, individuals reported that they would value sharing the narrative of their OCD in therapy, but that CBT had failed to involve this (Murphy & Perera-Delcourt, 2014). This suggests that the recommendation of CBT may not be uniformly appropriate and that such therapies may not adequately explore the meaning those with OCD attribute to their experience. Although cognitive theories of obsessional thinking provide an explanation of possible mechanisms involved and highlight the factor of personal significance, research has indicated that individuals with OCD can feel misunderstood by their therapist when engaging in CBT (Millar et al., 2020; Rachman, 1997). This suggests that in some cases the approach may fail to achieve a shared understanding of the personal significance unique to each individual. With limited qualitative accounts exploring experiences of individuals with OCD from their perspective, it may be that important and unique experiences that may aid therapists' understanding are overlooked. Considering the complexity of OCD, it seems crucial to broaden one's understanding of how people make sense of their experience considering individual and contextual differences.

Furthermore, while there is an array of potential therapeutic support, there are also many who may not seek support. On average, an OCD diagnosis is received 8 years after the onset of obsessions and compulsions (Wang et al., 2005). However, receiving a diagnosis would require treatment to be sought. Individuals experiencing unacceptable thoughts are often deterred from seeking treatment due to feeling ashamed of their symptoms, fearing judgement from others and hospitalisation (Glazier et al., 2015). Robinson et al. (2017), found that anticipated stigma from health professionals can also be a factor that may prevent individuals with OCD from seeking treatment. In their research, one individual with intrusive thoughts about abusing children reported fear that help-seeking might lead to criminalisation. This has important implications for individuals living with unacceptable thoughts and when or whether support will be sought. Indeed, Newth and Rachman (2001), suggest that individuals with OCD use concealment of the content and frequency of obsessions as a safety behaviour to avoid shame, guilt or the loss of control. They advocate for therapists to encourage clients to disclose in therapy so that these obsessions and associated catastrophic interpretations can be addressed.

Interpersonal and Social Aspects of OCD

As discussed earlier, the literature is often focused on OCD in general rather than primarily obsessional OCD specifically and this is certainly the case in relation to studies on support seeking and interpersonal relationships. Research suggests that in comparison to other types of anxiety or mood disorders, individuals with OCD are more likely to encounter social impairment (Torres at al., 2006). Furthermore, higher symptom severity has been associated with lower satisfaction within romantic relationships. The measure used was a Relationship Assessment Scale that considered factors such as; the extent to which individuals felt their needs and expectations are being met; the amount of love felt toward their partner; and the extent to which problems were experienced within the relationship (Abbey et al., 2007: Hendrick, 1988). Individuals with OCD have associated their symptoms with communicative difficulties with friends, family and spouses and reported that OCD symptoms cause them to feel lonely and misunderstood by others (Fennell & Liberato, 2007; Yazdi-Ravandi et al. 2018).

Seeking Support from Others: Accommodation and Reassurance-Seeking in Interpersonal Relationships

A key interpersonal issue in OCD is accommodation (Abramowitz & Jacoby, 2014). Accommodation describes how family or partners of the individual with OCD will try to help relieve the individual's distress, by assisting with ritualistic compulsions such as helping with rigid routines or offering reassurance (Storch et al. 2007). Interpersonal accommodation can create a 'system' that maintains OCD, because it can mean the problem remains unaddressed and therapy is not sought (Abramowitz & Jacoby, 2014). An example of a compulsion that can become accommodated is reassurance-seeking which has been linked to unacceptable thoughts (Kobori et al. 2012; Williams et al. 2011). Individuals with OCD sometimes seek reassurance from others as an attempt to reduce the perceived likelihood that the threatening situations depicted in their obsessions will occur (Rachman, 2002) (e.g., checking with others that they are not a violent person following an intrusive thought about harming someone). When OCD becomes accommodated into a relationship this may involve a partner believing that by giving reassurance, they are offering support and may feel like part of their relationship dynamic. However, they may not realise that by doing this they are perpetuating the problem. Although reassurance-seeking may cause issues within relationships, attempts to reduce reassurance-seeking by withholding reassurance can also create interpersonal problems (Halldorsson et al. 2016). Those caring for individuals with OCD can find themselves in a double bind where they know that offering reassurance can provide relief but that it can also exacerbate the problem, leaving them in a no-win situation (Halldorsson et al. 2016). Furthermore, accommodation such as this has been found to hinder symptom improvement after therapy and can lead to relational dissatisfaction in the partners of individuals with OCD (Boeding et al., 2013).

Relationships and Therapy

How OCD is managed within the context of intimate relationships has been highlighted as a potentially important consideration for therapists (Abramowitz et al. 2013). Neal and Radomsky (2020), noting the potential complications caused by withholding reassurance, have suggested that cognitive behavioural interventions based upon providing support may be more beneficial to couples, rather than interventions that offer reassurance. The researchers suggest that partners could convey confidence in their partner's ability to tolerate the distress associated with the obsession rather than providing reassurance. Their findings suggested that individuals with OCD and their partners perceived the support intervention as an acceptable option. However, research is yet to indicate the efficacy of such an approach. As reassurance-seeking is a covert compulsion linked to unacceptable thoughts it is possible that how it is managed within the relationships of individuals with primarily obsessional OCD could be a contributor to relationship satisfaction. Furthermore, withholding reassurance can create frustration and conflict within relationships (Halldorsson et al. 2016), which suggests that individuals with primarily obsessional OCD who involve family or partners in reassurance-seeking may experience difficulties in their intimate relationships and family lives.

Romantic Relationships

There is limited qualitative literature that has examined how OCD can impact relational dynamics and how this might be experienced by individuals with OCD. Walseth et al. (2017) investigated the impact of OCD on partner relationships. The results suggested that partners' attempts to support their partner with OCD could lead to the development of a helper/patient dynamic or power imbalance in the couple. Such a dynamic could be experienced positively if complementary to the couple's relational styles or could leave the individual with OCD feeling humiliated or under surveillance. The study also highlighted how distance can be created in partner relationships when individuals feel inclined to hide or disguise their OCD. This could be particularly relevant to the experience of primarily obsessional OCD when considering the shame and secrecy associated with this dimension. This study highlights the complexity of living with OCD in the context of partner relationships and illustrated the utility of conducting research that captures the nuances of lived experiences.

For some, distress within the context of romantic relationships is related to experiences where OCD involves intrusive thoughts and doubts regarding one’s relationship (Doron et al., 2014). Relationship OCD (ROCD) is a theme within primarily obsessional OCD that is characterised by a preoccupation with the quality of one’s romantic relationship and obsessive doubts about the suitability of the relationship (Doron et al., 2014; Farrell, 2022). For example, having an obsessive preoccupation with whether one’s partner is a compatible match or intrusive urges to end the relationship (Doron et al., 2014). These obsessions have been linked to covert compulsions such as seeking reassurance from others about the suitability of the relationship (Doron et al., 2014). In line with the intrusive thoughts described earlier, the relationship orientated obsessive thoughts are deemed as unacceptable by the individual and considered to be ego-dystonic (i.e., incongruous with the individual’s true feelings towards the partner) (Doron et al., 2014). Research has indicated that living with ROCD can be great source of distress for the individual and lead to relationship dissatisfaction for themselves and their partner (Doron et al., 2012). For those with ROCD, it may be difficult to maintain satisfying relationships (Doron et al., 2012). These insights suggest that the management of unacceptable thoughts within relationship may impact upon the ability for those with primarily obsessional OCD to maintaining mutually fulfilling relationships.

Social Context: Stigma and Subjective Experiences of OCD

OCD may be associated with stigma and this stigmatization may depend on the OCD characteristics. The public, and mental health professionals can exhibit greater stigma toward taboo obsessions than other obsessional themes (Cathey & Wetterneck, 2013; Glazier et al., 2013; McCarty et al., 2017). Researchers have used vignette studies to measure stigma toward different types of OCD symptoms from both the public and mental health professionals. Vignette studies have suggested that members of the public would be more likely to socially reject a person with sexual obsessions than those with contamination obsessions and have a greater desire for social distance from individuals with taboo obsessions than other obsession types (Cathey & Wetterneck, 2013; McCarty et al., 2017). Research has also suggested that by comparison to contamination obsessions, taboo thoughts are less recognisable as OCD symptoms by mental health professionals (Glazier et al., 2013). Steinberg and Wetterneck (2017), found clinicians were more concerned about sexual, harming and contamination obsessions than religious obsessions. These studies indicate a lack of in-depth understanding of unacceptable thoughts in OCD which may negatively influence individuals' interpersonal and therapeutic experiences. No known research to date has focused specifically on the interpersonal impact and help-seeking experiences of individuals experiencing unacceptable thoughts, so the current project aims to contribute to filling this gap in the literature.

There is a dearth of personal accounts of individuals' experiences of unacceptable intrusive thoughts and much of the current knowledge of the impact of these symptoms is restricted to quantitative findings or case studies (Bhattacharya, & Singh, 2015; Ferris et al., 2012; Jacoby et al., 2016; Nelson et al., 2006; O'Connor, & Aardema, 2011; Purdon, 2004; Vorstenbosch et al., 2012). This means that there is a limited depth of understanding or research that listens to the voices of participants, an area that this project will address. The dominance of quantitative research is problematic because it assumes that mental distress can be understood objectively and that there is a definitive truth that can be accessed through research (Sale et al., 2002). This view fails to consider the complexity of subjective meaning and experience that can be captured in qualitative research (Sale et al., 2002).

Qualitative research on lived experiences can add depth to existing OCD literature by considering individuals’ social context. Some researchers draw attention to the limited research into lived experiences of OCD and the limited public awareness of those experiences, as well as the different ways they can manifest in people's lives (Fennell & Liberato, 2007). The small body of qualitative research that does exist demonstrates the value of exploring lived experience. For example, Fennell and Liberato (2007) identified rich insights into the complex relationship individuals have with their OCD and how they experience and anticipate stigma. For example, experiences of attempting to pass as someone without OCD by hiding their experience from others. The authors also identified experiences of feeling misunderstood or met with prejudice within social interactions. Similarly, Keyes et al. (2018), explored experiences of young people with OCD and identified experiences of shame, social withdrawal, and feelings of being misunderstood, which presented a barrier to help-seeking. Although these findings are useful, they may be age group specific whereas the current study will be going beyond young people and focus on adults. Both studies contributed to the limited qualitative literature and revealed interesting insights but did not distinguish between different dimensions of OCD (Fennell & Liberato, 2007; Keyes, et al., 2018).

Considering the heterogeneity of OCD, the experience of living with different types of obsessions will likely influence how OCD is experienced. Therefore, this dimension-specific research will help to add to the understanding of these differences and complexities. There has been limited qualitative research that explores subjective experiences of different OCD presentations, making it difficult to identify how different dimensions may impact individuals' lives. Bhattacharya and Singh (2015) used a case study approach to explore how individuals living in India managed OCD in their personal, social, and professional lives and how OCD affected their self-concept. Most relevant to primarily obsessional OCD was the case of Shantanu who was preoccupied with sexual thoughts. The case suggested that Shantanu's obsessions led to social disconnection, withdrawal from friends and a sense of isolation. The researchers also suggested that perceived unacceptability and guilt around sexual thoughts may be associated with sexual themes going against the norms of Indian society. Thus, individuals' context may influence whether thoughts are perceived as 'unacceptable' and may add to the complexity of how primarily obsessional OCD is experienced. The limited literature looking into subjective experiences of different OCD dimensions may indicate that nuances of individuals experiences, such as contextual influences may be overlooked and that more research to increase understanding of these nuances would be beneficial.

Orientating the Current Research within the Context of Counselling Psychology

While a mixture of quantitative and qualitative studies has been discussed, many of the existing studies have been quantitative. Further, much of the existing research on OCD has been conceptualised in line with the medical model of psychological distress (e.g., Fawcett et al., 2020; Torres et al., 2006). This model views psychological problems as definable by a collection of objective measurable symptoms assumed to have a biological basis and that can be categorised into diagnosable disorders (Larsson et al., 2012; Pilgrim, 2007). This view considers psychological problems from a largely biological perspective, confining distress to be a problem residing within the individual in isolation from their relational, cultural, political, and historical context (Hare-Mustin & Marecek, 1997; Larsson et al., 2012). Underpinning the medical model is the positivistic philosophical assumption that we can access a singular and definitive truth through scientific enquiry and therefore distinctively categorise and generalise experiences of distress by objectively observing associated phenomena (Larsson et al., 2012). Research aligned with the medical model dominates psychological literature using quantitative methods that consider valuable evidence to be observations which are supposedly immune to subjectivity or potential diversity of meaning (Blair, 2010).

It is part of the ethos of counselling psychology to resist positivistic notions that one way of experiencing and knowing has superiority over another and the importance of recognising the social context of individuals (BPS, 2005 p.1-2). Therefore, it is important to acknowledge the difficulty in navigating between the humanistic values of counselling psychology and the dominance of medicalised terminology in the literature describing OCD (Larsson at al., 2012). The position taken in this project is to acknowledge that medicalised terminology cannot be negated from the discussion around OCD. Further, it will likely be used by participants in describing their experiences. In this thesis, the terms OCD and primarily obsessional OCD will be used as descriptors, but the experience that these terms aim to describe will be considered in terms of the social and relational context within which distress is experienced as opposed to assuming the problem has arisen from and resides within the individual alone (Hare-Mustin & Marecek, 1997).

Part of the counselling psychology identity is to recognise prejudice and discrimination and work in ways that seek to empower marginalised groups (BPS, 2005, pp. 1-2). Individuals with primarily obsessional OCD may be prone to marginalisation, subjected to stigma and experience a lack of recognition from the public and mental health professionals due to the nature of their ‘taboo’ obsessions (Cathey & Wetterneck, 2013; Glazier et al., 2013; McCarty et al., 2017). Counselling psychologists need to work to reduce stigma in society around mental health, including among mental health professionals (Galbraith & Galbraith, 2008). It is hoped that by studying perspectives of those potentially subjected to such stigma, this will offer insights and clarification to those in the professional sphere who may not fully understand the multifaceted nature of OCD, particularly primarily obsessional OCD. The ultimate motivation for the current project is to help individuals with primarily obsessional OCD by adding to the current understanding of this dimension in the OCD literature. It is hoped that in turn this will enable individuals with primarily obsessional OCD to feel heard, understood and accepted without harmful prejudice that could inadvertently indicate confirmation of their deepest fear that deep down they are bad or deviant.

Rationale

The present study will focus specifically on experiences of individuals with primarily obsessional OCD. This will help address the gap in the literature for studies focusing on specific OCD dimensions. This gap is likely due to the recency of the notion that OCD is heterogeneous and the increased interest in symptom dimensions (Lochner & Stein, 2003; McKay et al., 2004). Without seeking to understand more about different OCD presentations, specific features unique to a particular dimension may be overlooked. Such unidentified nuances may have important implications for individuals with OCD, and for mental health professionals. When holding in mind the different variations of OCD, primarily obsessional OCD (or OCD with unacceptable thoughts), stands out in the literature as difficult to treat without tailoring the therapeutic technique effectively to this dimension. It may also be more difficult for mental health professionals to recognise compared to other OCD presentations (Booth et al. 2014; Glazier et al., 2013; Grant et al., 2006; Williams et al., 2013; Rachman, 2003). This suggests that certain manifestations of OCD may require more focused attention. Researchers have highlighted that there is a need for further research into the different OCD dimensions to specialise and improve current treatment (Sookman et al., 2005). Furthermore, the stigma associated with unacceptable thoughts and the indication that they are less recognisable by professionals indicates a need for further research to increase understanding of these symptoms (Cathey & Wetterneck, 2013; Glazier et al., 2013; McCarty et al., 2017; Steinberg & Wetterneck, 2017).

Furthermore, because research has largely focused on individuals who have sought help, this limits the understanding of the condition to those who have been able to disclose their symptoms to a professional. Considering the shame and reservations about seeking help held by these individuals (Glazier et al., 2015), accessing information from individuals who have not sought professional help and those with a diagnosis may supplement the current understanding and implicate ways (barriers and access to) treatment might be improved. Furthermore, if shame is a barrier to treatment, this suggests that individuals with primarily obsessional OCD may employ alternative help-seeking strategies (Glazier et al., 2015). Robinson et al. (2017), found that support from members of online forums and representation of OCD in media encouraged individuals with OCD to seek professional help. Therefore, it is interesting to consider whether those with primarily obsessional OCD might have similar experiences or had moments of recognition outside a therapeutic setting that helped them to seek professional help.

The Current Study

The current study will use qualitative surveys and online interviews to explore lived experiences of individuals with primarily obsessional OCD. Areas of exploration will include how unacceptable thoughts relate to how individuals see themselves, how they relate to others and the way they experience and perceive help-seeking. By giving voice to these individuals, this study has potential implications for mental health professionals and those experiencing unacceptable thoughts. The current project will contribute to filling the existent gaps in the literature and developing further knowledge of the specificity and complexities of living with and managing unacceptable thoughts. The aim of the study is to gain a broad understanding of how individuals with primarily obsessional OCD experience their relationships and help-seeking in the context of their lives. The study sets out to answer the following research questions:

- How do individuals with primarily obsessional OCD manage their intrusive thoughts and covert compulsions in the context of interpersonal relationships?
- How do individuals with primarily obsessional OCD experience help-seeking outside of a therapeutic context?
- How do individuals with primarily obsessional OCD experience help-seeking within a professional therapeutic context?

By focusing on these topics, the objective is to study how individuals' experiences of primarily obsessional OCD interacts, fits within, or are shaped by their expectations and actual experiences of social, familial, and romantic relationships. The study also sought to identify what has helped individuals outside of a therapeutic setting and explore experiences of and perspectives on professional help-seeking. It is hoped that the findings will generate knowledge that has the potential to be useful to counselling psychologists and other mental health professionals into the complexity of primarily obsessional OCD by prioritizing the voices of those affected by the condition. Considering the gap between onset and help-seeking, issues with treatment and lack of understanding around lesser-known presentations of OCD, research that gains access to the perspective of those living with the condition could contribute to the existing literature and inform training and therapeutic practice.

Methodology

Overview

This research aimed to explore the lived experience of individuals with primarily obsessional OCD, focusing particularly on OCD within the context of their relationships, and how they experienced help-seeking both within and outside of a therapeutic context. A qualitative approach was chosen for this study because it focussed on individuals' subjective experiences, how they make sense of those experiences, and how they manage their primarily obsessional OCD in the context of their lives (Braun & Clarke, 2013; Willig, 2008). Qualitative enquiry is fitting with the field of counselling psychology and psychotherapy because it enables researchers “insight into the experiences of people who are living with specific problems”, hence this is highly fitting for a study focused on specific OCD dimensions (McLeod, 2011, p.7).

Theoretical Approach

In this project I took a Big Q approach to qualitative research - (research conducted using qualitative research tools within a qualitative paradigm) – and I now discuss this and my ontology and epistemology. Ontology is the philosophical perspective on “the nature of reality and being” (Braun & Clarke, 2013, p.291), whereas epistemology refers to the theory of knowledge acquisition or the extent to which we can gain access to reality and generate knowledge (Braun & Clarke, 2013; Ponterotto, 2005). These philosophical concepts need to be considered when conducting Big Q qualitative research as the principles guiding the researcher's perspective and approach will inform how the data is analysed and interpreted (Braun & Clarke, 2013). The ontological framework I selected for the current project was critical realism (Braun & Clarke, 2013). A critical realist position posits that research data can provide insight into individuals' experiences, but that the reported experiences will be nuanced by the contexts within which the participants reside, and therefore will not provide direct access to reality (Braun & Clarke, 2013; Willig, 2012). Within this ontology, our understanding of our data and our participants' realities will always be limited by our subjective awareness as researchers (Maxwell, 2012; Meteyard, & O'Hara, 2015; O'Hara & O'Hara, 2014). Critical realism was considered a good fit because the current research focuses on how the participants make sense of their experiences but recognises that the meaning derived from those experiences is influenced by social context and by the researcher's interpretations (Braun & Clarke, 2021b).

The epistemological perspective underpinning the research was contextualism (Braun & Clarke, 2021b). Contextualism is akin to critical realism epistemologically because it too is based on the notion that knowledge is always partial and inextricably situated within and mediated by a given context (Braun & Clarke, 2021b; Jaeger & Rosnow,1988; Madill et al., 2000). This framework complements the topic in that the concepts of obsessions and compulsions, and how these are experienced by the individuals will be influenced by the contexts within which they reside. The term context is used here to encompasses many features that influence our understanding of ourselves and the world from our geographical and socio-political environment to our interpersonal context and personal histories. Contextualism embraces the idea that there can be multiple perspectives and understandings of phenomena, rather than a single definitive truth (Braun & Clarke, 2021b; Maxwell, 2012). Therefore, it is expected that how individuals attribute meaning to their experience of primarily obsessional OCD, and the concept of OCD as a diagnostic term will be diverse and tied to contextual influences informing this understanding (Braun & Clarke, 2021b; Madill et al., 2000).

Reflexivity

The concept of reflexivity is important within Big Q qualitative research. Reflexivity is the acknowledgement of the role of the researcher and how their personal experiences, values and characteristics will inescapably influence the how the data is understood and the production of knowledge (Braun & Clarke, 2013; Willig, 2012). As a reflexive qualitative researcher, the contextual influences of my personal history and identity are embraced, rather than seen to be a limiting factor (Finlay, 2002; Gough, 2016; Gough, & Madill, 2012). Considering this, it is important to acknowledge that I identify myself as having primarily obsessional OCD. I was assessed for this in 2011 after seeking help from my GP who referred me to a clinical psychologist. My personal experience motivated me to gain a deeper understanding of the topic and conduct research that has the potential to help others going through similar experiences.

There are several potential benefits to conducting research where the researcher has shared experience and or identity with the individuals being studied. For example, there is less risk of the researcher inadvertently stereotyping the participants due to limited knowledge of the group, the insider researcher is likely to already have an awareness of the language used by the group and may have a greater chance of being accepted when approaching the group to be studied than someone not considered to be a member (Bonner & Tolhurst, 2002). In my case, I believe that being an insider helped me to be accepted by group moderators when requesting permission to recruit from online support groups. I made the decision to declare my insider status to some moderators to show I am sensitive to the experiences of those I would be recruiting from the group and that my interest in the research topic was guided by a meaningful pursuit to play a part in improving support for those struggling with a similar experience. Furthermore, my personal experience of using online support forums meant I had an existing knowledge of language used to describe different features of primarily obsessional OCD (Asselin, 2003). For example, I understood acronyms like ROCD (relationship OCD), to describe OCD involving intrusive thoughts regarding one’s relationship. This awareness of acronyms and other terminology enabled me to have what is likely a better understanding of the experiences participants conveyed in their accounts than if I was unfamiliar with descriptors used in online support forums.

Although there are benefits of researchers identifying as part of the group being studied, it is important to be aware of the risk of inadvertently focusing on information that fits within their own experience (Le Gallais, 2008). So on one hand it may be useful to have an initial understanding of the language that might be used by members of the group and common experiences described, but on the other, this may also limit the perspective of the researcher if their existing assumptions prevent deeper analysis of the meaning individuals attribute to their experience and there is a risk that some important nuances may be missed (Asselin, 2003; Field, 1991). Although qualitative research does not strive for objectivity, it is important to be critical of the researcher's role and consider the potential impact of their assumptions (Braun & Clarke, 2013). One way of identifying and reflecting upon these assumptions is by using a reflective journal from the outset of the project that enables the researcher to take note of the thoughts and feelings that may arise throughout the process (Braun & Clarke, 2013; Morrow, 2005). I kept a reflective journal throughout the research process to critically reflect on any potentially influential factors arising from my subjective experiences and insider status. This enabled me to notice my personal reactions to the data and where I was paying particular attention to stories like my own. Reflecting on this enabled me to step back from the data to take in the diversity of perspectives and experiences. I turn now to introduce the methods of data collection.

Online Survey

A qualitative survey was chosen to collect data, designed with open-ended questions to encourage participants to provide deep descriptions of their experience. Qualitative surveys were chosen for both topic-based and practical reasons. As qualitative surveys are an excellent tool for researching people's experiences they were a good fit for my study's aim and research questions (Terry & Braun, 2017). I was also aware that the topic would likely involve accessing participants who were harder to reach, so having a method that enabled participants ease of access, autonomy and the sense of anonymity achieved by not having the researcher present was important (Glazier et al., 2015; Rachman, 2003; Terry & Braun, 2017; Wilkerson at al., 2014). I was aware that I was approaching a sensitive topic that individuals may associate with shame and stigma, so I deemed qualitive surveys appropriate for these highly delicate personal accounts (Braun & Clarke, 2013; Glazier et al., 2015; Rachman, 2003; Wilkerson at al., 2014). The use of online methods also enabled access to participants who may have found attending a face-to-face interview uncomfortable or challenging (Deakin & Wakefield, 2014). The surveys enabled participants to decide how they respond to the questions, the location in which they respond, and how long they choose to spend on their responses (Terry & Braun, 2017). By giving the participants this freedom, this also allowed me to gain access to a greater breadth of responses that are not restricted by geographical location (Braun & Clarke, 2013).

Survey Design

I developed the survey questions based upon topics and issues identified within the broader OCD literature (e.g., interpersonal issues), and those specifically relevant to unacceptable thoughts (e.g., shame and self-concept). My areas of interest were also influenced by my own experience of primarily obsessional OCD such as the focus on romantic relationships and the potential strain that OCD can cause as well as the different avenues of support that individuals may seek instead of, or before to disclosing to a professional. Aside from the demographic questions, 13 questions were used to collect data relevant to participants experiences of primarily obsessional OCD which was a number determined by the recommended number of questions for this method which is between 3-30 (Braun & Clarke, 2013).

I worked with my supervisors to develop a strong set of questions, and piloting was also used before the survey was made available to a larger sample of participants. It was important to ensure that the questions were designed to be sensitive to the client group and were worded clearly. This is an essential consideration for surveys to avoid participants only providing partial data on account of misunderstanding the questions, particularly given the lack of opportunity to clarify or ask participants to elaborate on their answers (Braun et al. 2021). Questions need to be designed in such a way that they do not implicate any assumptions about the participants' experiences (Braun et al. 2021). This was achieved by keeping the questions broad and enabling participants to share perceptions about a topic even if was not personally relevant. For example: ‘Please can you share with me any ways in which intrusive thoughts and/or covert compulsions have impacted your relationships with your family (if they have).’ conveys the message that this may or may not be personally relevant but goes on to invite perceptions on the topic: ‘It may be that you don’t think your thoughts or compulsions have impacted these relationships and if that is the case I would still appreciate any thoughts you might have on the topic of OCD and relationships with family.”. This avoids suggesting what the participants might be experiencing whilst remaining inclusive and interested in the participant’s perspective.

The design process also involved editing questions in early versions to ensure that they were clear and had the potential to elicit rich responses. For example, the questions were originally designed to enquire about any potential impact primarily obsessional OCD may have had on a particular area of the participant’s life but if it was not relevant to them, invite them to share thoughts about the subject matter more broadly (see Appendix A). However, after piloting, some responses were brief and lacking detail so further prompts were added in the final version of the survey (see Appendix B). Furthermore, I included a simple glossary with the survey to ensure participants understood the terminology used in the questions (see Appendix B).

The order of questions was also important as beginning with broader questions can ease participants into the survey and allow them to share their thoughts. The survey (see Appendix B) began with a broad open question to ask generally about individual’s experiences of primarily obsessional OCD. I then addressed interpersonal factors by focusing on questions around the perception of others and how intrusive thoughts may have impacted relationships with family, friends, and romantic partners. The focus became more specific when exploring any ways that intrusive thoughts may have impacted individuals understanding of themselves, their values, and their identity. The questions in this section were designed to open the conversation around specific topics whilst acknowledging that they may or may not apply to the individual. Finally, questions around help-seeking were designed in a way to encourage participants to share their experiences of therapy or other resources as well as offering their perceptions of how therapists and psychologist might best support them. These questions were designed to capture experiences of therapy from a client's perspective and offer possible insight into therapeutic considerations that may be beneficial to this client group. Demographic information was collected in the surveys to obtain a clear idea of who has taken part in the study. These questions were placed at the end of the survey to avoid the potential for these to appear threatening and to increase the likelihood that participants will fill in this section (Braun & Clarke, 2013).

The survey was created using Qualtrics online survey software because this is a comprehensive online software package that is recognised as a General Data Protection Regulations (GDPR), compliant data collection tool by UWE. While qualitative surveys can capture rich detailed data and are advantageous for researching sensitive topics, they also have limitations in not being able to clarify questions or ask for elaboration (Braun & Clarke, 2013). I therefore used the survey to get a broad picture of the participants' experiences but also as a recruitment tool for participants who might be willing to take part in a potential online or telephone interview. This allowed me to use the data from participants’ survey responses to inform a personalised interview schedule enabling me to explore their experiences in depth and detail. Furthermore, because it can be difficult to determine the data collection method most suited to participants preferences, on the survey participant information screen I included the option for participants to take part in a telephone or online interview instead of the survey if they wished to.

Interviews

Interviews are a highly regarded method in qualitative research because they help researchers to "enter into the other person's perspective" and encourage participants to talk about their experiences (Patton, 2015, p.426; Rubin & Rubin, 1995). Including the option of a telephone or online interview in the current study, allowed for the opportunity to probe for further details beyond the responses provided in the survey. As with the surveys, the choice to conduct interviews remotely enabled me to include participants from wider geographical locations than would have been feasible if they were face-to-face and negated any need to source an interview location, enabled participants to engage without having to travel and allowed for greater flexibility with time (Cater, 2011; Deakin & Wakefield, 2014). Interviewing via video conferencing software has been found to carry many of the same benefits that would be expected in face-to-face interviewing such as establishing connection and rapport between researcher and participant and enabling non-verbal communication (Hamilton, 2014; Mirick, & Wladkowski, 2019). The interview questions were mainly determined by the survey responses and referred to participants answers to probe for further explanation. For example, when a participant alluded briefly to a specific experience in the survey, the interview provided an opportunity to ask about it and identify the meaning attached to it. An interview schedule with possible prompts was created and adapted for the interview participants who had completed the survey (Appendix H). For the one participant who took part in the interview only, the survey questions were used as a basis for the interview schedule with the addition of prompting questions used to encourage elaboration. Participants were given the choice between an audio or video interview enabling them to decide what mode felt most comfortable. Furthermore, the option of a telephone interview allowed for the engagement of participants who would find it preferential or may have difficulty using video conferencing software. The use of online and telephone interviews is useful for accessing hard to reach populations and has practical implications because scheduling can be more flexible and better suit participants schedules as they are not obliged to travel (Holt, 2010; Wilkerson et al., 2014). Conducting the interviews via telephone or online also enabled the research to take place during the COVID-19 pandemic without putting the participants or researcher at risk.

Recruitment

Participant Group Size

In line with the range of sizes recommended within qualitative research, I aimed to recruit approximately 50 survey participants (Braun & Clarke, 2013). In total 70 participants completed the survey. I aimed to conduct approximately 6 interviews which was dependent upon the number of participants who opted into an interview. Once there was sufficient interest in the interviews from survey respondents, I removed the interview option from the survey and removed the interview information from the survey participant information sheet (PIS). I conducted a total of 4 interviews. While 3 of the interview participants were recruited via the survey, one was a through a contact known to me who was approached via WhatsApp initially, then the participant read the information sheet and completed the consent form before taking part. The number interviewed was reduced from the original aim for 6 to 4 due to personal difficulties which are discussed in the discussion section.

Inclusion and Exclusion Criteria

To take part in the study participants were required to be over the age of 18, have experience of unacceptable thoughts and either self-identify as having OCD or have a clinical diagnosis of OCD. Purposive sampling was used to recruit these participants, this sampling method involves selecting individuals with characteristics relevant to the topic of the study and who hold information that should enable further understanding of that topic (Hennink et al., 2020; Patton, 2002). By moving away from strictly recruiting those with a diagnosis of OCD, the aim was to also involve those who have self-identified with primarily obsessional OCD who may not have sought therapeutic support or had not received a diagnosis from a professional when help was sought. This decision was based upon the research linking shame and fear of seeking support to the experience of individuals with unacceptable thoughts and therefore it was intended that by including those who self-identify with OCD, the survey would reach those who have not at this stage felt confident to or perhaps do not intend to approach therapeutic support services (Glazier et al., 2015; Rachman, 2003; Wilkerson at al., 2014). To avoid any confusion about suitability for the study for those participants who had self-identified as having OCD, information was added to the beginning of the survey questions to specify what was meant by primarily obsessional OCD. Furthermore, the inclusion criteria allowed for individuals with coexisting psychological problems or diagnoses as the survey questions make clear that it was the experience of primarily obsessional OCD that was being focused on. As individuals with OCD may experience intrusive thoughts or compulsions from different dimensions at different times, it was expected that some participants may have obsessions and compulsions that fall into different dimensions (Besiroglu et al., 2007; Rettew et al., 1992). Although this made it difficult to isolate the experience of primarily obsessional OCD, it was accepted that there would be some complexity in the responses if individuals had experienced different dimensions of OCD over time. It was also accepted that some individuals would likely have other co-occurring psychological problems such as generalised anxiety that may be difficult to disentangle from their experience of primarily obsessional OCD and this is further discussed in the discussion.

Methods of Recruitment

The recruitment strategy was to approach organisations and webpages offering support to individuals with anxiety disorders and/or OCD, and to ask for an advertisement poster to be displayed at my local GP surgery (for recruitment advertisements see Appendix G). With permission from the organisations approached (e.g., International OCD Foundation) and from the moderators of support pages, advertisements for participants were posted in online forums and support groups, organisations' Facebook pages, information websites and charitable organisations' research webpages (see Appendix F). Two of the organisations approached (No Panic and International OCD Foundation), also offered support with recruitment by allowing me to advertise the study in their newsletter (see Appendix G). Most of the respondents were recruited via Facebook support groups for those with OCD such as 'Intrusive Thoughts and Pure OCD' and 'Obsessive compulsive disorder (OCD)/Overthinkers Official community' (see full list in Appendix F). Most moderators of the webpages and forums were happy to oblige. One asked for my supervisor's details to contact prior to permission being granted but most were open to me posting directly into the group. The website Reddit was also used to advertise the study. This involved posting the advert on 'subreddits' which are pages focusing on specific topics. A range of appropriate topics were searched for, before posting the advert. Examples of subreddits were 'r/IdentityOCD', '/r/ROCD' and '/r/intrusivethoughts' (for full list see Appendix F). The online recruitment, aimed to access a larger, more diverse sample outside of the limitations of geographical location. Many participants indicated where they had accessed the survey; this data suggested that most participants were recruited from support groups on social media (see Table 1).

Table 1

Recruitment Sources

Recruitment Source	**%**	**Count**	
Facebook Support Webpage/Group	51.85%	28	
OCD UK	9.26%	5	
Reddit	25.93%	14	
No Panic Newsletter	1.85%	1	
International OCD Foundation website or newsletter	9.26%	5	
Other (please specify below)	1.85%	1	Text: “I was scouring google”
Total	100%	54	

Demographics

Of the participants that provided their demographic information (N=66 out of 71), participants’ ages ranged from 18 – 68 years old (M= 32). The majority identified as female, were able-bodied, heterosexual, white and middle class, or middle/working class (for full demographic information see Appendix J). Most participants were in relationships with a partner(s), married or in a civil partnership. Further demographic details are displayed below.

Table 2

Demographic Information

Gender	***%***	***Count***
Woman	63.29%	50
Man	16.46%	13
Trans	2.53%	2
Cis	11.39%	9
Agender	1.27%	1
Genderqueer/genderfluid/non-binary	3.80%	3
Questioning/unsure	1.27%	1
Other	0.00%	0

Sexuality	***%***	***Count***
Answer		
Heterosexual	66.67%	44
Asexual	1.52%	1
Bisexual	15.15%	10
Gay	0.00%	0
Lesbian	1.52%	1
Pansexual	10.61%	7
Queer	3.03%	2
Other	1.52%	1

Other – Text
Heterosexual with bisexual interest

Racial/Ethnic Background	**%**	**Count**
Algerian/Arab	1.52%	1
White	72.73%	48
Very White - exclusively Northern European ancestry	1.52%	1
Mexican	1.52%	1
Asian. Indian to be precise.	1.52%	1
White (Irish-American)	1.52%	1
South Asian – Athiest	1.52%	1
White British	1.52%	1
Pacific Islander	1.52%	1
European White	1.52%	1
White Christian	3.03%	2
White Australian	1.52%	1
White british/irish	1.52%	1
Polish (born in Poland)	1.52%	1
Mestizo – Hispanic	1.52%	1
White and 1/4 thai	1.52%	1
Spiritual Agnostic	1.52%	1
Hispanic	1.52%	1

Social Class		
Answer	***%***	***Count***
Upper class	7.58%	5
Middle class	34.85%	23
A mixture of middle / working class	39.39%	26
Working class	13.64%	9
Lower class	3.03%	2

Other	1.52%	1

Disability		
Yes - If you are willing to share then please list your disabilities.	22.73%	15
No	77.27%	51

Relationship Status		
Answer	***%***	***Count***
Single	30.30%	20
With a partner (or partners)	40.91%	27
Married/Civil Partnership	24.24%	16
Separated	0.00%	0
Divorced/Civil Partnership Dissolved	3.03%	2
Other:	1.52%	1

Piloting

The piloting phase began in January 2021, gathering data from 8 of participants, in line with the recommended number of 5-10 for pilots (Braun & Clarke, 2013). This enabled me to assess how well participants engaged with the survey questions and informed edits required before advertising more widely. To acquire a small sample, I advertised the study in two Facebook support groups (Appendix F, G), and reposted frequently to ensure the advertisement was likely to be seen by different group members who may have missed previous posts. The responses gathered indicated a good level of engagement with the survey questions. Participants had written extensively about their experience except for in response to specific questions regarding identities that may not apply to all (e.g., questions regarding sexuality and gender). Some questions regarding religious, moral, and cultural values (See Appendix A), seemed to confuse most of the pilot participants and it was decided that these questions would be removed at this stage.

Ethics and Data Protection

Ethics is a crucial aspect of conducting qualitative research in counselling psychology and research with individuals with OCD (Hakami, 2022; Morrow & Smith, 2000). Features relevant to both were the importance of informed consent, the right to withdraw and the attention that is paid to the potential influences of the research process and the relationship between researcher and participant (Hakami, 2022; Morrow & Smith, 2000). Before beginning the survey, a PIS was displayed outlining details of the study and highlighting the risk of distress (Appendix B). The provision of support services is particularly important within this topic, and while the study was designed to try to avoid any distress to participants, sources were carefully selected so that participants could seek support if required. This is particularly important given my position as a trainee counselling psychologist where I might be seen as someone who could directly offer support when this would not be ethically appropriate. Support services were selected based upon their suitability and included charities offering help and support to those with OCD specifically, or anxiety disorders in general. I also considered that not all participants would necessarily be in the UK, Therefore I included both UK and international resources. There was also a reminder of the support services displayed at the end of the survey. There was also a digital consent form (Appendix D), that made clear the participants right to withdraw at any point before the data analysis. Ethics were approved by the Faculty Research Ethics Committee (FREC), (HAS.20.06.184), and a risk assessment was also completed (Appendix I).

All data was anonymised and stored on UWE OneDrive as per UWE's data management requirements. My supervisors and I had access to the Qualtrics survey. Participants' email addresses were provided by those willing to be contacted about an interview. These were removed from the data downloaded from Qualtrics and stored in a separate password protected spreadsheet that was deleted after the withdrawal period had expired. Participants contact information was used only for the purpose of the research and correspondence related to the research. After the correspondence was complete, emails received and sent to participants were deleted from my Outlook account.

Procedure

Participants interested in taking part in the study accessed the survey via a URL or QR code on the recruitment advert. The survey first displayed the PIS followed by the consent form. The survey was designed in such a way that the participants could only continue once they provided their consent. Participants were then taken to the survey followed by the demographic questions. Participants were able to write as much or as little as they wished in the text boxes provided for each question and were able to leave sections blank if preferred. Those who expressed interest in taking part in an interview provided their email address and were emailed a PIS specific to interviews (Appendix C) and were asked to sign and return a consent form (Appendix E). We then arranged a date and time and method of communication. Three interviews took place via Microsoft Teams, and one was a telephone interview. The planned duration for each interview was an hour and half including an hour's interview time and a 15-minute description and opportunity for questions beforehand and a debrief and second opportunity for questions upon completion of the interview.

Analysis

Textual data from the survey answers were collated into Microsoft Word documents and audio recordings from the interviews were orthographically transcribed using the adapted notation system from Jefferson (2004), described by Braun and Clarke (2013). Both sets of textual data were anonymised by removing any information that might identify participants. Reflexive thematic analysis (RTA) was chosen for the current study because it is a flexible method designed to be used within a qualitative paradigm and is appropriately suited to ontological and epistemological stance of the study (Clarke & Braun, 2018; Braun & Clarke, 2006, 2013, 2021). RTA enables patterns of meaning to be generated across a large data set and is a method deemed particularly suitable for qualitative survey data (Braun & Clarke, 2013). RTA also embraces the inevitable role of the researcher’s subjectivity, which was important with my converging identities as a researcher, practitioner, and insider (Braun & Clarke, 2006, 2013, 2021).

There are choices that need to be made when using RTA because it is a theoretically flexible method. Therefore, unlike other methods (e.g., interpretive phenological analysis), it does not come with a pre-determined methodology (Braun & Clarke, 2006; Braun & Clarke, 2021 a, b). It was therefore important to identify my ontological and epistemological position which was a critical realist ontological position and a contextualist epistemology (see above). It was also important to consider whether the analysis would be inductive (generating meaning directly from the data), or deductive (where data analysis is directly informed by existing theories), (Braun & Clarke, 2006, 2021). An inductive thematic analysis was used to analyse the survey and interview data together. The analysis was largely inductive because I approached analysis with the view of identifying the meaning conveyed through the participants descriptions given my emphasis on giving them voice. However, my thinking was also informed by previous literature on the topic and how elements of the data resonated with previous findings. The analysis followed the six-phase process of RTA (Braun & Clarke, 2006; 2013; 2021).

- The first phase was familiarisation. This started at the piloting phase when I gained my first few responses and read through and made notes about interesting features. Familiarisation with the interview data began when I transcribed the recordings using voice recognition software. This involved reducing the speed of the audio recording, listening carefully, and repeating the content out loud. This method of transcription facilitated an immersive understanding of the data because verbally reproducing the responses enabled an embodied experience of entering the participants perspective (Brooks, 2010; Perrier & Kirkby, 2013).

- Following data collection, the survey data were collated into Microsoft Word documents. Immersion in the survey and interview data involved reading and re-reading listening again by using the Word dictation tool. This enabled in-depth immersion through both visual and auditory processing. During this process, I made note of interesting features of the data. The interview and survey data were read in a randomised order to avoid the interview data dominating the analysis. This involved reading several surveys between each interview reading and changing the order the items were read for each read through. As I read, I noticed thoughts and feelings that were coming up for me, particularly feelings of concern for participants, but also a sense of recognition. Some experiences stood out as like my own, but there were also many differences which were captured in the analysis. At times I found it emotionally challenging to read through the data as some stories conveyed such hopelessness that it was hard not to feel sadness. It was important to reflect on these feelings and be aware not to cause myself distress in this stage of the process. I therefore took breaks from the data, made sure to stay connected with others. I also needed reflect on whether my own experience of primarily obsessional OCD may be influencing the aspects of data that were standing out to me.

- During coding, I organised the data into tables on Microsoft Word with two columns, for the data itself and for initial codes (See Appendix L). I then went through the dataset again in a randomised order with the research questions in mind, identifying interesting features and generating initial codes. In this phase I was looking to generate both semantic codes, which are descriptive codes capturing overt aspects of the data, and latent codes which capture less obvious aspects that convey implicit meaning (Braun & Clarke, 2021b). I completed two thorough rounds of coding before reviewing and refining my code labels to ensure consistency (Braun & Clarke, 2021b). The codes tended to be short phrases such as “selective disclosure” and “social withdrawal”. Some codes such as “misunderstood by others” later formed the basis for a candidate theme if they captured broader meaning across the data rather than a distinct feature. The codes were assigned to the data in the Microsoft Word document using speech to text software.
- Themes were developed from the coded data by collating codes and data extracts into initial themes that were each focused around a central organising concept (Braun & Clarke, 2013). A central organising concept is an idea that captures the meaning generated from the data and is the essence of a theme that coherently holds together codes and data (Braun

& Clarke, 2013). The themes were reviewed to ensure they reflected the initial codes and the original data. To avoid inadvertently representing patterns that were unique to the interviews, I reviewed the themes carefully against the original data to ensure patterning was consistent across both survey and interview data. I initially generated copious candidate themes (See Appendix M) capturing different elements of the data for the original research questions which previously included a question about self-concept. However, inclusion of all initial themes was beyond the scope of the study. I therefore amended my research questions and refined my focus on parts of the overall story of the data that were most prominent. I refined these by establishing which themes were most interesting, rich, and detailed. The research questions were edited to remove the question regarding self-concept and the questions on relationships and help-seeking were honed to fit coherently with the rich patterns within the data. I then constructed ten different candidate themes (see Appendix K), which were later refined to four. For example, the initial theme *"Thanks, but no thanks – Unhelpful Responses/Misinterpretation from Others"* turned out to fit better as part of the theme initially titled *"Misunderstood by Others"* which was later re-named to become *"Perceived Misunderstanding and Misinterpretation of OCD in Personal and Professional Contexts*". Most theme refinement took place prior to beginning the write up, but some refining and reworking occurred through the process of developing the overall analytic narrative.

- Producing the written report was the final stage where interesting examples of data were selected and presented. Each theme was discussed in the final writing up to include my interpretation of the data and the story it was telling. As I constructed the narrative I held my research questions in mind and how different aspects of themes related to these questions. I noticed associations that came to mind with previous literature and made sure to note these down. I was initially unsure whether to tie in the previous literature to the findings so initially added aspects of this and making notes regarding relevant literature in a separate document. However, it was finally decided that I would reserve drawing from previous literature until the discussion section.

Results

Overview

Four overarching themes were developed from the thematic analysis (Table 3), each capturing threads of meaning across the data. The first theme, *"The Social Isolation of OCD: Physically and Psychologically Distancing and Disconnecting from Close Relationships*" captures participants' stories of OCD becoming a barrier to connection with others. The second *"Hidden in Plain Sight: The Predicament of Disclosure"* captures the double bind in which individuals can appear as though they do not have OCD due to the covert nature of the condition, but also having others underestimating the distress they are experiencing. Thirdly, *"Perceived Misunderstanding and Misinterpretation of OCD in Personal and Professional Contexts"* captures participants' experiences of both expecting and encountering misunderstandings and misinterpretations from others in their lives, and from therapists. Finally, "*Support Outside the Therapy Room – Help or Hinderance"* captures participants perceptions of what aspects of social support they find helpful but also the pitfalls that can arise from support seeking both within their interpersonal relationships and online.

Table 3

List of Themes and Subthemes

Theme Number	**Theme Title**	**Subthemes**	**Illustrative Quotes**
Theme 1	The Social Isolation of OCD: Physically and Psychologically Distancing and Disconnecting from Close Relationships	a) Disruption to close relationships through physical and psychological withdrawal.	*"When I'm struggling, I lose much time that could be spent interacting with loved ones by being "in my head"." (Pam, 55)*
		b) OCD as a threat to establishing and maintaining romantic relationships.	*"Eventually we broke up because he felt neglected, which was very fair, and I haven't dated since." (Lisa, 23)*

		c) Distress through Disconnect in Sexual Intimacy & Disruption to Sexual Identity	*"Sometimes intrusive imagines or thoughts would pop into my head when we had sex and I would just instantly cry […]" (Alex, age unknown)*
Theme 2	Hidden in Plain Sight: The Predicament of Disclosure		*"Very few understand what it is or how distressing it is. Particularly as on the surface I am able to function" (Dorit, 68)*
Theme 3	Perceived Misunderstanding and Misinterpretation of OCD in Personal and Professional Contexts	a) Misunderstanding and Unhelpful Responses in Interpersonal Relationships	*"People don't see me as having OCD because they don't understand what OCD truly is, especially Pure O." (Jenna, 29)* *""I have tried to explain to my mother, but she discards my experience as me "making things up"." (Matilda, 44)*
		b) Misunderstood and misbelieved by professionals	*"My therapist still doesn't believe that I have it, which makes it really hard for me to open up to her […]." (Jenna,29)*

Theme 4	Support Outside the Therapy Room – Help or Hinderance?	a) Acceptance and Recognition in Personal Relationships and Online Communities	*“I was like, oh my god, like maybe I’m not this monster like this person is experiencing the same things […]” (Jess, 20)*
		b) Risks and Challenges of Support Seeking in Personal Relationships and Online Communities	*“My mother worries about me and I feel bad discussing with her, I don’t like burdening her.” (Molly, 24)*

Theme 1 - The Social Isolation of OCD: Physically and Psychologically Distancing and Disconnecting from Close Relationships

This theme encapsulates the shared experiences of individuals who find that managing their OCD can lead to social isolation within their close relationships. There are two ways participants felt that they withdraw within their relationships. Firstly, a physical withdrawal, in which individuals separate themselves from others to manage their intrusive thoughts, spending time on their own and avoiding social interactions. This also involved a felt need to protect loved ones due to the nature of the thoughts and the propensity for the thoughts to involve imposing harm or inappropriate behaviour toward that person. Secondly, some participants suggested an internal withdrawal where they are still objectively present in relationships but find that they mentally withdraw in the process of managing their OCD.

Disruption to close relationships through physical and psychological withdrawal

There was a pattern within the data conveying a sense of physical withdrawal where individuals intentionally or unintentionally separate themselves from others. Individuals reported that they felt their OCD has taken away the ability to fully connect with others. They perceived OCD as an influence leading them to impose restrictions on their level of engagement in social interaction and suggest that this interferes with how close the individual can get in their relationships. This carries with it a sense of loss and isolation that stands out from some of the stories regarding disconnection with family and friends. The idea of feeling like quality time with loved ones has been lost due to the individuals' need to withdraw physically and mentally was evident in their talk:

> *"When I'm struggling, I lose much time that could be spent interacting with loved ones by being "in my head"." (Pam, 55)*
>
> *"My thoughts have also led me to exclude myself from family time." (Victor, 32)*
>
> *"Having OCD definitely made me less available and withdrawn from my family to some extent, and from friends to a great extent. In that sense it was quite isolating." (Sian, 45).*

Pam’s account suggests that the internal management of OCD leads to a sense of isolation from others and that being in their head is a lonely place even when they are not alone. Similarly, Victor explains how managing OCD can involve a felt need to opt out rather than an exclusion imposed by others. There is a sense that individuals feel compelled to withdraw from others to attend to the management of their OCD. They are all too aware that by doing so they find themselves feeling alone and isolated from social interactions. Sian conveys sadness as she describes how living with OCD has led to break down of social connections with family and friends and a sense of loneliness. In some cases, there is a message conveyed that their OCD oversees the individual’s life through calling the shots on whether they interact with others:

> *“I have found myself avoiding friendships or social situations when my thoughts are too ‘loud’ in my head for me to focus on anything else. .” (Lizzie, 22).*

Lizzie describes OCD as if it were an internal entity that loudly dictates the extent to which they can engage with others and that dominates through its demands for their attention that make it too difficult to be present in social interaction.

For some, the need to socially withdraw seemingly serves a protective function. Avoiding social interaction was perceived as a way of keeping the individual safe as well as protecting themselves from fears of acting out intrusive thoughts. Elijah conveys how he manages his beliefs about being dangerous or a risk to others by purposefully avoiding interpersonal interaction:

> *“I’m very scared to interact with my family based on my intrusive thoughts that I have regarding them. I feel disgusting because of my own thoughts and prefer to limit my time around them because I’m terrified of making the thoughts become a reality. I haven’t been able to receive support because I’m not open about OCD with them.” (Elijah, 21)*

Elijah’s account suggests that not only do individuals feel alone in their heads, but there is a sense of emotional burden in this solitude as OCD leaves them feeling disgusted and uncomfortable with themselves. Elijah also suggests that his attempt to protect himself from distress and others from harm has the unfortunate effect of causing himself harm in a sense as it presents a barrier to connection with his family and a barrier to seeking help. It is as if individuals feel they are managing an unpredictable and uncontrollable part of themselves that is a threat to both the self and others. Furthermore, individuals convey a feeling of inevitability that their thoughts will come into fruition:

> *“I just distance myself from them because eventually I feel like I'm going to hurt them emotionally or otherwise and I would hate myself for that. It's a weird feeling looking at yourself like you are some monster.” (Ryan, 21)*

It is inferred that participants feel they must manage this undesirable, dangerous aspect of the self within the context of their interpersonal relationships. Like the burdensome feeling of self-disgust described by Elijah, Ryan’s account suggests that OCD can leave individuals with the perception of themselves as monstrous.

It is inferred that participants feel they have no choice but to wrangle and tame this perceived malicious aspect of the self by isolating themselves. There is also a kind of moral requirement conveyed to avoid family members as being around them either gives rise to feelings of disgust of guilt or self-hatred or the expectation of these feelings if their feared action were to materialise.

For some, social withdrawal can cause strain in relationships and the subsequent desire to disclose to maintain connection:

> *"When I was having sexually violent thoughts about my best friend, I had to discuss it with them because we were spending a lot of time together and I would share their bed with them. It had upset me to the point where I began distancing myself from them which caused a strain on our relationship." (Charlie, 28)*

Charlie's account suggests they feel inclined to withdraw from others to protect them against any possibility that an intrusive thought could become an action but in doing so runs the risk of causing strain on the relationship. As Charlie conveys, for some, it is perceived that the reason for their withdrawal needs to be revealed to the other person. This suggests that for those who can discuss the presence of thoughts involving their relationships, disconnection and isolation may be managed or avoided.

OCD as a threat to establishing and maintaining romantic relationships

What was also evident in these participants' talk was a sense that OCD can present a threat to romantic relationships enduring. Some aspects of romantic relationships were like friendships and family relationships, in that the story is seemingly one of withdrawing. However, in this subtheme, I demonstrate that the experience and impact for romantic relationships is also different. The difference is that intrusive thoughts often comprise of doubts about the suitability of one’s relationship as well as the need to protect partners, not necessarily from acting on their thoughts but rather not telling their partners about the nature of their thoughts to avoid hurting their feelings.

The accounts convey a sense of frustration and difficulty managing intrusive thoughts within the context of romantic relationships. There was also a sense that the management of these thoughts made it difficult for participants to maintain a romantic connection with their partner. In some circumstances, this involved participants’ perceived need to conceal the nature of their thoughts within the relationship. This is prevalent in those experiencing relationship OCD (ROCD) (intrusive thoughts about romantic relationships, such as the doubts about one’s feelings toward their partner) (Doron et al., 2014). When discussing the management of ROCD, individuals allude to the strain this can present to themselves and their relationships:

> *“I absolutely struggle with Relationship-OCD. I constantly find myself questioning if I even like my partner, if I find them attractive, if I know what love is, etc. This makes it VERY hard for me to be in any relationships as I will worry about these things but internalize them so that my partner*

> *is unaware and then becomes anxious when they notice me pulling away or acting distant.” (Lizzie, 22)*
>
> *“I haven’t been able to establish a relationship for a while, I start to have the basics of rocd, I even reached the point where I don’t even know how to identify liking/loving someone romantically, it has got that bad, right now I’m talking with someone and I’m struggling so much to not flight from it as I have before, I’m just so afraid to hurt them […] recently I just been thinking if just giving up and telling him is not coming together is the best thing to do...” (Jess, 20)*
>
> *“My boyfriend knew that I had OCD, but I did not explain to him what this meant for me specifically. I remember feeling anxious constantly, always worried that I wasn't feeling the correct feelings about the relationship. […] The relationship felt like one massive exposure exercise in many ways, and I regret the ways in which I inadvertently hurt him.” (*Lisa*, 23)*
>
> “*It was a pretty average kiss (though I have nothing to compare it to), and I couldn't stop analysing it and using it as evidence that I must be a lesbian.*” (*Lisa, 23)*

For these individuals, relationships can be seen as highly distressing due to the related intrusive doubts and the fear of hurting their partner. Lizzie perceives that her internal preoccupation with her thoughts and subsequent withdrawal within her relationship caused anxiety for her partner. Jess illustrates an internal battle as she tries to manage her OCD and protect her partner from being hurt by her intrusive doubts. However, she conveys that this process negatively impacts her by leaving her feeling like she cannot connect romantically with others. Lisa conveys this conflict in relation to her doubts about her sexuality and the suitability of her relationship. She suggests a perception that being in a heterosexual relationship inevitably involves anxiety and intrusive thoughts about that relationship. The internal battle is once again conveyed as Lisa conceals the reason she feels anxious from her partner.

There is a sense that the individuals are aware that the presence of relationship orientated intrusive thoughts are creating distance between them and their partner, but due to the nature of the obsessions it feels too risky to attempt to explain the reason for this distance. The accounts suggest that withholding an explanation of this distance can lead to perceived dissatisfaction from their partner and in some cases, ultimately the end of the relationship:

"Eventually we broke up because he felt neglected, which was very fair, and I haven't dated since." (Lisa, 23)

In other cases, participants' spoke of how they chose to end a relationship due to their OCD. The following quote exemplifies how both physical avoidances related to OCD and becoming internally preoccupied with intrusive thoughts created intense strain and the subsequent end of a relationship:

> *"I had a relationship breakdown due to a particular bad episode of pure o. My pure o made me develop panic disorder and insomnia and I kept cancelling our dates because of it. When I was spending time with him my*

> *intrusive thoughts were making it difficult for me to concentrate or feel happy. I told him I was suffering from anxiety but didn't mention the pure o that was behind it all. I guess I felt ashamed and embarrassed. In the end I ended the relationship because my pure o had just got too bad, it was interfering with everything." (Brenda, 47)*

This suggests that it may be difficult for individuals with primarily obsessional OCD to maintain mutually satisfying relationships when their OCD presents impediments to connection with their partner. Brenda's account conveys that there is also a heavy emotional burden of shame and embarrassment, so not only is she impacted by OCD in terms of connecting, but also in terms of her sense of self. Brenda's account suggests that managing OCD in the context of relationships creates further distress and difficulty in her life and that ending the relationship was perceived to be the best solution.

The accounts convey that although individuals want to be in romantic relationships, they are aware that with this comes the constant unwanted companion of anxiety and intrusive thoughts. For some, internally withdrawing from romantic relationships was perceived to inadvertently lead to relational issues if a partner does not have the opportunity to understand why this is happening:

> *"In my past relationships, I have prided myself [on] not being the one who leaves. But recently, I figured out that I actually do leave by withdrawing inwardly, and not expressing concerns, frustration, and even sometimes*

> *anger. The other person always feels that and says that I shut them out and become unavailable. And so, once again, I will fixate on that and try to figure out what exactly they meant and if I actually did that. It's exhausting. And it always leaves me alone again." (Darren, 57)*

Darren suggests significant work is involved in managing the impact of his OCD on establishing and maintaining relationships. He reports ongoing evaluation of relationships and partnerships and portrays OCD as a burdensome load that he continually carries into his personal and social life. Darren conveys that not only does the management of his OCD make it difficult to stay connected in his relationships, but he feels unable to voice difficult feelings to romantic partners. His account conveys a perceived sense of inevitability that he will be alone.

Concerns about protecting others from intrusive thoughts or doubts and withdrawing from relationships dominated the data. Unlike the relationships with friends and family detailed previously, there is a sense of participants trying to protect partners from doubts that have the potential to raise concern about the security of the relationship. They also spoke of the impacts not only of their OCD directly, but of the disconnection that they perceived to be a result of their efforts to manage the relationships.

Distress through Disconnect in Sexual Intimacy & Disruption to Sexual Identity

The theme of disconnection extended to some participants' experiences of sex and intimacy. Participants convey distress because of the disruption caused by OCD to sexual intimacy and for some, their sexual identity:

> *"I have a hard time focusing on the task at hand (no pun intended) either because I'm uncomfortable with myself or because of intrusive thoughts about sex or literally anything else." (Fran, 26)*

Participants' accounts suggest that there can be a struggle with the presence of intrusive thoughts interrupting sex causing them distress and making it difficult to remain in the moment. Fran conveys that OCD interferes both practically in her being unable to engage her attention fully in the activity, but also sense of vulnerability. It is as if OCD takes away the ability to feel confident in herself and enjoy the experience of sex.

For others it is the way OCD interacts with their self-perception and how intrusive thoughts bring their sexual identity into question:

> *"I am bisexual so my OCD loves to play on that. I am currently with a male partner, so every once and a while, especially during sex, OCD loves to make me question if I am with the right sex." (Rosie, 29)*
>
> *"OCD has made it challenging for me to fully accept or honor this part of my identity. I think bisexuality is pretty ideal OCD fuel—it is culturally perceived as uncertain, it perplexes both gay and straight people, and it is surrounded by a great deal of cultural baggage and judgment" (Millie, 32)*

Rosie speaks about OCD like a vindictive presence that has become intertwined with her sexuality and taunts her with doubts in her most intimate moments. Similarly, Millie describes the interaction between her OCD and her sexuality, it is as if she sees OCD as a bully that plays on her insecurities and cultural perceptions to torment her. This makes it more difficult to untangle OCD doubts from her sexual identity. Millie suggests that the taunting, infiltrating force of OCD can grow if it is fed by wider cultural judgements about bisexual identity, making it more difficult for her to feel comfortable in her sexual identity.

A thread running through participants' sexual experiences was the sense that OCD intrudes then steals, distracts, or pulls away one's attention from what would usually be considered a pleasurable pursuit. As clearly articulated by Alex, OCD is experienced as a force that serves to take away one's ability to enjoy life and enjoy sex:

> *"Sometimes intrusive imagines or thoughts would pop into my head when we had sex and I would just instantly cry because I felt I couldn't enjoy anything anymore." (Alex, age unknown)*

Furthermore, for some, their experience of OCD has taken away their interest in pursuing sex at all:

> *"Having rough OCD responses postpartum impacted my interest in sex for quite some time which frustrated my spouse even though he understood." (Pam, 55)*
>
> *"Honestly, ever since postpartum, I have had no interest in sex whatsoever. Every time I have sex, I am never present. I get intrusive thoughts the whole time and it takes me out of it." (Rosie, 29)*

In both examples above, participants relate their loss of interest in sex to postpartum experiences. It is as if OCD arising following the birth of a child has shed a different light on the act involved in creating the child. Although not explicitly stated, it is as if some participants are saying that OCD has both infiltrated the experience of motherhood, but also the act of reproduction. This suggests that the pleasure connected with sex has been taken away by the experience of OCD following birth, as well as the ability to feel engaged with the other person whilst intrusive thoughts are coming to mind.

In other accounts, individuals suggest that they have had to involuntarily avoid having a sex life. It is as if it feels safer to avoid sex and the prospect of intrusive thoughts becoming entangled with sexual experiences which may become a barrier to pursuing sexual relationships:

> *"I have forced myself to go fully asexual, I basically block out sexual thoughts and behaviours because at the end of the day If I run the risk of having the whole intrusive thoughts about my sexual regressions I would be reassured that I never did anything. So far it works, as I have been doing it for over 2 years." (Ryan, 21)*

> *"Pocd [Paedophilia OCD] basically took a part of me when I reached the lowest point of it, I do want to experience to have a sexual life, but it is so distant to me right now, masturbating has become a compulsion to see if I can do it without having any sexual intrusive thought, and I started to feel so anxious and afraid before doing it that I decided to stop, I'm afraid that*

> *when I finally experience sex, pocd related intrusive thought comes in the way, and ruins it, and basically traumatize me. " (Jess, 20)*

Ryan's account suggests that they have had to push down an aspect of themselves and deny their sexuality to manage the potential distress that OCD could create within a sexual context. The use of the word "*forced*" implies that Ryan has fought against the part of himself that wants to engage in a sexual life in the interest of not having to question whether he has done anything inappropriate. Ryan conveys how the pursuit of sexual pleasure is not worth the pain brought about by the intrusion of OCD, both within and following the encounter. For others the prospect of sex may be seen as something fearful when the individual is battling with sexual intrusive thoughts that are perceived to bring their sexual inclinations into question. For Jess, her experience of OCD and sense of her sexuality has become so entangled, such as the description of how masturbation became a compulsion. It is as if she so desperately wants to separate OCD from her sexual experience and feels that sex with another person cannot be possible until she has achieved this. There is a sense of hopelessness as Jess is prevented from engaging in the life that she wants to live and from pursuing the pleasure of sex. This suggests that the presence of taboo sexual intrusive thoughts may present a significant barrier for individuals with primarily obsessional OCD wanting to engage in sexual relationships and masturbation.

Across this subtheme, there is a sadness conveyed in the accounts as participants' experience of their sexuality is so overridden by their OCD experience that the prospect of engaging in sex without causing distress is perceived as unattainable. For some, OCD creates a distraction from their sexual experience preventing them from connecting with their sexual partner. For others, there is the expectation that engaging in sex inevitably brings intrusive doubts about sexual identity. There is an overarching sense that that sexual acts have become associated with fear rather than pleasure and for some the idea of sex with a partner can become a terrifying prospect.

Overall, the theme of distance and disconnection encapsulates how participants feel unable to connect fully within their interpersonal relationships alongside managing their intrusive thoughts and covert compulsions. Furthermore, in their attempts to manage intrusive thoughts (e.g., performing internal mental rituals or becoming mentally preoccupied) and to protect others by physically avoiding them, creates a sense of isolation for the individual with OCD. This may also inadvertently lead to distress and frustration on the part of the partner or family of the individual. This could indicate that the covert or hidden characteristics of primarily obsessional OCD could make it difficult for partners or family to interpret the meaning of the individual's objective aloofness as OCD.

Theme 2 - Hidden in Plain Sight: The Predicament of Disclosure

This theme encapsulates the hidden nature of primarily obsessional OCD and the considerations and cautions around how much individuals' share with others about their experience. The accounts suggest that the absence of clear visible compulsions enables individuals to appear as if they are managing well in their daily life from an outside perspective. However, the hidden nature of their OCD can contribute to the problem as they perceive that others do not understand their distress:

> *"Very few understand what it is or how distressing it is. Particularly as on the surface I am able to function" (Dorit, 68)*
>
> *"I worry that people don't understand how severe it is because there aren't visible compulsions." (Victoria, 20)*
>
> *"Sometimes, I feel like they underestimate for what I'm going through, just because the majority of it is covert and also because I try to be as high functioning as possible, but there are times I'm really struggling and nothing adds up and everyone thinks I'm just having a blast […]" (Pam, 55)*
>
> *"[…] they think since my physical compulsions aren't as bad I must be "getting it out of my system" now. Definitely not the case" (Fran, 26)*

The idea that individuals feel that others see them as functioning "normally" conveys a sense of suffering in silence, as others are unaware to the full extent of their OCD and related internal torment. Indeed, as Fran illustrates, individuals can experience perceptions from others that they are improving if physical compulsions decrease. Considering the covert nature of primarily obsessional OCD, this suggests that individuals' distress may go unnoticed or unrecognised in their relationships if it is not explicitly disclosed or picked up on externally. It is inferred that if compulsions are not visible then the individuals' distress also remains invisible. The distress associated with mental compulsions may be overlooked by others by comparison to physical compulsions and the individual may therefore carry the emotional burden of this alone.

When it comes to consideration of disclosure, the accounts suggest a caution and a need for selectivity about both who they disclose to and the extent of their disclosure. Many participants reported that they had only disclosed about their OCD to select people in their life - those that they are close to. Participants often reported that they had shared only with their romantic partner only and/or to a professional:

> *"I haven't told anyone other than my therapists and current partners." (Sean, 25)*
>
> *"Only my doctor and psychiatrist really know what is going on." (Alice, 26)*
>
> *"Well not many people do know. I did tell a few non professionals a long time ago and would be very wary of doing so again." (Sam, 48)*
>
> *"The only person that has ever known about it in it's entirety is my husband, I hid it from everyone else as I feared their reaction. I think it is a very easy condition to misunderstand, which could then harm someone's recovery." (Sian, 45)*

There is a cautiousness conveyed about who they disclose to. These accounts suggest that individuals want to disclose to somebody who is perceived as likely to understand (e.g., a mental health professional) and who is trustworthy. For others, negative experience of disclosure may impede the extent to which they would be comfortable to disclose again:

> *"well, as I've got older I became much more cagey about what I disclose, for example, [….] told a couple of people [….] on my master's degree about it and they totally went around telling people that I was a psycho…" (Sam, 48)*

Sam coveys that disclosure is a risky business. Due to the hidden nature of primarily obsessional OCD, individuals' need to be explicit in sharing with others, and the decision to do so has potentially significant consequences for them and their wellbeing. This means that because it is understood as invisible, they can choose to hide it. Individuals feel it is necessary to conceal their OCD from others to avoid judgement, stigma, or misunderstandings. Although the process of concealing rather than disclosing can be difficult or distressing, participants convey that they are in an uncomfortable no-win situation. Although they can hide their OCD, they can find that this is not good for them, they need to be explicit in sharing and it is perceived to be, and actually is, risky - with potentially detrimental effects.

For some disclosure is favoured and concealment is considered problematic due to the difficulty not sharing presents for the individual:

> *"I don't want to hide it as it's exhausting and the more open and less awkward I am the less awkward others are about it and I can ask for help easily when needed." (April, 27)*

> *"I just feel like I'm always constantly lying to everyone around me because I keep having to mask the anxiety that's actively working to ruin my life." (Elijah, 21)*

April suggests that it is better to disclose to relive the distress of concealment and enables her to be supported by others. There is a sense that it is too much to manage OCD in isolation and that disclosure enables the individual to share the emotional burden. For Elijah, there is a suggestion that concealment feels like a deception and prevents others form understanding his experience. His account suggests that he needs to hide but that this keeps him isolated in his distress. Like April, there is a sense that it is burdensome having to hide his experience, but there is also an inference of guilt about hiding it.

For others, selectivity about the extent of disclosure is perceived as a necessary exercise in the management of OCD:

> *"I haven't told her everything because you know, even with her I think… I just can't. You know, it's very, very difficult for me to disclose you know.. this part of me thinks well, do I have to? It's not like being secretive, it's just […] I don't feel like I need to say every little thing […] you know there is a part may face rejection and upsetting her, you know." (Sam, 48)*

Sam infers a sense of partial disclosure and an internal debate about how much to open-up. There is selectivity about who individuals disclose to but also how much they choose to disclose. Sam suggests a perception that no matter how understanding his partner may be, disclosing the full extent of his experience could risk rupturing his relationship. Similarly, participants convey a feeling that understanding or acceptance from others is contingent upon moderating disclosure:

> *"I think my partner is very understanding although he doesn't probably know the extent of it." (Selena, 34)*
>
> *"I have shared with many people that I have OCD and Pure O but nobody knows about the thoughts I've had in detail not even my therapist. I'm scared of the reaction or making people uncomfortable or scared of me." (Bella, 19)*

There is a sense that participants are navigating whether to disclose or not disclose or somewhere in between. Rather than a binary of being out and open versus keeping it hidden there is a more complex contemplation conveyed in terms of who they share with and how much they share. There is a sense that there is a process of weighing up the extent of disclosure through exhaustive and constant internal negotiation. There is also a vulnerability communicated as if opening-up about their experience may leave individuals feeling exposed to negative interpersonal reactions.

Across multiple accounts, it was common for participants to conceal some or all the content of their intrusive thoughts. The decision to conceal appears closely aligned with fear of sharing taboo intrusive thoughts and the potential for vulnerability if they are misunderstood. The accounts below exemplify how individuals can share to an extent with others, but with certain themes it is more challenging:

> *"she knows I have OCD and intrusive thoughts, and I have been able to tell her that I fear being a bad person but I have not been able to say those dreaded words ""I'm scared that I'm a paedophile"". Why? Because I'm afraid. I'm afraid of what she'll think, I'm afraid that she won't feel the same way about me, that she won't understand. How could she understand?" (Georgia, 31)*
>
> *"My boyfriend knows the most, he is the best. He knows all except the [paedophile] one. that again is one I can't be bothered to explain. I know what the thoughts are, but others don't and it is just too risky to have to explain everything to someone who might not understand." (India, 26)*

This pattern suggests that some individuals with primarily obsessional OCD may consider some thoughts and doubts more acceptable or safe to share than others. Interestingly, both the accounts above referred to concealing intrusive thoughts relating to paedophilia. The data suggested that thoughts of this nature were particularly difficult to divulge as they were strongly connected to fear about the potential outcome of disclosure.

Overall, this theme conveys the idea that individuals with primarily obsessional OCD may have a choice due to the hidden nature of their OCD as to how much to disclose to others. On one hand, the ability to hide their internal experience enables the individual to avoid perceived misunderstanding and judgement, whereas on the other, being unable to talk about one's distress can be an isolating, potentially alienating experience. For some, hiding their OCD can feel like they are deceiving others, suggesting that individuals would rather not have to manage their distress on their own, but feel compelled to hide their experience. This suggests that if individuals with primarily obsessional OCD wish to disclose their experience to others in the context of their lives and relationships, it may prove challenging if they feel others are not likely to understand.

Theme 3 – Perceived Misunderstanding and Misinterpretation of OCD in Personal and Professional Contexts

This theme encompasses a pattern in the data of participants feeling they had been misunderstood by others in their interpersonal relationships, as well as within a professional help-seeking context. This theme also encompasses experiences where individuals have been met with negative responses or misinterpretations from others, including therapists and the potential for this to lead to distress in both personal and professional contexts.

Misunderstanding and Unhelpful Responses in Interpersonal Relationships

This subtheme encapsulated experiences where participants have struggled to get support within their interpersonal relationships and felt that others did not understand when they have tried to explain their OCD experience. Participants convey both an expectation of being misunderstood and experiences of trying to explain OCD to others, but not being able to get the message across:

> *"Nobody knows because I feel almost no one would get it." (Edward, 24)*

> *"Most people dont know and dont understand the condition when explained." (Gemma, 32)*

Edward suggests that he feels there is no point in sharing about his experience because of the expectation that people will not understand. This expectation conveys that the individual has made up their mind that they will be misunderstood but does not tell others about their experience and therefore may not learn whether this expectation is true. This potentially leaves individuals in the state of being further isolated within their relationships and others may not have the opportunity to try to understand their experience. Participants shared perceived misunderstanding and misrecognition from others both broadly and in relation to specific relationships.

> *"My best friends know about my OCD* […]*. They do not understand it at all, even my partner doesn't understand it, but they know." (Rosie, 29)*

> *“I think most people who haven’t experienced OCD/intrusivity don’t understand or recognize what is actually happening. I think I’m brushed off as ‘weird’ or ‘nervous’” (Julie, 34)*
>
> *“I think a lot of people understand the anxiety and may have had some of the same thoughts but they don’t understand how debilitating it is and how hard it is to break out of negative cycles.” (Denise, 51)*
>
> *“People don’t see me as having OCD because they don’t understand what OCD truly is, especially Pure O.” (Jenna, 29)*
>
> *“I know my family wants to support me but I don't think they have the capability of understanding how intrusive thoughts work. They very seriously believe I should just try harder not to think about it. To my knowledge none of them know any more of the symptoms of OCD other than hand washing and some pickiness about how things are aligned or organized. It's a very ""television"" understanding of OCD.” (Fran, 26)*

In some cases, perceived misunderstanding, or lack of recognition from others can leave individuals feeling unable to open-up about their OCD, or when they do, feel unsupported and dismissed. In some cases, participants feel that people can relate to certain aspects of it, but not quite understand the severity of the impact it has. Individuals may therefore have difficulty accessing social support and subsequently have to manage their anxiety, intrusive thoughts and compulsions in isolation. The data also suggests a lack of understanding societally about the different ways in which OCD can present. This may leave those experiencing primarily obsessional OCD to feel marginalised, living with what is already felt to be a "*lonely and isolating*" experience (*Denise, 51*). For Jenna and Fran, there is a sense that the lack of understanding from others comes down to not understanding the nature of OCD or having a preconceived ideas about OCD. Fran's account suggests a perception that others expect OCD to involve outwardly observable compulsions. This presents a difficulty for those with primarily obsessional OCD who have largely covert compulsions. If media representations of the condition have shaped common public knowledge to expect certain characteristics more closely aligned with other OCD dimensions, those with covert compulsions may be more vulnerable to misunderstanding or misbelief from others.

What was also evident was some participants try to put right misunderstandings through attempting to educate others:

> *"I try to explain that it's not colloquial - it's a real, debilitating disorder. I share some of my symptoms and the consequences, as well as my treatment journey. People are generally curious but ultimately not invested. I think it's important for people with OCD to share their experiences with those who don't know much about it - IF they feel comfortable/safe. It will help remove stigma, as well as potentially educate people to notice symptoms in themselves or others and seek treatment." (Julie, 34)*

> *"At first, I think she thought I was a lesbian. Until I told her my thought process and how it disturbed me and my daily life. It took a couple of days for her to fully get it, and I felt relieved that I told someone and they understood." (Oonagh, 19)*

It is suggested that participants want others to understand their condition so they can feel understood and can feel that raising awareness would reduce social judgment and improve recognition. However, individuals convey that it is not an easy experience to explain, let alone for others to grasp. There is a sense that because primarily obsessional OCD predominantly involves internal experiences and covert compulsions rather objectively observable behaviours, this presents a challenge in educating others. Participants like Oonagh are tasked with verbalising an experience that can often not be seen objectively and thoughts that could be taken at face value rather than seen as an unwanted source of distress. There is an overarching sense that individuals want support from others, but that this is not workable without their understanding.

In addition to being misunderstood by others in interpersonal relationships, participants also shared experiences of receiving unhelpful, harmful, or stigmatising responses from others:

> *"When I was married it really did put a strain on our relationship. My husband would say...oh not this crap again...and then would go to the pub" (Ruth, 50)*

"Eventually I told my partner after 15 years and he thought I was making a mountain out of a molehill. He thinks I go looking for problems, which belittles my suffering. This added insult to injury, as I knew for years I wanted to tell him about this very personal area of my life." (Sandra, 56)

""I have tried to explain to my mother, but she discards my experience as me "making things up"." (Matilda, 44)

"my family take it personally and think I'm just being dramatic and lazy" (April, 27)

Each account suggests that others have responded in an invalidating way, from not believing that the individual has OCD to being unwilling to tolerate the individuals OCD. The data suggests that when explaining their OCD or seeking support, individuals' partners or family may not always be supportive. Indeed, Sandra suggests that her distress was increased by their partner's reaction. Within interpersonal relationships, attempting to explain one's OCD experience did sometimes add further distress when met with a negative response. For some, this involves frustration from the partner or family member, as the persons' OCD experience becomes a problem within the relationship. The above accounts convey that others can have a difficulty empathising with the experience of the individual with OCD. Both Ruth and Sandra's experience carry the assumption that they are being seen as at fault in some way. Furthermore, there is the suggestion that for some, family members may not believe the individual has OCD. This suggests that individuals may not only have difficulty explaining their condition but may not be believed or receive responses from family that have the potential to increase their distress or alienate them further.

Beliefs within the data about stigma are not exclusively related to experiences where individuals have directly encountered negative responses from others. In some cases, these perceptions are shaped by how people talk generally about OCD. A shared feeling among participants was that others without OCD often trivialise, make light of, or joke about OCD characteristics:

> *“Wish it was on tv more. Everyone sees ocd as a joke or washing hands 20 times a day or just being obsessive in straightening things and stupid memes about bricks being wonky.” (Alison, 36)*
>
> *“People often joke about how they have OCD as well, which is quite demeaning. I try to explain that it’s not colloquial - it’s a real, debilitating disorder. I share some of my symptoms and the consequences, as well as my treatment journey.” (Julie, 34)*

Alison notes that she would like more representation on television of OCD to rectify misguided understandings of OCD. This also speaks to the shared perception that others often have a stereotypical view of OCD. Many of the accounts that discuss experiences of others ‘joking’ that they also have OCD convey a sense that this is an unhelpful response. In some cases, this is due to the feeling that the other person is making a joke about OCD and taking away from how difficult the experience is. This is experienced as hurtful by the individual with OCD when others respond this way.

Several participants experienced others responding to the revelation of their OCD with claims about having OCD themselves. The accounts infer that these experiences are frequent and perceived as barriers to communication and to feeling understood by others:

> *"I have mentioned having ocd but 99% of the time am met with oh me too or I know just what you mean. At that point I say nothing more." (Alison, 36)*
>
> *"When I do tend to tell people I have pure O they respond with "I think I have ocd as well because I like things neat" this is frustrating because ocd is so much more than that" (Michelle, 38)*
>
> *"I've told my Mamas about it. She then proceeded to tell me that's she's OCD because she needs her keys to be in the same direction. I'll be talking to her about that because she's clearly not OCD truly. She's just throwing that word out." (Gloria, 30)*
>
> *"I feel like sharing with friends is a waste, because people think it's a joke or not serious and just makes them look at you like...I don't think you have it cause your car is a mess, or people think it's not being able to step on lines. It's almost always met with a bit of pity for how weak you are to want everything symmetrical, even though that's not even your compulsions necessarily." (Penny, 39)*

Again, these experiences reflect responses from others that seem to be influenced by more widely recognisable presentations of OCD or preconceptions about what it means to have OCD. There is a sense that the individual feels that the person they have disclosed to does not understand OCD and that it is unhelpful that they have assumed what OCD looks like. It is inferred that these responses are perceived by participants as a communication of a narrow understanding of OCD that invalidates their personal experience. For Gloria, although it could be construed that her mother is attempting to relate to her by comparing it to her own characteristics, this is experienced as unhelpful and again trivialising the OCD experience. The accounts suggest that participants expect others to trivialise or stereotype what it is like to live with OCD and what it means to have OCD. Many accounts refer to other peoples' preconceptions about OCD involving characteristics of other OCD presentations. It is perhaps understandable that the accounts such as Penny's, convey a belief that there is no point in opening up about the individuals experience with others as there is an expectation of misinformed, judgemental or trivialising responses.

Overall, the accounts suggest that individuals expect others not to understand their OCD and have had experience of attempting to explain but finding that others have misunderstood. The accounts convey that it can be challenging for individuals to get others to understand their OCD and being misunderstood or not taken seriously, can be an invalidating experience for the individual. This has the potential to leave individuals feeling isolated and disinclined to share their experience with others. However, if they do get others to understand or at least raise awareness of it in others, this is a relief for the individual, and it feels good. This also adds to the wider picture within the data of how individuals experience seeking support within the interpersonal context. This subtheme illustrates how a lack of understanding from others or lack of belief, has the potential to add further distress to the individual with primarily obsessional OCD as they attempt to reach out to those that close to them. In some cases, this leaves individuals resistant to speak out about the condition to others as they expect to be met with unhelpful or misguided responses.

Misunderstood and Misbelieved by Professionals

The notion that individuals with primarily obsessional OCD feel misunderstood or misinterpreted by others, also extended to some experiences within a therapeutic context. Several participants reported experiences of feeling misunderstood by therapists or a lack of recognition or belief that it was OCD that they were experiencing:

> *"I have tried counselling and CBT that I was referred to through the NHS and it didn't help. The therapist didn't really understand what I was going through." (Brenda, 47)*
>
> *"My therapist still doesn't believe that I have it, which makes it really hard for me to open up to her about these thoughts or to get support from her for the OCD symptoms." (Jenna,29)*
>
> *"The first psychologist I spoke to was just generally kind of useless, and did not understand OCD. When I said I thought I had OCD she said ""you don't have OCD; my patients with OCD are really messed up"" (Lisa, 23)*

These accounts evidence that participants saw therapy as a route for support with their OCD. However, for some, there was a lack of acknowledgement of their OCD from the therapist and the perception that they did not understand the individuals' experience. Jenna's experience infers that if therapists do not believe or take on board the client's beliefs that they have OCD this may leave individuals unable to talk about their experiences in therapy or receive relevant support. Lisa's experience above conveys that she has been treated appallingly by her therapist, not only by dismissing her experience, but so too by speaking in a derogatory manner about those with OCD. This also has the potential to communicate to Lisa that if she does have OCD, this will be judged in a negative light.

It could be that the heterogeneity of OCD makes it a difficult condition to recognise by those who do not specialise in OCD or do not have a broad understanding of the different ways it manifests:

> *"When I would discuss the diagnosis that I thought I had, my family and friends and even therapist would say I did not have OCD because I did not fit the "stereotype" of OCD (compulsively cleaning, counting, checking locks, etc). (Rosie, 29)*

Rosie's account suggests that individuals may expect others in their lives to not understand or recognise their OCD but the choice of words *"even therapist."* suggests an expectation that the therapist should be more knowledgeable about and better able to recognise the different manifestations of OCD. It is particularly concerning that this can be individuals' experience of therapy considering that it can be tough to seek help in the first place. It is outrageous to think that for those who have braved seeking help, there may actually be a risk of making it worse through lack of belief, or at best lack of understanding. Other accounts more specifically suggest that there is an absence of recognition of OCD presenting with the lack of visible compulsions. April illustrates how assessment within a help seeking context might overlook OCD as a possibility due to the lack of physical compulsions typically associated other manifestations of OCD:

> *"I spoke once again to the IAPT* [Improving Access to Psychological Therapies] *triage service who asked if I washed my hands all the time or liked everything to be neat and tidy. When I said I wash my hands the normal amount and don't really mind mess they told me I couldn't possibly have ocd and to get it out of my head. I got sent to a cpn who picked it up immediately and I was referred to my day unit where I have been receiving treatment for 3 years, with only 3 sessions left as I am doing so well!" (April, 27)*

This appalling experience suggests that professional assessment of OCD may not necessarily pick up primarily obsessional presentations and that individuals' experience can be dismissed when reaching out for help. Furthermore, this suggests a massive lack of training among health professionals working in a service that many will go to, that is based on overly simplistic understandings of what OCD means. This could result in individuals with this presentation not receiving the support that they need. Worryingly, such accounts suggest that counselling and support services are letting people with OCD down in a way that is massively problematic, particularly for those with primarily obsessional OCD.

Furthermore, in multiple accounts participants share the perception that therapists lack understanding about primarily obsessional OCD and that there is a need for education about the different variations of themes present in OCD. Participants inferred that therapists need to have greater knowledge about primarily obsessional OCD to better support individuals seeking help:

> *"I think all therapists should be aware of the idiosyncrasies of OCD in order to know when to refer people to someone who understands the condition." (Pam, 55)*
>
> *"Recognise the different forms of it! Do your research! Read the online communities and forums!" (Selena, 34)*
>
> *"The mental health world needs to be more educated on different OCD themes (Which honestly could be anything), how sticky and loud the thoughts are, and what overt and covert compulsions look like. (Rosie, 29)*

The accounts convey that for people with OCD to have the care and support they need; therapists need to be better educated on the nuances of OCD. It is apparent that from the participants perspective, the emphasis is on the therapist to educate themselves. This indicates that there may be a need for a greater emphasis on the heterogeneity of OCD during counselling psychology training and in continued professional development courses. Furthermore, as the above quotes illustrate, participants are conveying that those with OCD and those within online OCD communities have a deep understanding of OCD that therapists could learn from to better understand and support them. This indicates that the integration of subjective accounts of different OCD manifestations into training programmes may help counselling psychologists and other therapists to have a better understanding of their clients with OCD. Learning more about the identified manifestations of OCD should enable counselling psychologists to come to a shared understanding with the client of what they have been struggling with. Overall, the participants are inferring that they want therapists to work harder to understand individuals with OCD so that they feel seen when entering therapy.

There were some accounts where therapists' beliefs about diagnosis left the participant feeling unsupported or infuriated by the lack of acknowledgement:

> *"My second cbt therapist (high intensity) - told me I had ocd, didn't explain it, every session was listening to his music to practise mindfulness. After this I called my second counsellor back because we had a good relationship and she helped me get through my depression (and haven't had depression since!) and she said 'I did notice you had ocd symptoms but I don't believe in diagnoses so I didn't tell you' which was infuriating." (April, 27)*

> *“I don’t talk about OCD* [to my counselling psychologist] *really at all…because when I have in the past when I tried to like tried explaining to her. I think I have OCD. I’ve got all everything la la . Then she said to me.. one time she said to me “we don’t believe in diagnosis”..* […] *…Another time she said to me like the DSM was created by like white middle-aged men, and it’s constantly changing, so we can’t rely on it um.. And she just negated the whole OCD experience. “(Laura, 26)*

April’s narrative suggests that lack of recognition has a negative impact on the client, and that incongruence between the client’s and therapist’s beliefs about diagnosis could have the potential to impact negatively on the therapeutic relationship. Furthermore, Laura’s account suggests that the counselling psychologist’s perspective on OCD diagnosis not only invalidated her experience, but also prevented her from talking about it. This suggests that when individuals’ beliefs about their distress is misaligned with the therapist’s, this may present a barrier to communication within the therapeutic encounter. This may lead the client feel unable to open-up about their experience and get the help that they seek. It is concerning that there is a common thread through these accounts where individuals are effectively being silenced when seeking professional help and interpreting the world as a place that is not safe or supportive. Although there will be variations in how therapists perceive diagnosis and willingness to give a diagnosis, not acknowledging or disputing clients’ understanding of their experience could prevent the individual from speaking about the problem they are facing.

What was also interesting was the experiences where individuals had encountered difficulties with the therapist's approach to their OCD. For example, when the therapists' interpretation of their experience was misaligned with what they felt they needed from therapy. Some accounts described seeking support through counselling or psychodynamic approaches. Such approaches involved less emphasis on identifying OCD or providing tools for managing intrusive thoughts, and more on uncovering meaning and understanding past experiences in relation to the clients' presenting concerns. Therapeutic experiences involving this type of interpretation in relation to intrusive thoughts were experienced by some participants as at best unhelpful and at worst, prompting further distress.

> *"Currently, I have a therapist who works in a counselling style. I would like to find a OCD specific therapist again to be able to build up trust and openly talk about this disorder. I mentioned the OCD / deaths with this therapist and she read into one of the intrusive thoughts in a sort of psychodynamic* [way], *which I knew was a massive red flag. She is very helpful in other areas so I felt it was best to ignore and wait until I felt content with where we were at until I embarked on finding an OCD specific therapist." (Becky, 26)*

Becky's account infers a sense of wariness around psychodynamic approaches and a perception that it would be unsafe to bring up OCD with a therapist using such an approach. Indeed, Becky insinuates that she has a preconception about the use of meaning-making approaches for OCD, suggesting that she was preinformed that such approaches pose a risk to those with OCD. Since most participants were recruited from online communities, it may be that information sharing among those in these communities or personal research about therapy options have informed perceptions about different types of therapy. Other accounts described experiences of past-orientated approaches that had been unhelpful for the individual in moving forward or lead to further preoccupation with intrusive thoughts:

> *"Therapy approaches such as narrative, feminist, attachment have been unhelpful for me. I can only talk about my childhood trauma so much. It has not helped me get past my OCD or manage it better. I'm not saying to ignore it completely, but I do believe I should have sought out a specialist a long time ago." (Rosie, 29)*

> *"…and then she told me. Maybe so, with OCD with the suicide theme, she said to me. Maybe you unconsciously at one point wanted to die, and she's like "I'm thinking about when you are young" and I was like huh? And like obviously at the time when I'm like constantly in a fierce cycle it did not help me because that's like, then it made it worse in a way because I was thinking, "oh my God has my….is my brain wanting me to die" and like "do I somewhere deep down in me want to like die" like that sort of thing, so it just was really unhelpful" (Laura, 26)*

Laura exemplifies above how the pursuit of meaning and interpretation of intrusive thoughts can lead clients to feel confused and further question the significance of their thoughts. Considering distress in primarily obsessional OCD is attributed to the personal significance attached to intrusive thoughts, it is understandable that therapeutic approaches seeking to explore and interpret personal significance could be counterproductive and even harmful (Rachman, 1997).). Indeed, Laura, goes on to voice this point:

> *"I don't know I feel like OCD is one of those things that just has to be CBT-based. It would be really unhelpful and detrimental to go down psychodynamic route*
>
> *… I think it just encourages more time spent on things that we've.. we've already spent too much time on so.. so it's encouraging actually the opposite of what we need as OCD sufferers." (Laura, 26)*

Overall, this theme conveys the struggle that individuals with primarily obsessional OCD experience in seeking to find understanding within the context of their personal lives and in some cases in a therapeutic setting. Participants frequently discuss experiences of attempting to share what they are experiencing with others, but often feel like others are unable to make sense of their experience. The accounts suggest that participants often feel that they are tasked with the responsibility of educating others about their condition but can find it difficult to explain. Furthermore, the experiences of being misunderstood in therapy or encountering therapeutic approaches that seem misaligned or unhelpful, convey a sense of helplessness as individual's do not feel understood by the person they would most expect to understand. Understandably, the individuals' accounts suggest that it is seen as important that therapists can acknowledge and recognise OCD and that the help they provide is an appropriate fit.

Theme 4: Support Outside the Therapy Room - Help or a Hinderance?

This theme encompasses how participants experience help-seeking outside of a therapeutic context. This encapsulates how individuals value support around them within their interpersonal relationships and in online communities. This was particularly appreciated when they felt others accept them and recognise their OCD as separate to their identity. The theme also addresses the concept of hindrance in several ways. This includes the challenge for some individuals to differentiate between when they are helping or hindering themselves. For example, delineating between when they are seeking support from their loved ones, or seeking reassurance, and therefore performing a compulsion. There is also the sense of individuals feeling that they are hindering their loved ones by being a burden or putting strain on their relationships. Finally, there is the detail in the experiences that suggests OCD can negatively impact others in the participants life, leading to perceived frustration with the individual with OCD. Social support can be experienced as highly beneficial and validating, but there can also be pitfalls when the lines between support and accommodation become blurred or the person offering support is negatively affected by the experience.

Acceptance and Recognition in Personal Relationships and Online Communities

Many participants' accounts discussed the importance of support from others within their personal relationships in relation to their OCD and support found in online settings. It is perhaps unsurprising to see that an aspect of social support which was seen as particularly important is feeling understood and accepted by others. Individuals feel supported if they have the knowledge that others can accept and understand that OCD is separate from, and not indicative of, their identity. When participants and their intrusive thoughts are accepted by others this enables them to believe that their thoughts do not dictate their character, nor their intent. Therefore, the understanding of others helps participants to feel understood and supported:

> *"well, she just… It's kind of hard to explain. She just sort of… She just knows it's not me, she's always accepted.. she's always accepted that. It's like a mental health condition. She's never said maybe we better not be around kids or anything like that." (Sam, 48)*
>
> *"I have disclosed most of not all of what I've dealt with regarding Pure O to my husband, who was immediately understanding and supportive. Prior to telling him, particularly because of sexual orientation obsessions I was experiencing at the time, I was terrified that speaking those thoughts allowed would somehow make them true, or give them more power, or that he would believe the thoughts were true and be heartbroken by them." (Millie, 32)*

> *“My oldest and best friend seems to understand, she says that she knows i’m not a bad or dangerous person, and she supports me. My other friend has read up on it, and he supports me aswell and seems to understand that it’s something i’m struggling with.” (Grace, 24)*

The accounts infer that it is important to individuals to be able to perceive OCD as a separate entity distinct from who they see themselves to be and that it is important that others understand that differentiation. Some participants have highlighted where others have understood this distinction which has enabled them to feel understood and accepted. But for some, such as Millie, this is tenuous, and perhaps more difficult to discuss if there are strong doubts and uncertainty around one’s identity. Running through the accounts is the implicit notion of relief in others confirming to the individual or demonstrating their awareness that they do not take the intrusive thoughts as truth. For Sam and Grace this is about others confirming they are not a danger to others. As suggested by Millie’s account, individuals may also find it difficult to disclose to their partner because there is a risk of being misunderstood, therefore having a partner who is supportive, and understanding was perceived as important. Grace’s account also shares the view of the importance of others being able to recognise that the features of OCD are not indicative of immorality or bad intent and that it is helpful if others are able to educate themselves about OCD and approach support from an informed perspective.

There is an overarching sense that individuals believe that to feel supported they need to feel fully understood by others. For some this support was found within the context of online OCD communities. Where online communities were discussed in the data, there was a sense that the online spaces provided a place where individuals felt that they could recognise their experience within the stories of others and realise they were not alone. The accounts suggest that online environments provide validation, reassurance, and the ability to safely discuss their experience without others seeing them as at risk of living out their intrusive thoughts. Furthermore, notably within these environments, individuals were able to identify that their experience of intrusive thoughts fit with an OCD diagnosis rather than an indication of their character. For some who had yet to identify they had OCD and had not sought professional support before, being able to have the recognition and clarification that their experience was indicative of OCD helped them feel less alone:

> *" […] I reached the lowest point, I was practically delirious wouldn't know what was real or not, basically accepting that maybe I was a P* [paedophile] *and most likely would have to end with my life later on. Found support groups, found someone else with pocd, explained everything to me, and basically saved me," (Jess, 20)*

> *"I was like, oh my god, like maybe I'm not this monster like this person is experiencing the same things in this person is saying to me that I'm not*

> *this, that he has that too, so it was really it was a great experience." (Jess, 20)*

Jess was able to identify that she was not alone and that her thoughts were not indicative of her identity without having to risk disclosing to a professional. This comes across as extremely significant for her as she suggests that without finding the group and having this support she envisioned having to *"end with my life later on*". This suggests that being able to find identification in this way may be a lifesaving avenue for some who have yet to understand their OCD and receive help formally. This highlights the level of distress individuals can be living with and the importance of having their experience recognised and understood by others. Furthermore, this indicates that normalisation of taboo thoughts and careful risk assessment are important considerations for counselling psychologists and other professionals when working with individuals with primarily obsessional OCD. In the subsequent interview (second quote above), Jess shared more about how hearing from this person enabled her to reevaluate the meaning she attributed to her intrusive thought in relation to her identity. There was a sense across the data that OCD is perceived as a malevolent entity making individuals feel like they might be a monster. It is clearly a significant experience for Jess to assuage this idea though finding online support and recognition from others with OCD. This also comes across from other accounts conveying that it has been very helpful to find others who understand OCD first-hand:

> *"Being in a Facebook-group related to intrusive thoughts has given me a sense of community and a sense of having shared experiences with other people who would understand me if I were to share something." (Lila, 26)*

> *"I ended up looking at instagram pages where people with the same experience talk about it and helped me understand my symptoms." (Andrea, 24)*

> *"Mostly I have browsed forum posts (reddit) for people suffering from the same thing. I do also read articles but reading other people going through something similar has helped." (Greta, 29)*

Lila indicates that within these online environments, there is a sense of safety to disclose individual experiences as those reading them may have experienced similar thoughts or have an awareness that these thoughts are a feature of OCD. Furthermore, the above accounts give a sense that these environments enable individuals to realise they are not alone. This feels particularly significant when considering the overarching sense of loneliness conveyed through many of the accounts. These accounts also suggest that online support sites provide a way individuals can gain insights about intrusive thoughts experience without having to disclose their own. This unique feature of online spaces enables individuals to look in at others experiences from the outside. Instead of feeling stuck in their own minds they gain perspective from seeing others sharing and learning what is happening in the minds of others with similar experiences. Some participants comment on how they use social media or online communities to read about others' experiences which seems to provide a normalising quality, enabling people to understand their experience in a safe and anonymous way.

The accounts suggest that individuals can find it helpful to receive support in an interactive capacity, or browse and observe other experiences, enabling a sense of belonging and recognition without necessarily having to actively disclose or engage with others. Unlike other routes of seeking support that involve disclosure and the fear and vulnerability associated with this, observing, or recognising oneself in others experiences online is risk free. There is a sense that participants can feel supported in the safety of an online space without the same sense of risk as disclosing their experience offline.

Risks and Challenges of Support Seeking in Personal Relationships and Online Communities

Despite the many significant experiences shared of the value of support in online settings, finding support in such environments was not a guarantee. In some cases where others provided support there were perceived challenges for those offering the support and/or a perceived risk that support could inadvertently perpetuate OCD. While some participants reported that groups offered opportunities for belonging and shared experience, others told quite different stories of how these spaces could be as risky as in real life:

> *"Facebook support groups were actually awful because any time you mention that your intrusive thoughts involve women or children and are of a sexual or violent or sexually violent nature, you are essentially told*

> *you should be in jail which goes against the entire purpose of a support group and only speaks to people's own misunderstanding of how the illness manifests." (Charlie, 28)*
>
> *"Sexual intrusive thoughts regarding children will shake you to the core and probably aren't shared much even in OCD support groups." (Cassie, 37)*

Charlie describes how support groups can be a source of distress when comments from others suggest misunderstanding or confirmation of the individual with OCD's greatest fears. This account also suggests that online support forums may not always feel like a safe place to share experiences. This seems particularly pertinent for those with primarily obsessional OCD who typically experience taboo or controversial intrusive thoughts. Describing such thoughts in online communities, particularly if not well regulated, may leave some individuals vulnerable to stigma. Although responses from others online around taboo topics can be helpful, there is also an indicated risk of judgement and of increasing individuals' distress rather than the offer relief or support. Accordingly, taboo thoughts may be less likely to be shared within online communities, this could potentially be due to the risk of having an experience like Charlie's.

For others, being in groups online is thought to put them at risk of remaining fixated on the OCD experience rather than moving on and trying to recover:

> *" I felt like it was a room full of people bonding over being stuck in one perspective and I felt that was toxic and I didn't need more negativity because I was swimming in my own negativity and I felt like I were drowned…" (Pam, 55)*

> *"I saw my story and some of their stories and in some ways it was affirming and in other ways I felt that I had gotten beyond that, and I didn't want to relive it so, and I didn't. I don't want ..and while I will put something in there but I dont want to get enmeshed and drawn into a Facebook site that will take life away from me because I get too enmeshed "(Pam, 55)*

For Pam, there is a sense that she feels that although it can be helpful to recognise herself in the stories of others there is a risk that engaging with the groups could become more harmful than a source of support. Pam's experience suggests that when individuals feel that they are managing their OCD well, involvement in such groups could hinder or setback their progress. The idea of becoming enmeshed in groups also relates to other experiences when individuals feel that support groups can also be misused:

> *"You know, we all we all know that reassurance isn't good for OCD sufferers so I try not to seek it from other OCD sufferers, so you know I don't go into to support groups and say 'hey does anybody else here do such and such a thing'" (Sam, 48)*

Sam indicates that support groups can be used as an avenue for reassurance-seeking. This indicates that although finding recognition and community online may be useful for some, for others the use of groups may become entangled in the individuals' OCD experience if they are used for reassurance-seeking and may indeed hinder rather than help. This raises an interesting issue of where the line is drawn between reassurance and support which will be discussed further below. Arguably, a certain level of reassurance initially for an individual unaware that they are experiencing OCD to realise they are not alone and are not secretly a monster is a helpful aspect of seeking support online. However, excessive reassurance-seeking can also be a compulsion for those with OCD so Sam is perhaps indicating that online support groups may also become a place where compulsive reassurance-seeking is played out online (Parrish & Radomsky, 2010).

Another topic frequently discussed within the data is that of strain within the individuals' relationships related to primarily obsessional OCD. This typically refers to interactions between the participants and other people related to seeking support or reassurance. It is not clear from all the accounts the extent to which it is social support that is being sought from others rather than reassurance. It could be argued that to the person with OCD, seeking reassurance is a method, albeit maladaptive, of seeking support. There is a pattern within the accounts of some individuals feeling that their OCD is having a negative impact upon others within their interpersonal relationships, particularly regarding reassurance-seeking. There is a sense that others in the individuals' lives can struggle with having to give reassurance repeatedly:

> *“They also have worn people out by me reassurance seeking a lot during episodes which makes people grow tired of telling me the same thing over and over.” (Skyler, 32)*
>
> *“I am a burden to my boyfriend, constantly asking him questions about how I feel about him, how I feel about X or Z situation just for him to calm me down, saying that's just how my brain works so I feel, momentary, calmer.” (Nina, 29)*

The accounts suggest that participants perceived that their partners or family members may become frustrated with them due to having to repetitively provide reassurance. This may indicate a need for education for partners and family members around the effects of providing reassurance. As illustrated by Nina, the anxiety reducing effects of seeking reassurance can be short lived. It is indicated that the management of intrusive thoughts within the context of interpersonal relationships can prove taxing for the individual as they are concerned about the impact on those involved in supporting them. Individuals can feel that they are causing their loved one’s distress by seeking support from them:

> *“My mother worries about me and I feel bad discussing with her, I don’t like burdening her.” (Molly, 24)*
>
> *“My OCD has affected my relationship with my wife severly over the years. My wife tries her best but my OCD weighs very heavily on her.” (Hugh, 43)*

> *"If I am disturbed by thoughts it can mean that I perceive myself as being negative with family & perhaps getting them down. I am conscious not to over burden them with things so I try not to talk too much about it until it gets too much for me to contain." (Denise, 51)*
>
> *"It almost destroyed my relationship. We couldn't have a constructive argument about things important to the health of the relationship with me completely losing it psychologically. That ended up deterring him from bringing up issues that needed addressed for fear I would break down. He drove me to the hospital once even mid-fight. I know it was a big stressor for him and he must have been so relieved when I got help. I ended up with a lot of guilt for putting him through that, and didn't enter another relationship for several years after ours was over." (Julie, 34)*

Some accounts suggest that individuals attempt to avoid seeking reassurance or support from family due to the perception that this can have a negative impact on them. But there is also a sense that the distress of the individual with OCD builds up when they avoid seeking reassurance or support until they no longer feel able to hold onto the intrusive thoughts alone. For Julie and Hugh, their experience of primarily obsessional OCD was perceived to present an immense strain on their partner. There are different patterns within romantic relationships in how couples attempt to manage OCD together. Julie's account conveys that there is a lot of perceived strain presented to the couple as the partner attempts to help but at the cost of leaving relational issues unaddressed. In many accounts there is an imbalance conveyed in that the individual with OCD becomes dependent on their relationships to manage their distress. Furthermore, the partner or family members are perceived to take on the role of protecting and soothing the individual which may come at the cost of bearing some of the distress themselves.

Some of above accounts convey that the individual does not wish to put upon their partner or family members by involving them in the management of their OCD. However, it is conveyed that some individuals either feel compelled to involve others, or the partner adapts in response to the individual's experience seemingly in attempt to relieve their distress. Furthermore, there appears to be an underlying sense of guilt about the perceived effect that offering support and reassurance has on family members or partners. This suggests that not only do individuals become distressed by the experience of managing their OCD, but also by guilt arising from help seeking and relational issues associated with their OCD. Those related to the individual with OCD involved in their interpersonal support seem to be presented with the dilemma of how best to support their loved one:

> *"They still struggle to know how to help me or how to support . That part is not indulging me in these behaviours they still struggle with that like they really their not really sure how to do it, so I try to.. I try to deal with them myself more than putting on them." (Jess, 20)*

Overall, this subtheme encapsulates the difficult territory to navigate for individuals with primarily obsessional OCD when receiving social support.

Furthermore, the challenge for family members and partners in knowing how to respond to OCD within the context of their relationships is highlighted. From the perspective of the individual with OCD, the accounts convey the importance of support and feeling accepted by others but also the struggle of avoiding OCD becoming part of the fabric of their relationships. Individuals seem concerned by the extent to which they are seeking reassurance particularly in relation to how this impacts those that it is sought from. Furthermore, it is suggested that there is strain within relationships as partners or family members attempt to manage the OCD within the family or couple.

Discussion

Overview

The aim of the current project was to gain a broad understanding of how individuals with primarily obsessional OCD manage their OCD within the context of their interpersonal relationships. It was also hoped that the research would shed light on how individuals experience help seeking outside of therapeutic settings as well as experiences of seeking professional support. This section will begin with a discussion of the overarching results in relation to previous literature. The summary of results will be discussed in line with the research questions to show how these were answered. I will also discuss how these results compare to and differentiate from the findings in previous research. The novelty of the research will be demonstrated and the features of the findings that build upon our existing knowledge in this area will be elucidated. The implications of the findings for the practice of counselling psychology will be considered followed by a critical evaluation of the study and recommendations for future research.

Results

Four themes that encapsulate the experiences of individuals with primarily obsessional OCD within their interpersonal contexts and their experience of seeking support were developed. These themes capture the challenges these individuals faced in being heard and understood by others in relation to their OCD, both within their personal lives and in therapy. Many individuals reported that it was a challenge to know how to navigate disclosure of their OCD, or the extent to which they could help others understand. For some, who chose not to disclose their OCD they found themselves on one hand, avoiding any risk of negative consequences that might come with sharing their experience, but on the other hand, suffering in silence as they perceived that those around them either overlooked or misinterpreted the extent or presence of their distress. The data suggests that managing primarily obsessional OCD within the context of relationships can be highly distressing for the individual as they describe a sense of being compelled to avoid others or that OCD infiltrates their experience and takes away their ability to feel present and connected to friends, family or romantic partners.

Managing Primarily Obsessional OCD within Interpersonal Relationships

There were several ways in which individuals attempted to manage their OCD within the context of their interpersonal relationships. A prominent pattern was experiences where individuals found they withdrew from others in the process of managing their OCD. The withdrawal served as an attempt to protect others from any possibility that the individual might act upon intrusive thoughts. This finding is consistent with the theory regarding thought-action fusion as the individuals' talk suggests that they believe their intrusive thoughts are indicative of likelihood that they might harm their loved ones (Rachman, 1993; Shafran et al., 1996; Sookman & Pinard, 1999). There is a sense that individuals feel deep shame about the presence of unacceptable intrusive thoughts involving family members, partners, or friends, as well as the need to limit time spent with them to manage such thoughts. The avoidance of interaction with loved ones illustrates how living with primarily obsessional OCD can lead to unintentional alienation, limiting the person's ability to connect or establish or maintain close friendships and intimate relationships. From a cognitive behavioural perspective, this distancing from situations in which the individual expects to encounter distress would be understood as avoidance, a covert compulsion that maintains the individual's OCD (Rachman, 2003; Williams et al. 2011).

The tendency to isolate oneself from others in part maps onto previous qualitative research findings. Keyes et al. (2018) reported that young people with OCD tend to withdraw from others due to shame, the need to hide compulsions and fear of acting on violent thoughts. The choice to withdraw to avoid acting on intrusive thoughts is similar to the current study in that participants reported separating themselves from family due to fear of acting out their intrusive thoughts. Aside from the fact that the present study focused on adults rather than young people, the results differed from these previous findings as there was less of an indication that participants felt the need to hide compulsions, likely because primarily obsessional OCD does not involve clearly observable compulsions. The current study more so indicates the experience of primarily obsessional OCD and withdrawal. This withdrawal can take the form of becoming aloof or unengaged with family members because of the preoccupation with intrusive thoughts, rather than withdrawal to hide identifiable compulsive behaviour. Social isolation from friendships due to OCD has been previously found, with some reference made to mental preoccupation as a relevant factor, however this aspect has not been previously discussed in depth (Yazdi-Ravandi et al., 2018). Unlike previous research discussing mental preoccupation, the current study has developed depth of understanding of the sense of loss individuals can experience when missing out due to these preoccupations. Furthermore, the study elucidated how these attempts to internally manage intrusive thoughts may inadvertently communicate rejection to their partner.

Some of the current findings showed similarities but also differences with research conducted by Bhattacharya and Singh (2015) who reported themes where individuals with OCD felt disconnected from parents, siblings, or peers. The sense of loneliness conveyed in the present study in relation to withdrawal is consistent with these previous researchers' theme 'Connection vs. Disconnection' (Bhattacharya, & Singh, 2015). Similarly, to the current study, this previous research suggested that those with OCD may become withdrawn feeling unable to disclose their experience to peers and parents, leading to feelings of isolation (Bhattacharya, & Singh, 2015). The theme around disconnection developed in this previous study was strongly focused upon difficulty participants had in talking about their symptoms with others, and the absence of support within their family. Therefore, different aspects of Bhattacharya and Singh's (2015) disconnection theme show similarities with aspects of the themes in the current study, such as issues around disclosure and strain within relationships. However, the current research broadens the focus on interpersonal issues related to OCD by developing themes based on issues of disconnection within romantic relationships, within sexual experiences and in relation to perceptions of sex.

An important feature in the current findings were difficult experiences managing primarily obsessional OCD within romantic relationships, and the distance that can be created. This was prominent for those experiencing intrusive thoughts relevant to relationships (ROCD), or intrusive thoughts and doubts regarding their sexuality. Researchers have previously found an association between severe obsessional thinking and reduced intimacy (Abbey et al., 2007). However, due to their correlational design, they were unable to identify whether it was intimacy giving rise to increased obsessional thinking or the obsessional thinking preventing intimacy (Abbey et al., 2007). The current study suggests that both may be the case. For some, intrusive thoughts regarding one’s relationship conveyed a sense of disconnection due to having to manage intrusive thoughts arising about the relationship. Sexual intimacy was also avoided because intrusive thoughts took away the ability to be present sexually with a partner. However, for some, such as the participant experiencing intrusive doubts about her bisexuality, the sex/gender of her partner contributed to her obsessional doubts arising during sex. Accordingly, the current research suggests that it is perhaps not either/or in terms of whether obsessional thinking reduces intimacy or intimacy increases obsessional thinking, but both, dependent on the individual and the nature of their obsessions. The fact that the current study looked at primarily obsessional OCD within interpersonal contexts enabled a more detailed insight into subjective experiences of intimacy and how a breakdown in intimacy may occur in relation to obsessive thoughts.

The notion that distance can be created between partners when the individual with OCD attempts to conceal their intrusive thoughts is similar to the findings of previous research looking at partner relationships (Walseth et al., 2017). What the present study brings new knowledge of is the internal battle that individuals with primarily obsessional OCD can face in their relationships. Although individuals suggest that they want to have romantic relationships, their effort to protect partners from intrusive doubts about the relationship may ironically create relational issues based upon their partners perceived misinterpretation of this process. Some participants perceived issues arising from their attempts to manage their intrusive thoughts about their relationship. They perceived that their partners may misinterpret their attempt to manage their OCD as a lack of presence and that avoidance of intimacy could lead their partner to feel dissatisfied or neglected. This suggests that the covert nature and very subtle overt indicators of primarily obsessional OCD may lead the individual to be vulnerable to misinterpretation and difficulties forming or maintaining mutually satisfying relationships.

The similarities with previous findings from studies on OCD in general suggest that the need to withdraw from others may be a common factor in different presentations of OCD. However, there are some subtle distinguishing features arising from the current study that may be particularly and specifically relevant to primarily obsessional OCD. This shores up the importance of focusing in on different dimensions of OCD. Such nuances include the largely covert nature of primarily obsessional OCD and how the aloofness of mental preoccupation can lead to potential misunderstandings from others regarding their interest within their relationships. This unseen preoccupation carries with it a sense of loss and isolation for the individual. Furthermore, this study highlights how self-perceptions regarding ones believed potential to cause harm to others plays an important role in the choice made to separate oneself from others.

Issues of Sexuality

Within the context of sexuality and sexual relationships participants shared the ways that intrusive thoughts can interrupt or prevent sexual experiences. Some individuals want to have sexually intimate relationships, but their sexual desire is perceived as threatening to themselves and others due to the presence of intrusive thoughts regarding sexual acts. This is consistent with previous literature suggesting that when individuals with OCD see their sexual desire as threatening, this can increase the number of sexual intrusive thoughts they experience and thus may prevent their engagement in sex (Wetterneck et al., 2011). Some aspects of the current findings regarding disconnect in sex and intimacy had similarities with previous qualitative research findings. Boulton (2020) also found that individuals with OCD can find sexual experiences difficult, due to the presence of intrusive thoughts during sex, leading them to avoid sex or partner relationships. Similarly, to the present study, Boulton (2020) also found that some drew on asexuality in relation to their OCD. Although Boulton's result suggested that individuals may be unclear as to whether they are genuinely asexual or are asexual because of their OCD. In contrast, the present study suggested that individuals might intentionally force themselves to be asexual to avoid the potential for distress arising from the interaction of OCD with their sexuality or sexual experiences.

In the current study it was suggested that obsessional doubts around sexual identity can interfere with engaging in sex, of note, those with a bisexual identity. There is some similarity with Boulton's (2020) finding that individuals with OCD can experience distress around being unable to identify their true sexual identity and that OCD can be experienced as a bully, bringing the person's identity into question. This is consistent with the finding in the present study where one participant discussed the presence of intrusive thoughts regarding her sexuality as a barrier to sexual intimacy. Furthermore, there was also a general sense in the current data that OCD was perceived by participants as like a separate entity from their true selves who acts as a bully and controls them. Uncertainty, fear and doubt around one's true identity is not unusual in primarily obsessional OCD (Rachman, 2003, p. 6; Weingarden & Renshaw, 2015). What was particularly interesting about this aspect of the data was that reference was made to the how OCD plays upon cultural perceptions and prejudice around bisexual identity. Research has suggested that it is common for bisexual people to encounter prejudice from others regarding the stability or legitimacy of their sexuality (Brewster & Moradi, 2010). This aspect of the data indicates the potential for internalised societal prejudices to become interwoven with intrusive thoughts and doubts in primarily obsessional OCD. The current study highlights a potential interplay between contextual social factors such as prejudice becoming intertwined with OCD and impacting upon individuals understanding of themselves and ability to engage in satisfying sexual relationships.

Visibility and Invisibility: Deciding to Hide or Risk Disclosure

Visibility is a key topic in relation to how individuals with primarily obsessional OCD navigate their experiences within their interpersonal relationships. Having a manifestation of OCD that is predominantly covert presents both benefits and challenges to the individuals that are highlighted in the theme "*Hidden in Plain Sight: The Predicament of Disclosure*". Previous qualitative research by Fennell & Liberato (2007) indicated a similar experience to those detailed within the theme in their theme “*Passing*”. This theme encompassed experiences of individuals attempting to conceal their OCD experience from others and cautions around who they do disclose to and to what extent they disclose the details of their experience. However, they were looking at OCD broadly, rather than focusing on those with covert compulsions. Their results indicated detail about having to manage observable compulsions and how these might be perceived by others. In contrast, in the current study individuals with primarily obsessional OCD could appear as if they do not have OCD because their compulsions are covert. However, as noted in the analysis, individuals felt that this can lead to underestimation from others as to the level of distress that they are experiencing. On one hand, having an outwardly identifiable presentation of OCD that fits wider understandings may enable individuals to feel their condition and associated distress is more recognisable and understood by others. On the other hand, being able to conceal, albeit potentially distressing to do so, allows individuals to keep their experience private. However, this is double edged sword because individuals may appear well externally but carry the burden of suffering in silence.

The idea of feeling the need to hide OCD is also consistent with the previous literature conducted by Yazdi-Ravandi et al. (2018) who found that individuals can hide their OCD due to shame. The researchers do not clarify the type of OCD being concealed, so it is unclear whether this refers to those with overt or covert compulsions or both. Other literature has however highlighted the presence of shame in primarily obsessional OCD (Rachman, 2003). The tendency to conceal or restrict levels of disclosure about primarily obsessional OCD conveyed in the current study’s data is consistent with previous literature suggesting that concealment is used by individuals with OCD to avoid shame (Newth & Rachman, 2001). The current findings indicate that individuals carefully consider and monitor their level of disclosure particularly regarding intrusive thoughts perceived as strongly taboo in nature. Many accounts alluded to restriction on the level of information shared or the types of themes that were revealed. The topic of disclosure was complex and multifaceted with decisions around disclosure varying from not disclosing at all, disclosing partially, or disclosing fully to others. Across the accounts of disclosure there was a sense of risk and fear of how others might respond. This aligns with the previous studies regarding shame as it is clearly conveyed that the potential for others to respond badly to certain intrusive thoughts was present in the data (Newth & Rachman, 2001). Research has suggested that concerns regarding disclosure of some intrusive thoughts may not be unwarranted. For instance, without prior education regarding paedophilia-related thoughts in relation to OCD, others can misunderstand this presentation and believe the thoughts are indicative that the individual is a paedophile (Snethen & Warman, 2018). Furthermore, considering the previous research literature on OCD and stigma, the expectation of stigma apparent in the current data, particularly by those uneducated about OCD, sadly, does not seem to be unrealistic (Cathey & Wetterneck, 2013). This suggests that the highly taboo nature and the lack of wider social understanding of intrusive thoughts in primarily obsessional OCD may make it more difficult for individuals to feel safe to disclose to others. This is another potential factor adding to people's perceptions of isolation that can come with managing their intrusive thoughts without support.

Help-Seeking Outside a Therapeutic Context

One important aspect of the data was feelings of alienation experienced by those with primarily obsessional OCD when attempting to seek support from others. Previous literature has noted the importance of social support. For those recovering from OCD, having a supportive environment is considered important for the maintenance of progress in therapy (Steketee, 1993). Negative reactions from support networks have been found to predict the likelihood of individuals with OCD relapsing following therapy (Steketee, 1993). It is therefore unfortunate that participants frequently related experiences of, or expectations of being misunderstood or misinterpreted by others**.** Previous qualitative studies have identified experiences where young people and adults report that their OCD was misunderstood or misinterpreted by friends, family, medical professionals, and school staff (Fennell & Liberato, 2007; Keyes et al., 2018). There are close similarities between aspects of the results from the current study, and these previous studies, whereby participants reported experiences of being misunderstood by family, friends, and professionals and in some cases being met with negative reactions regarding their OCD. There was also similarity in how some participants expected to be misunderstood, mirroring Fennell and Liberato's (2007) finding that individuals with OCD anticipate stigma from others.

Where the current project differentiates from the above literature, and of relevance to primarily obsessional OCD, is the notion that individuals frequently alluded to experiences of others not recognising their experience as OCD. This was largely because it does not fit with widely recognised and represented variations of OCD characteristics. There is a potential issue for those with primarily obsessional OCD, that mainstream mass media depictions present a dramatised representation of OCD to the wider public (Martin, 2017). Such depictions potentially impact public perceptions of OCD and those with OCD (Martin, 2017). The current analysis demonstrates that individuals in participants' lives may attempt to convey an understanding of OCD in line with available representations that they have been exposed to. Recent literature documents that individuals with OCD can find that media derived societal understandings of OCD present a helpful opportunity to explain the complexities of OCD not represented in these depictions (Werner, 2021). However, in contrast, the narrow societal understanding of OCD deterred others from opening up with others about their experience (Werner, 2021). In the current study, participants reported that others attempt to convey understanding of OCD based upon the portrayals they have seen. This inadvertently leads participants to feel frustrated and further misunderstood as their experience does not map onto typical representations of OCD in the media and generally in the public awareness. This suggests, in line with previous research, there is a risk that lack public awareness of different OCD presentations can make it challenging for individuals with primarily obsessional OCD to explain their experience to others and to feel understood (Werner, 2021).

Delineating Support Seeking and Reassurance Seeking

Another issue conveyed through the data in relation to individuals managing their OCD within relationships, was that of how those around them were able to offer support and what aspects of that support were helpful. The question was also raised about the line between receiving support and receiving reassurance. As discussed in previous literature, offering reassurance can be a way OCD can be accommodated within relationships and kept going by the involvement of others in this compulsive behaviour (Abramowitz & Jacoby, 2014; Storch et al. 2007). For many, feeling supported and accepted by others within relationships was incredibly valuable. Their accounts detailed the value of others in their lives when they were able to accept that the presence of their intrusive thoughts was not indicative of their identity or intent to act upon them. Similarly, the sense that others understood that intrusive thoughts could be understood as part of the OCD rather than a cause for concern or indication of risk to others was also seen as a relief and supportive. These experiences both applied to experiences within interpersonal relationships, but also within online communities. For some, reassurance from others was seen as supportive, whereas others suggest that seeking any reassurance is problematic. What remains unclear is how both the individual with OCD, and those in relationship with them, can distinguish between whether it is support or reassurance being sought or given. This is an important yet subtle distinction and brings into question to what extent it is possible to clearly differentiate between the two. Aligning with previous literature discussing reassurance-seeking and the potential impact on others, it is noteworthy within the accounts that partners or family members, were perceived by participants as under strain or frustrated by the need to provide repeated reassurance (Kobori & Salkovskis, 2013; Radomsky et al., 2018; Rector et al., 2011).

Seeking reassurance from others when feeling anxious or facing uncertain circumstances is not usually considered problematic (Neal, & Radomsky, 2020). Seeking reassurance is considered an ordinary behaviour in regulating anxiety and thought to begin during early development as children seek reassurance from caregivers before gradually developing the ability to reassure themselves (Kobori & Salkovskis, 2013). Seeking reassurance is considered problematic in maintaining anxiety, when it is sought repetitively despite having already received an initial reassuring communication (Parrish & Radomsky, 2010). In some accounts, repetitive reassurance-seeking was clear, however, in others it is hard to distinguish. Some participants conveyed that it was helpful when others accepted and understood that their intrusive thoughts were not indicative that they were a risk to others. On one hand, it could be considered that this level of acceptance may have been achieved by their friends, family, or partners becoming aware and educated about primarily obsessional OCD, perhaps by participants. A few supportive discussions with others may have helped individuals feel understood and accepted. Or it could be that participants have achieved their understanding that others accept them through persistent reassurance-seeking. Either way, there is something about knowing others understand that their intrusive thoughts are not indicative of their intent.

Theory regarding early relationships with primary caregivers may also shed light on why reassurance is sought and why acceptance from others, as detailed in the analysis, is deemed so important. The development of an anxious attachment style is thought to arise from the fear that significant others may become unavailable or abandon the child (Brennan et al., 1998; Van Leeuwen et al., 2020). When exposed to an anxiety evoking situation, individuals with an anxious attachment style may excessively seek reassurance from others to gain a sense of security (Mikulincer et al., 2003; Van Leeuwen et al., 2020). This suggests that the reassurance-seeking following the evocation of anxiety following an intrusive thought may be understood as a way individuals seek safety within their relationships. Reassurance-seeking may be an attempt to ward off the risk of abandonment by seeking to confirm that they are accepted in the eyes of others despite the nature of their thoughts (Mikulincer et al., 2003). This would map onto accounts in the data that highlight the importance of feeling accepted within relationships, as well as participants fears about disclosing thoughts that may not be accepted or understood by significant others. This may have important implications for counselling psychologists and other professionals engaging in therapeutic work with individuals with primarily obsessional OCD. This knowledge may inform both the relationship they have with the client and consideration of their wider interpersonal context and the role significant others can play in supporting them.

Implications for Therapy

Integrating a Relational Perspective into Therapy

The complexities of seeking reassurance as appropriate or potentially problematic has implications for conceptualising the therapeutic interaction from a relational perspective. The use of the therapeutic relationship as a vehicle through which to examine interpersonal processes involved in OCD (such as reassurance-seeking) has previously been presented within the counselling psychology literature (Kohlenberg & Tsai, 1987; 1991: Vandenberghe, 2007). Exploration of clients' significant past and present relationships, and knowledge derived from being in the therapeutic relationship may be important when thinking about how best to support individuals with primarily obsessional OCD. Considering this may shed light on both the client's management of their intrusive thoughts on their own, but also how support is negotiated with others.

Another way the role of relationships may be examined is consideration of how individuals need for reassurance might relate to early relational experiences. For instance, the relationship between early attachment and OCD has been considered in the literature as a potential predisposing factor helping to explain anxious or avoidant behaviour in relationships with others (Van Leeuwen et al., 2020). It has been noted in the literature that understanding the potential underlying attachment processes relevant to OCD can be an important consideration in therapy (Nielsen et al., 2019; Van Leeuwen et al., 2020). Researchers have suggested that this consideration enables reflection upon how clients' attachment style may influence the extent of their engagement with therapy and ability to tolerate anxiety in therapeutic techniques such as ERP (Nielsen et al., 2019; Van Leeuwen et al., 2020). Furthermore, enabling insight into potential relational factors driving compulsive behaviours and how these may be manifesting in present relationships could promote deeper self-understanding and may be a useful supplement to CBT interventions.

Relational experiences that may have given rise to a lack of trust in the self to tolerate anxiety and uncertainty without seeking reassurance may be reparable through the therapeutic relationship (Clarkson, 2003). If the need to seek reassurance repetitively relates to early experiences where the child's ability to trust themselves is brought into question, therapists could provide a reparative relationship through communicating their trust in the client (Clarkson, 2003). By providing this type of the relationship the client could gradually internalise the relationship with the therapist and no longer require external reassurance (Clarkson, 2003). The notion of communicating confidence in the individual with OCD also aligns with Neal, and Radomsky's (2020) idea for support orientated interventions in CBT as opposed to interventions aimed at reducing reassurance-seeking. Their approach suggests that if others can convey confidence and trust in the individual to tolerate distress without seeking reassurance, this is preferable and more helpful than the withholding of reassurance (Neal, & Radomsky, 2020). For loved ones who may have difficulty knowing how to support individuals with primarily obsessional OCD, family, or partner involvement in interventions may be beneficial (Neal & Radomsky, 2020).

Family and Partner Involvement in Therapy

The potential benefits of family involvement in therapy for OCD has been supported in previous literature in addressing family accommodation and in providing support with therapeutic intervention such as ERP (Renshaw et al., 2005). However, previous research has also highlighted the need to consider the frustration and negative responses from family members when involving them in therapy (Steketee & Van Noppen, 2004). Carefully considered involvement of family members or partners in therapy would take into consideration the interpersonal aspects of living with primarily obsessional OCD that appear to add additional layers to the individual’s distress. For example, relationship strain or breakdowns attributable to managing OCD within the relationship or individuals feeling unable to discuss their experience with others. Having an opportunity to discuss their OCD and educate partners and family members within therapy may help improve the quality of individuals’ relationships. This could help others in their life understand the reasoning for their behaviour and subsequently the individuals with OCD may feel less alone and misunderstood.

Experiences of Professional Help-Seeking Contexts

Recognition, Use of Diagnostic Terms, and Implications for Counselling Psychologists

The multiple experiences of being misunderstood by professionals in the present study is consistent with the previous research indicating that professionals more frequently misinterpret taboo and sexually intrusive thoughts than other reported obsessions (Glazier et al., 2013; Steinberg & Wetterneck, 2017). It is concerning that many individuals have had experiences of being misunderstood when seeking help from professionals, particularly when this was a fear highlighted in previous research, and a potential barrier to help-seeking (Robinson et al., 2017). An interesting feature of the data was the participants distress in not having their experience recognised as OCD. This opens a wider discussion about the use of diagnosis. On one hand, the pathologisation of distress moves away from the humanistic roots of counselling psychology that prioritises subjective experience (Larsson et al., 2012). On the other hand, as the data indicates, individuals can value the idea of having a diagnosis that fits their understanding of their experience.

The use of diagnostic labels is a contentious subject in counselling psychology, and therefore this implication and discussion around this may be controversial (Milton et al., 2010). It has been noted that more and more clients are entering therapy with a pre-existing understanding of their distress informed by a self-identified, diagnostic information (Jutel & Nettleton, 2011). Strong et al.

(2015) suggest that the rise of self-diagnosis is in part attributable to the rise in public awareness of diagnostic information and that the absence of alternative explanations for people's experiences. This rise in self-diagnosis may hold relevance to experiences within the data where individuals have not been believed by others or taken seriously when disclosing their experience. However, having a diagnosis also potentially gives others something concrete to draw upon when individuals attempt to explain their experience.

It has been suggested that self-diagnosis is the outcome of individuals drawing upon cultural narrative to make sense of their experience (Strong & Knight, 2012). For some, identifying a diagnostic label may serve the purpose of clarifying that they are not crazy and enable a reduction in shame around bewildering experiences by assigning a predefined meaning for such experiences (Giles & Newbold, 2011; Strong et al., 2015). Considering the confusing, potentially frightening, and often shame imbued experience of primarily obsessional OCD, it is understandable that individuals would be drawn to making sense of those experiences. Particularly in a way that enable separation of intrusive thoughts from the self and their intent. Being able to assign pre-determined meaning to distress can be a significant relief for many and with scientific, medically characterised definitions comes the hope that a corresponding solution may be possible (Strong et al., 2015). Although it was not highlighted specifically within the themes, it was noteworthy in certain accounts within the data how having a name or discovering an existing understanding of their experience was a huge relief. In one case where intrusive thoughts were resulting in one’s identity being brought into questions and belief that life could not continue if the feared identity were true, being able to assign a name to their experience was considered lifesaving.

Potential Implications of Resistance to Diagnosis

Resistance to discussing predetermined diagnostic characteristics of OCD, particularly unacceptable thoughts could present a barrier to individuals with primarily obsessional OCD receiving the support they need. As previously discussed, finding recognition and normalisation of individuals experience of unacceptable thoughts for some can be lifesaving, so arguably the sooner this can happen the better. Early recognition may be crucial in the service of keeping individuals safe from self-blaming, self-hating perspectives escalating into risky behaviours. Individuals with OCD are at high risk of suicide and among the factors strongly associated with increased risk of suicidality is the presence of unacceptable intrusive thoughts (Albert et al., 2018; Albert et al., 2019; Angelakis et al., 2015). This along with mentions of suicide within the participants accounts suggests that those with primarily obsessional OCD are more vulnerable to suicidal thoughts and behaviours than other OCD presentations. This highlights the importance of helping individuals to feel able to come forward and feel safe to discuss their experience and receive appropriate help to reduce this risk. As noted in the analysis, for some it is difficult to open-up about their experience with others. Attempts to do so with a professional can also be hindered by a lack of understanding and recognition. This has the potential to leave individuals feeling unheard and unable to talk about their experience. Improving professionals' ability and preparedness to identify those with primarily obsessional OCD may help to avoid further marginalisation of these individuals and enable suitable therapeutic approaches to be employed.

Use of Diagnosis to Externalise OCD

For some participants, having a diagnosis seemed to enable them to disconnect their experience of OCD from their identity. This is important as many found that OCD was interfering with their sense of self, and some saw themselves as monstrous due to their experience. Strong et al. (2015) suggests that externalising, or separating the person from their presenting problem enables reflection upon the meaning of said problem within the cultural and historical context and the client's relationship to it. It has been argued that the use of diagnostic language may enable clients to externalise the problem as a separate entity to be related to and examined through the therapeutic dialogue (Brinkmann; 2014; Strong et al., 2015). Arguably, since many participants alluded to feelings of self-hatred and others to the benefits of separating OCD from the self, this suggests that having a name for what they are experiencing may serve an important therapeutic purpose. Considering that it was important to participants to have their experience recognised as OCD by professionals, it may be beneficial for counselling psychologists to take a pluralistic perspective to value the client's sense making and subjective understanding of their experience (McAteer, 2010). Pluralism involves valuing multiple perspectives and working in ways that does not privilege one perspective over another or one approach or set of techniques over another, but rather focuses on collaboration and shared understanding with the client (Cooper & Dryden, 2016). So it may be that we can use the client's chosen terminology to describe their experience, such as OCD, but also consider different perspectives alongside this, insofar as they are useful and applicable to the client.

A Point of Reflection for Counselling Psychologists

The results of the current study indicate that individuals with primarily obsessional OCD may value therapists acknowledging their experience as OCD rather than avoiding the use of diagnostic terminology. As counselling psychologists, the suggestion of leaning into the use of diagnosis may feel counterintuitive or at odds with our non-pathologising stance (Larsson et al., 2012). However, as discussed above, using diagnosis may be important in mitigating risk associated with unacceptable thoughts and enabling the client to externalise their OCD rather than seeing it as evidence of an unacceptable aspect of their identity (Albert et al., 2018; Albert et al., 2019; Angelakis et al., 2015; Brinkmann; 2014; Strong et al., 2015). As the results indicate that participants want therapists to recognise their experience as OCD, it seems integral that we take this into account, particularly given its potential therapeutic value. If we are to honour our clients' perspective, it may be that we need to put aside our inclination to avoid diagnosis. Of course, the question remains of how this works in practise and how we name OCD without pathologising the client's experience.

Counselling psychologists might aim to bring together multiple sources of information (including diagnosis) to form a holistic clinical picture that considers the therapeutic needs of the client (Blair, 2010). As discussed above, this may involve holding theoretical tensions within our pluralistic stance (Cooper & Dryden, 2016). This might mean using the diagnostic terms alongside our chosen theoretical orientation and embracing the use of the term for its therapeutic value for the client. Rather than providing instruction on how this is done or a definitive solution, I wish to prompt reflection on this matter. Counselling psychologists can consider how they might take on board the implications of the current study and integrate this knowledge within their professional practice.

Strengths and Limitations of the Present Study

An area where the present study showed strengths, was in the chosen data collection methods. Surveys were chosen because they facilitate the exploration of individuals' experiences in an anonymous way enabling individuals vulnerable to shame a way to share their experiences without needing to identify themselves (Glazier et al., 2015; Rachman, 2003; Terry & Braun, 2017; Wilkerson at al., 2014). As hoped and expected due to previous indications in the literature regarding qualitative research methods, participants provided rich, detailed information about their experience in the survey responses (Terry & Braun, 2017). This also enabled me to access information from individuals who may not usually discuss their experience openly due to shame and other barriers to help seeking. Another strength of the present study was my identities as a trainee counselling psychologist, researcher, and insider with lived experience of primarily obsessional OCD. These interweaved identities both enhanced my engagement with the research and presented some difficulties. As an insider researcher, I had experience of using online support sites, so knew where I might recruit online. I also understood the language used within support groups, and keywords that helped me search for participants (Bonner & Tolhurst, 2002). Being an insider also helped me to construct survey and interview questions relevant to issues that may arise for individuals with primarily obsessional OCD. I was also able to resonate strongly with the experiences shared by participants but also recognise those that differentiated from my own. As a trainee counselling psychologist, it was an advantage being familiar with psychological terminology and acronyms used by participants such as ERP or ACT. I was also able to use therapeutic skills such as empathy and active listening to help interview participants feel comfortable to talk to me about their experiences (Louw et al., 2011).

However, the interview process also led to personal vulnerabilities and insecurities related to my dual role as a trainee counselling psychologist and as a researcher. I found it difficult to hold the highly distressing experiences of those interviewed, without being able to help them therapeutically (Orb et al., 2001). This difficulty in part related to my developmental stage as a therapist at the time. It was also partly attributable to my exaggerated sense of responsibility associated with my own OCD. Previous literature has suggested that researchers can have difficulty navigating the boundaries between research and therapy when studying sensitive topics (Dickson-Swift et al. 2006). It is important that, researchers reflect on this during the research process through their own self-awareness and in supervision (Dickson-Swift et al. 2006; Hermansson, 1997). Research on sensitive topics involving hearing troubling material can also risk causing distress to the researcher, leaving them emotionally vulnerable (Dickson-Swift et al. 2007; Melville & Hincks, 2016). It was therefore important when I noticed an increase in my distress that I protected my wellbeing by seeking supervision and agreeing to stop after 4 interviews. Persisting with the interviews may have given further insight into the nuances behind the experiences described in the surveys. However, paying attention to my own wellbeing was an important ethical aspect of conducting this research.

A potential limitation of the present study was the primary method of recruitment being online, particularly through social media. Social media is now commonly used by many and recruiting this way enables access to individuals who would be harder to reach otherwise (Braun & Clarke, 2013; Deakin & Wakefield, 2014). However, not everyone chooses to engage with social media, has access to it or has the skills to use technology (Lunnay et al., 2015; Ryan & Xenos, 2011). Therefore, not all members of the population of those with primarily obsessional OCD will be necessarily represented in this study. Furthermore, using social media to communicate and recruit participants can expose researchers to distressing posts that can have a negative impact on their well-being. This happened within the current study, as I found that a member of an online group had commented on my recruitment post with a comment suggesting they were contemplating suicide. I was in a difficult position, not knowing who this individual was and having limited access to information through their online profile. In this circumstance, after seeking advice from my supervisor, I identified which country the individual lived in and provided details of relevant emergency support services. Comments of this nature are not unusual in online mental health forums and forums generally have safety procedures, such as automated support messages for those feeling suicidal and moderators who may respond to such comments (Shing et al., 2018). Although a moderator had responded to the comments I found on my recruitment post, it was distressing to see. I felt a sense of responsibility and helplessness in not knowing how to help with such limited information. These sorts of experiences have the potential to affect researchers' mental health when recruiting in these environments and should be an ethical consideration when planning research recruitment online.

Another possible limitation was that the study's sample could be described as representing "the usual suspects" (Braun & Clarke, 2013). This describes participants frequently seen in psychological research who have an overrepresented point of view within the literature (Braun & Clarke, 2013). Thus, the fact that most participants were white, heterosexual, and middle-class should be considered in relation to the findings rather than assuming other sexualities, ethnicities and classes are fully represented (Braun & Clarke, 2013). Furthermore, in the present study it was also accepted that some individuals would likely have other co-occurring psychological problems such as generalised anxiety that may be difficult to disentangle from their experience of primarily obsessional OCD. Therefore, despite it being made clear to participants that OCD was the focus of the present study, individual experiences may have also been influenced by co-occurring difficulties.

Another potential limitation was the decision to include participants without a formal diagnosis of OCD. The intention of recruiting those who had self-diagnosed, was to access those who may not yet have or do not intend to seek help. This decision was also prompted by the review of the literature that associated shame with primarily obsessional OCD and the barrier this presents to help-seeking (Glazier et al., 2015). However, this may bring into question whether the findings are transferable to clinical populations (Stenfors et al., 2020). Self-diagnosis is a topic that future researchers may wish to investigate further. As previously discussed, being able to name their experience was important for some participants. Although, this should not deter researchers from acknowledging the individualistic, illness narrative created by the medical model and the wider implications of this (Blair, 2010).

The decision to remove the survey question relating to religion/spirituality was a potential limitation (See Appendix A). The question was removed due to lack of engagement during piloting. However, reworking the question may have improved engagement and led to additional insights about contextual features that may have shaped individuals’ experiences. Future researchers may wish to further explore this area.

Future Research

The present study has revealed potential avenues for continued research. As the study added to the sparse literature that explores dimensions of OCD, future researchers may further explore dimension specific experiences. This may have implications for individuals with OCD and mental health professionals. Many of the results of the present study were specific to primarily obsessional OCD, therefore others may find similar nuances through exploring other OCD dimensions. Furthermore, there is a paucity in the literature of the perspectives of those in relationships with individuals with OCD. Although responses of partners and family members have been highlighted in the present data, future research could further supplement this by exploring this topic from the perspective of the partners or family members themselves. Such research could gain a broader perspective of the interpersonal context of primarily obsessional OCD and how partners or family members may feel about providing support. This could further inform family involvement in interventions, couples therapy and sex therapy. Further research could also seek to delineate where the difference might lie between support seeking and reassurance seeking perhaps drawing upon perspectives from psychologists, individuals with OCD and their family members. Considering this may help to inform therapeutic interventions and how partners and relatives might better support individuals with primarily obsessional OCD. Finally, future research could explore perspectives on diagnosis of those with OCD, counselling psychologists, and other mental health professionals to aid a more in-depth critical discussion about the use of diagnostic terms.

Conclusion

The current study has built upon previous literature to add to our current understanding of primarily obsessional OCD. The study has offered insights into interpersonal issues which had not been previously investigated in such detail specifically in relation to primarily obsessional OCD. The study has also highlighted issues individuals with primarily obsessional OCD experience around seeking support both within and outside the therapy room. Important questions have been raised about how individuals might best be supported by others in their lives, particularly since many issues interrelated into the experience of OCD are interpersonal in nature. This study has also highlighted issues that can arise from therapeutic interactions that can hinder individuals with primarily obsessional OCD receiving the support they need. It is hoped that the findings of the current study will have the potential to add further depth of understanding to counselling psychologists' perspectives on OCD and how to better support those presenting with primarily obsessional OCD in the therapy room.

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Appendices

Appendix A- First Draft of Survey Questions

Understanding the Impact of Intrusive Thoughts in Pure O (primarily obsessional OCD)

Can you start by telling me a bit about your experience of Pure O.

You might want to start by explaining how and when your intrusive thoughts first began, your experience of identifying as/ being diagnosed with Pure O, and how it plays out in your day to day life.

How do you imagine having Pure O might impact on the way others see you?

Please can you share with me any ways in which your intrusive thoughts/covert compulsions have impacted your relationships with friends and family.

It may be that you don't think your thoughts or compulsions have impacted these relationships and if that is the case I would still appreciate any thoughts you might have on the topic of OCD and relationships with friends and family?

Please can you tell me about any experiences you might have had where your intrusive thoughts/covert compulsions have impacted your current or past romantic relationship(s). *It may be that you don't think your thoughts or compulsions have impacted your relationships and if that is the case, I would still appreciate any thoughts you might have on the topic of OCD and relationships?*

Please can you tell me about how (if at all) having Pure O has impacted the way you see yourself as a person.

Please can you tell me about any experiences you might have had where intrusive thoughts have impacted the way you perceive your sexuality.

It may be that you have not experienced any impact of this kind, if that is the case, I would still appreciate any thoughts you might have about intrusive thoughts and sexuality?

Please can you share with me any experiences you might have had where your intrusive thoughts have impacted the way you perceive your gender.

It may be that you have not experienced any impact of this kind, if that is the case, I would still appreciate any thoughts you might have about intrusive thoughts and gender?

Please can you tell me about any experiences you might have had where intrusive thoughts have conflicted with your moral, spiritual and/or religious values?

It may be that you feel this question may not be applicable to you, if this is the case I would appreciate any thoughts you might have on the topic of Pure O and moral, spiritual and/or religious values?

Please can you tell me about any experiences you might have had where intrusive thoughts have conflicted with your cultural values?

It may be that you feel this question may not be applicable to you, if this is the case, I would appreciate any thoughts you might have on the topic of Pure O and cultural values?

Please tell me about the ways (if any) you seek help/information related to your intrusive thoughts/covert compulsions.

You might want to discuss things like counselling/mental health services, forums, YouTube videos, books, podcasts but you may have other sources of help/information too.

Have you had, or are you having, any therapy in relation to your Pure O?

○ Yes (1)

○ No (2)

Display This Question:

If Have you had, or are you having, any therapy in relation to your Pure O? = Yes

How would you describe your experience of therapy?

I would like to invite you to reflect on how therapists and psychologists might best support those with Pure O.

It may be that you do not have any suggestions, but if you have, what might you say to someone working with individuals with Pure O about what they should know, or what they could do to best support them?

Would you like to say anything else about Pure O?

Would you be interested in taking part in a one-to-one interview via Skype, Microsoft Teams or telephone to share more of your experience of Pure O with the researcher?

Demographic Questions

How old are you?

____

How would you describe your gender? (please include all that apply and add your own if need be)

- ○ Woman (1)
- ○ Man (2)
- ○ Trans (3)
- ○ Cis (4)
- ○ Agender (5)
- ○ Genderqueer/genderfluid/non-binary (6)
- ○ Questioning/unsure (7)
- ○ Other (8) ____

Are you a student?

○ Yes, full time. (1)

○ Yes, part time. (2)

○ No (3)

Do you currently work?

○ Yes, full time. (1)

○ Yes, part time. (2)

○ No (3)

Display This Question:

If Do you currently work? = Yes, full time.

And Do you currently work? = Yes, part time.

What is your occupation?

____

Display This Question:

If Do you currently work? = No

How would you describe your employment status if not currently working?

(e.g. retired, unemployed, homemaker, volunteer)

____

How would you describe your sexuality?

○ Heterosexual (1)

○ Asexual (2)

○ Bisexual (3)

○ Gay (4)

○ Lesbian (5)

○ Pansexual (6)

○ Queer (7)

○ Other (8) ____

How would you describe your racial/ethnic background? (e.g. White; Black; White Jewish; Asian Muslim)

____

Which of the following terms best describes your social class:

○ Upper class (1)

○ Middle class (2)

○ A mixture of middle / working class (3)

○ Working class (4)

○ Lower class (5)

○ Other (6)

Do you consider yourself to be disabled?

○ Yes - If you are willing to share then please list your disabilities. (1)

____

○ No (2)

How would you describe your relationship status?

○ Single (1)

○ With a partner (or partners) (2)

○ Married/Civil Partnership (3)

○ Separated (4)

○ Divorced/Civil Partnership Dissolved (5)

○ Other: (6) ____

Do you have children?

○ Yes (1)

○ No (2)

If you answered yes, please list your child/children's age(s).

____

Have you received an OCD diagnosis?

○ Yes- from a mental health/medical professional (1)

○ Yes - Self diagnosed (2)

○ No (3)

Do you have any other identified mental health conditions?

○ Yes (1)

○ No (2)

Display This Question:

If Do you have any other identified mental health conditions? = Yes

What other mental health condition/s do you have?

____

Appendix B -Final Version of Survey

An Exploration of the Lived Experience of Pure O (primarily obsessional OCD): A Qualitative Survey

An Exploration of the Lived Experience of Pure O (primarily obsessional OCD): A Qualitative Survey Participant Information Sheet

Who are the researchers and what is the research about?

Thank you for your interest in this research project focusing on understanding the experiences of individuals with Pure O (including those with or without a formal OCD diagnosis). My name is Virginia Guy and I am a trainee counselling psychologist in the Department of Health and Social Sciences, at the University of the West of England (UWE). I am completing this research for my doctoral thesis. My research is supervised by Dr Nikki Hayfield and Dr Zoe Thomas (see below for their contact details). Pure O is an important topic but there is currently limited research looking into the lived experience of this specific type of OCD. It is hoped that the findings from this study will increase current knowledge and understanding in this area.

What does participation involve?

You are invited to take part in an online qualitative survey (where you write answers to questions in your own words, rather than ticking boxes). The survey should take no more than 30 minutes to complete. There are no right answers – I am interested in the range of opinions and thoughts that people have. You can write as much as you want in response to the survey questions, but I would be appreciative if you could provide detailed answers. If you do not wish to answer certain questions but are happy for the partial data from the survey to be submitted simply leave blank the question(s) you do not want to answer and click submit when the other questions are complete. After you have completed the survey questions, there are also some demographic questions for you to answer (some of these will be tick box questions). This is for me to gain a sense of who is taking part in the research. You also need to complete a consent question, to confirm that you agree to participate, before beginning the survey.

Who can participate?

Adults over 18 who self-define as having Pure O or have been diagnosed with OCD without overt compulsions.

How will the data be used?

The data will be anonymised (i.e., any information that can identify you will be removed) and analysed for my research project. This means that anonymous (non-identifiable) extracts from your survey responses may be quoted in my thesis and in any publications and presentations arising from the research. The demographic data for all participants will be collected together and compiled into a summary table and included in my thesis and in any publications or presentations arising from the research. The information you provide will be treated confidentially and personally identifiable details will be stored separately from the data. Any personal and identifiable details provided during the research process will be deleted or destroyed after the final project has been submitted. If you contact me, I will have your email address. This will be treated as confidential and used only for the purposes of this research. When our correspondence is complete, I will delete your emails from my inbox, sent items, and deleted items folder.

What are the benefits of taking part?

I hope that participants will find it interesting taking part and by participating in this research, you will be contributing to the developing understandings of an important psychological issue.

How do I withdraw from the research?

If you decide you want to withdraw from the research please contact me via email Virginia2.Guy@live.uwe.ac.uk quoting the unique participant code you will be asked to create before completing the survey. Should you wish to withdraw, all answers, personal details and any email correspondence will be permanently deleted. If you wish to withdraw during the survey process you will be able to simply exit the survey before completion and no data will be saved. Please note that there are certain points beyond which it will be impossible to withdraw from the research – for instance, when I have submitted my thesis. Therefore, I strongly encourage you to contact me within a month of participation if you wish to withdraw your data. I’d like to emphasise that participation in this research is voluntary and all information provided is anonymous where possible.

Are there any risks involved?

We don’t anticipate any particular risks to you with participating in this research; however, there is always the potential for research participation to raise uncomfortable and distressing issues. For this reason, we have provided websites with information about how to seek support online, over the phone and/or face-to-face in your local area, see:

For **emergency support,** if you or someone else is at risk of immediate harm please call **999.**

Support can be sought through your **GP** or **GP out-of-hours service.**

Mind - Offers information and advice about seeking support for OCD and other mental health concerns.

https://www.mind.org.uk/information-support/types-of-mental-health-problems/obsessive-compulsive-disorder-ocd/treatments-for-ocd/

NHS Website - Provides information about how to access local mental health support services. https://www.nhs.uk/using-the-nhs/nhs-services/mental-health-services/how-to-access-mental-health-services/

OCD Action – Offers information and support specific to OCD through their website, forum and helpline. https://www.ocdaction.org.uk/

Anxiety UK- Provides information about accessing mental health support and offers specialised helpline support for individuals diagnosed with anxiety-related disorders. https://www.anxietyuk.org.uk/

No Panic – Offers help and support to individuals with anxiety-related disorders including a confidential helpline. https://nopanic.org.uk/contact-us/

Support Outside the UK:

For help in an **emergency** in Europe please call **112** or in the USA call **911.**

International OCD Foundation- Provides information about accessing support for individuals with OCD.

https://iocdf.org/

N**AMI, the National Alliance on Mental Illness-** Offers help and support resources to individuals experiencing mental health problems in America.

https://www.nami.org/home

Anxiety and Depression Association of America- An international organisation that helps people experiencing mental health problems to find resources and support.

https://adaa.org/

If you have any questions about this research, please contact me in the first instance:

Virginia Guy Email: Virginia2.guy@live.uwe.ac.uk

Or if you would like to contact my supervisors:

Dr Nikki Hayfield, Department of Health and Social Sciences, Frenchay Campus, Coldharbour Lane, Bristol BS16 1QY Email: nikki2.hayfield@uwe.ac.uk

Dr Zoe Thomas. Department of Health and Social Sciences, Frenchay Campus, Coldharbour Lane, Bristol BS16 1QY Email: zoe2.thomas@uwe.ac.uk

This research has been approved by the Faculty Research Ethics Committee (FREC) HAS.20.06.184

Understanding the Impact of Intrusive Thoughts in Pure O Obsessive-Compulsive Disorder (OCD): A Qualitative Survey and Interview Study

Consent Screen

Thank you for agreeing to take part in this research on Pure O OCD.

My name is Virginia Guy and I am a trainee counselling psychologist in the Department of Health and Social Sciences, University of the West of England, Bristol. I am collecting this data collection for my doctoral thesis. My research is supervised by Dr Nikki Hayfield and Dr Zoe Thomas. They can be contacted at the Department of Health and Social Sciences, University of the West of England, Frenchay Campus, Coldharbour Lane, Bristol BS16 1QY. Tel: Dr Nikki Hayfield: (0117) 32 82139 / Dr Zoe Thomas (0117) 32 83794 Email: nikki2.hayfield@uwe.ac.uk / Zoe2.Thomas@uwe.ac.uk .

If you have any queries about the research please contact me via email: Virginia2.Guy@live.uwe.ac.uk

Please confirm that you can confirm each of the following statements and consent to take part in the research:

I am over 18 years of age

I identify myself as having Pure O

I have read the information sheet

I have had the opportunity to ask the researcher any questions

I am taking part voluntarily

I understand that I am free to refuse to answer a question

I understand that I can withdraw from the research (as described on the information sheet)

You are also the 'expert'. There are no right or wrong answers and I am interested in everything you have to say.

○ **Please tick this box to show that you have read the information on this screen and that you consent to participate in the research.** (1)

Please create a unique participant code using the second letter of your first name, the third letter of the road that you live on, and the date today.

E.g., if my name were Victoria and I lived on Merrydown Road and I were completing on 1st Feb then my code would be IR010221.

____

<u>Questions about your experience of Pure O</u>

Please feel free to write as much as you like about your experiences. I would be appreciative if you are willing and able to share in some depth and detail where possible.

Glossary

Below are some brief descriptions of the terms used in this survey. To read a broader explanation of Pure O please see:

www.verywellmind.com/pure-o-primarily-obsessional-ocd-4159144

Pure O:

(*Also known as Pure OCD/ Purely Obsessional OCD/Primarily Obsessional OCD/ OCD with covert compulsions/OCD without overt compulsions)*

This is a type of OCD where individuals experience unwanted intrusive thoughts that they find highly distressing and anxiety-provoking. Unlike other forms of OCD where individuals might perform clearly observable compulsive behaviours such as handwashing in an attempt to relieve anxiety, individuals with Pure O are said to use less obvious compulsive strategies (covert compulsions) in attempt to suppress or neutralise intrusive thoughts. Instead, compulsions might include mental rituals (e.g. praying), checking bodily reactions to thoughts, asking for reassurance or avoiding certain places or situations.

Intrusive thoughts:

Uncontrollable and unwanted thoughts/images/urges that come to mind seemingly out of nowhere and usually have sexual, violent, religious/blasphemous themes.

Covert compulsions:

Strategies to relieve anxiety caused by an intrusive thought that would not be clearly identifiable by other people as a compulsion (e.g., telling others the content of intrusive thought so they can reassure the individual that they are not a bad person or going to act upon it.

What has been your experience of Pure O?

You might want to start by explaining how and when your intrusive thoughts first began, your experience of identifying as/being diagnosed with Pure O, and how it plays out in your day-to-day life.

How do you think other people perceive you in relation to your Pure O?

How open are you with others about having Pure O? *If you have disclosed your Pure O to others, you could write about your decision/s to do this, how this went and how it made you feel. You could also write about how much detail* *you decided to share when opening up to others. If you have not disclosed your Pure O, you could write about your decision/s not to disclose and how it feels.*

Please can you share with me any ways in which intrusive thoughts and/or covert compulsions have impacted your relationships with your family (if they have).

If applicable, you might like to use the following questions to help you reflect on your experiences, but please feel free to share anything not covered by these questions:

If you have received support from family related to your Pure O – In what ways? How have you felt about their support? If you have not received support from family, how has this felt to you? In what ways (if any) do you support yourself?

It may be that you don't think your thoughts or compulsions have impacted these relationships and if that is the case I would still appreciate any thoughts you might have on the topic of OCD and relationships with family.

What are your experiences of how your Pure O impacted on your partner relationships (if they have)?

If applicable, you might like to use the following prompts to help you reflect on your experiences, but please feel free to share anything not covered below:

How any intrusive thoughts and/or covert compulsions have an impacted *your past/current partner relationship(s) (if they have). If you have received support from a partner related to your Pure O – In what ways? How have you felt about their support? If you have not received support from a partner, how has this felt to you? In what ways (if any) do you support yourself?*

It may be that you don't think your thoughts or compulsions have impacted your relationships and if that is the case, I would still appreciate any thoughts you might have on the topic of OCD and relationships.

Please can you share with me any ways in which intrusive thoughts and/or covert compulsions have impacted your relationships with your friends (if they have).

If applicable, you might like to use the following questions to help you reflect on your experiences, but please feel free to share anything not covered by these questions:

If you have received support from friends related to your Pure O – In what ways? How have you felt about their support? If you have not received support from friends, how has this felt to you? In what ways (if any) do you support yourself?

It may be that you don't think your thoughts or compulsions have impacted *these relationships and if that is the case I would still appreciate any thoughts you might have on the topic of OCD and relationships with friends?*

In what ways do you think Pure O has shaped you and the ways you see yourself as a person?

In what ways (if any) has Pure O impacted the way you perceive your sexuality and/or your gender?

You might like to consider any intrusive thoughts in your response too.

It may be that you have not experienced any impact of this kind, if that is the case, I would still appreciate any thoughts you might have about intrusive thoughts and sexuality and/or gender.

Have you sought support or tried to find information in relation to your Pure O?

○ Yes (4)

○ No (5)

Display This Question:

If Have you sought support or tried to find information in relation to your Pure O? = Yes

What was your experience of seeking support / finding information?

You might want to discuss things like counselling/mental health services, forums, YouTube videos, books, podcasts but you may have other sources of help/information too. Please elaborate on what (if anything) has been useful/not useful to you about these resources.

Display This Question:

If Have you sought support or tried to find information in relation to your Pure O? = No

Can you tell me about whether you have ever felt in need of support / information?

If so, you might like to elaborate on what type(s) of support/information you feel/felt you need(ed).

If relevant, you might describe the obstacles preventing you from accessing the support you need(ed)?

Have you had, or are you having, any therapy in relation to your Pure O?

○ Yes (1)

○ No (2)

Display This Question:

If Have you had, or are you having, any therapy in relation to your Pure O? = Yes

How would you describe your experience of therapy?

If applicable, please share specific examples of experiences you may have had that you have found useful/not useful and why you feel this way. Furthermore, if *there's anything you would change about your experience of therapy, please could you share this.*

How do you think therapists and psychologists could best support those with Pure O.

It may be that you do not have any suggestions, but if you have, what might you *say to someone working with individuals with Pure O about what they should know, or what they could do to best support them?*

Would you like to say anything else about Pure O?

<u>Demographic Questions</u>

How old are you?

How would you describe your gender? (please include all that apply and add your own if need be)

☐ Woman (1)

☐ Man (2)

☐ Trans (3)

☐ Cis (4)

☐ Agender (5)

☐ Genderqueer/genderfluid/non-binary (6)

☐ Questioning/unsure (7)

☐ Other (8)

____

Are you a student?

○ Yes, full time. (1)

○ Yes, part time. (2)

○ No (3)

Do you currently work? (paid employment)

○ Yes, full time. (1)

○ Yes, part time. (2)

○ No (3)

Display This Question:

If Do you currently work? (paid employment) = Yes, full time.

And Do you currently work? (paid employment) = Yes, part time.

What is your occupation?

____

Display This Question:

If Do you currently work? (paid employment) = No

How would you describe your employment status if not currently working?

(e.g. retired, unemployed, homemaker, volunteer)

How would you describe your sexuality?

○ Heterosexual (1)

○ Asexual (2)

○ Bisexual (3)

○ Gay (4)

○ Lesbian (5)

○ Pansexual (6)

○ Queer (7)

○ Other (8) ____

How would you describe your racial/ethnic background? (e.g. White; Black;

White Jewish; Asian Muslim)

____

Which of the following terms best describes your social class:

○ Upper class (1)

○ Middle class (2)

○ A mixture of middle / working class (3)

○ Working class (4)

○ Lower class (5)

○ Other (6)

Do you consider yourself to be disabled?

○ Yes - If you are willing to share then please list your disabilities. (1)

____

○ No (2)

How would you describe your relationship status?

○ Single (1)

○ With a partner (or partners) (2)

○ Married/Civil Partnership (3)

○ Separated (4)

○ Divorced/Civil Partnership Dissolved (5)

○ Other: (6) ____

Do you have children?

○ Yes (1)

○ No (2)

If you answered yes, please list your child/children's age(s).

____

Have you received an OCD diagnosis?

○ Yes- from a mental health/medical professional (1)

○ Yes - Self diagnosed (2)

○ No (3)

Do you have any other identified mental health conditions?

○ Yes (1)

○ No (2)

Display This Question:

If Do you have any other identified mental health conditions? = Yes

What other mental health condition/s do you have?

____

Please can you share where you found this survey?

○ Facebook Support Webpage/Group (1)

○ OCD UK (6)

○ Reddit (7)

○ No Panic Newsletter (8)

○ International OCD Foundation website or newsletter (9)

○ Other (please specify below) (13)

____

<u>Reminder of Support Resources</u>

For **emergency support,** if you or someone else is at risk of immediate harm please call **999.**

Support can be sought through your **GP** or **GP out-of-hours service.**

Mind - Offers information and advice about seeking support for OCD and other mental health concerns.

https://www.mind.org.uk/information-support/types-of-mental-health-problems/obsessive-compulsive-disorder-ocd/treatments-for-ocd/

NHS Website - Provides information about how to access local mental health support services.

https://www.nhs.uk/using-the-nhs/nhs-services/mental-health-services/how-to-access-mental-health-services/

Anxiety UK- Provides information about accessing mental health support and offers specialised helpline support for individuals diagnosed with anxiety related disorders.

https://www.anxietyuk.org.uk/

OCD Action – Offers information and support specific to OCD through their website, forum and helpline.

https://www.ocdaction.org.uk/

No Panic – Offers help and support to individuals with anxiety related disorders including a confidential helpline.

https://nopanic.org.uk/contact-us/

Support Outside the UK:

For help in an **emergency** in Europe please call **112** or in the USA call **911.**

International OCD Foundation- Provides information about accessing support for individuals with OCD.

https://iocdf.org/

N**AMI, the National Alliance on Mental Illness-** Offers help and support resources to individuals experiencing mental health problems in America.

https://www.nami.org/home

Anxiety and Depression Association of America- An international organisation that helps people experiencing mental health problems to find resources and support.

https://adaa.org/

Queries

If you have any questions about this research, please contact me in the first instance:

Virginia Guy Email: Virginia2.guy@live.uwe.ac.uk

Or if you would like to contact my supervisors:

Dr Nikki Hayfield, Department of Health and Social Sciences, Frenchay Campus, Coldharbour Lane, Bristol BS16 1QY Email: nikki2.hayfield@uwe.ac.uk

Dr Zoe Thomas. Department of Health and Social Sciences, Frenchay Campus, Coldharbour Lane, Bristol BS16 1QY Email: zoe2.thomas@uwe.ac.uk

Appendix C - Participant Information Sheet for Interview

Understanding the Impact of Intrusive Thoughts in Pure O Obsessive-Compulsive Disorder (OCD): A Qualitative Survey and Interview Study

Interview Participant Information Sheet

Who are the researchers and what is the research about?

Thank you for your interest in this research project focusing on understanding the experiences of individuals with pure O. My name is Virginia Guy and I am a trainee counselling psychologist in the Department of Health and Social Sciences, University of the West of England. I am completing this research for my doctoral thesis. My research is supervised by Dr Nikki Hayfield and Dr Zoe Thomas (see below for their contact details). Pure O is an important topic because there is currently limited research looking into the lived experience of this specific type of OCD. It is hoped that the findings from this study will increase the current knowledge and understanding in this area.

What does participation involve?

You are invited to participate in a qualitative interview via Skype or telephone – a qualitative interview is a ‘conversation with a purpose’; you will be asked to answer questions in your own words. The questions will cover the answers that you gave to the survey and ask for further clarification and/or elaboration of some of the point that you made. The interview will be audio recorded and I will transcribe (type-up) the interview for the purposes of analysis. Before the interview, I will ask you to read and sign a consent form and return it to me via email. I will discuss what is going to happen in the interview and you will be given an opportunity to ask any questions that you might have. You will be given another opportunity to ask questions at the end of the interview.

Who can participate?

Adults over 18 who self-define as having pure O or have been diagnosed with OCD without overt compulsions.

Participants should have no other known psychological conditions.

How will the data be used?

Your interview data will be anonymised (i.e., any information that can identify you will be removed) and analysed for my research project. This means extracts from your interview may be quoted in my thesis and in any publications and presentations arising from the research. The demographic data for all of the participants will be compiled into a table and included in my thesis and in any publications or presentations arising from the research. The information you provide will be treated confidentially and personally identifiable details will be stored separately from the data. Any personal and identifiable details provided during the research process will be deleted or destroyed after the final project has been submitted. If you contact me, I will have your email address. This will be treated as confidential and used only for the purposes of this research. When our correspondence is complete, I will delete your emails from my inbox, sent items, and deleted items folder.

What are the benefits of taking part?

I hope that participants will enjoy taking part and by participating in this research, you will be contributing to the developing understandings of an important psychological issue.

How do I withdraw from the research?

If you decide you want to withdraw from the research please contact me via email Virginia2.Guy@live.uwe.ac.uk. If you choose to withdraw, I will permanently delete all audio and transcribed textual data from the interview I will also delete all personal data including any email correspondence between us. Please note that there are certain points beyond which it will be impossible to withdraw from the research – for instance, when I have submitted my thesis. Therefore, I strongly encourage you to contact me within a month of participation if you wish to withdraw your data. I'd like to emphasise that participation in this research is voluntary and all information provided is anonymous where possible.

Are there any risks involved?

We don’t anticipate any particular risks to you with participating in this research; however, there is always the potential for research participation to raise uncomfortable and distressing issues. For this reason, we have provided websites with information about how to seek support online, over the phone and/or face-to-face in your local area, see:

Mind - Offers information and advice about seeking support for OCD and other mental health concerns.

https://www.mind.org.uk/information-support/types-of-mental-health-problems/obsessive-compulsive-disorder-ocd/treatments-for-ocd/

NHS Website - Provides information about how to access local mental health support services.

https://www.nhs.uk/using-the-nhs/nhs-services/mental-health-services/how-to-access-mental-health-services/

Anxiety UK- Provides information about accessing mental health support and offers specialised helpline support for individuals diagnosed with anxiety related disorders.

https://www.anxietyuk.org.uk/

OCD Action – Offers information and support specific to OCD through their website, forum and helpline.

https://www.ocdaction.org.uk/

No Panic – Offers help and support to individuals with anxiety related disorders including a confidential helpline.

https://nopanic.org.uk/contact-us/

If you have any questions about this research, please contact me in the first instance:

Virginia Guy Email: Virginia2.guy@live.uwe.ac.uk

Or if you would like to contact my supervisors:

Dr Nikki Hayfield, Department of Health and Social Sciences, Frenchay Campus, Coldharbour Lane, Bristol BS16 1QY

Email: nikki2.hayfield@uwe.ac.uk

Dr Zoe Thomas. Department of Health and Social Sciences, Frenchay Campus, Coldharbour Lane, Bristol BS16 1QY

Email: zoe2.thomas@uwe.ac.uk

This research has been approved by the Faculty Research Ethics Committee (FREC)

HAS.20.06.184

Appendix D - Online Survey Consent Screen

Understanding the Impact of Intrusive Thoughts in Pure O Obsessive-Compulsive Disorder (OCD): A Qualitative Survey and Interview Study

Consent Screen

Thank you for agreeing to take part in this research on Pure O OCD.

My name is Virginia Guy and I am a trainee counselling psychologist in the Department of Health and Social Sciences, University of the West of England, Bristol. I am collecting this data collection for my doctoral thesis. My research is supervised by Dr Nikki Hayfield and Dr Zoe Thomas. They can be contacted at the Department of Health and Social Sciences, University of the West of England, Frenchay Campus, Coldharbour Lane, Bristol BS16 1QY. Tel: Dr Nikki Hayfield: (0117) 32 82139 / Dr Zoe Thomas (0117) 32 83794 Email: nikki2.hayfield@uwe.ac.uk / Zoe2.Thomas@uwe.ac.uk .

If you have any queries about the research please contact me via email: Virginia2.Guy@live.uwe.ac.uk

Please confirm that you can confirm each of the following statements and consent to take part in the research:

I am over 18 years of age

I identify myself as having Pure O

I have read the information sheet

I have had the opportunity to ask the researcher any questions

I am taking part voluntarily

I understand that I am free to refuse to answer a question

I understand that I can withdraw from the research (as described on the information sheet)

You are also the 'expert'. There are no right or wrong answers and I am interested in everything you have to say.

○ **Please tick this box to show that you have read the information on this screen and that you consent to participate in the research.** (1)

Appendix E - Interview Consent Form

Understanding the Impact of Intrusive Thoughts in Pure O Obsessive-Compulsive Disorder (OCD): A Qualitative Survey and Interview Study

Consent Form (Interview)

Thank you for agreeing to take part in this research on Pure O OCD.

My name is Virginia Guy and I am a trainee counselling psychologist in the Department of Health and Social Sciences, University of the West of England, Bristol. I am collecting this data collection for my doctoral thesis. My research is supervised by Dr Nikki Hayfield and Dr Zoe Thomas. They can be contacted at the Department of Health and Social Sciences, University of the West of England, Frenchay Campus, Coldharbour Lane, Bristol BS16 1QY. Tel: Dr Nikki Hayfield: (0117) 32 82139 / Dr Zoe Thomas (0117) 32 83794 Email: nikki2.hayfield@uwe.ac.uk / Zoe2.Thomas@uwe.ac.uk .

If you have any queries about the research please contact me via email: Virginia2.Guy@live.uwe.ac.uk

Please confirm that you can confirm each of the following statements and consent to take part in the research:

- I am over 18 years of age
- I identify myself as having Pure O
- I have read the information sheet
- I have had the opportunity to ask the researcher any questions
- I am taking part voluntarily
- I understand that I am free to refuse to answer a question
- I understand that I can withdraw from the research (as described on the information sheet)

You are also the ‘expert’. There are no right or wrong answers and I am interested in everything you have to say.

Please sign this form to show that you have read the contents of this form and of the participant information sheet and you consent to participate in the research:

__________________________ (Signed)

__________________________ (Printed)

______________ (Date)

Please return the signed copy of this form to me.

This research has been approved by the Faculty Research Ethics Committee (FREC) HAS.20.06.184

Appendix F -Online Recruitment Sources

Online Recruitment Sources	
Reddit - www.reddit.com **Subreddit Names**	**Facebook –** www.Facebook.com **Support Group Names**
❖ /r/Anxiety/ ❖ /r/Anxietyhelp/ ❖ /r/HOCD/ ❖ /r/IdentityOCD/ ❖ /r/intrusivethoughts/ ❖ /r/mentalhealth/ ❖ /r/OCD/ ❖ /r/pureo/ ❖ /r/ROCD/	❖ Intrusive Thoughts and Pure-OCD ❖ Living with Pure Ocd ❖ SANE Mental Health Charity ❖ Anxiety and OCD sufferers ❖ Made if Millions Foundation ❖ OCDtalk ❖ OCD Friends ❖ Friends with OCD ❖ Obsessive Compulsive Disorder “Pure O” ❖ Intrusive thought disorder (OCD) support group. ❖ Living with Pure Ocd ❖ OCD Recovery ❖ OCD Recovery Group ❖ OCD Help ❖ No Panic

	❖ Obsessive compulsive disorder (OCD)/Overthinkers Official community ❖ Everything OCD ❖ Anxiety Support Group ❖ Obsessive Compulsive Disorder (OCD) sufferers friendship and support group ❖ Anxiety & OCD Sufferers ❖ Intrusive Thoughts
Charitable Organisations	
❖ International OCD Foundation- https://iocdf.org/research/research-participants-sought/ ❖ No Panic - https://nopanic.org.uk/ ❖ OCD Action https://ocdaction.org.uk/an-exploration-of-the-lived-experience-of-pure-o-primarily-obsessional-ocd-a-qualitative-survey/	

Appendix G- Advertisements for Participation

Facebook Advert

Virginia Guy shared a link.
7 December 2021 ·

Participants Needed for Research Study on 'Pure O' OCD

Are you an adult with 'Pure O' OCD?

Would you be willing to answer some questions about your experiences?

Adults who have experience of living with Pure O (sometimes referred to as primarily obsessional OCD/pure obsessional OCD/ obsessions without visible compulsions) are invited to take part in an anonymous online survey for my doctoral research project.

The survey questions will be open-ended and ask you about what it is like to live with pure O including topics such as your friendships and relationships and what it has been like to seek support (if you have).

Research participants often report that they enjoy taking part in research studies and sharing their experiences. It is hoped that you will value contributing to developing understandings of an important psychological issue.

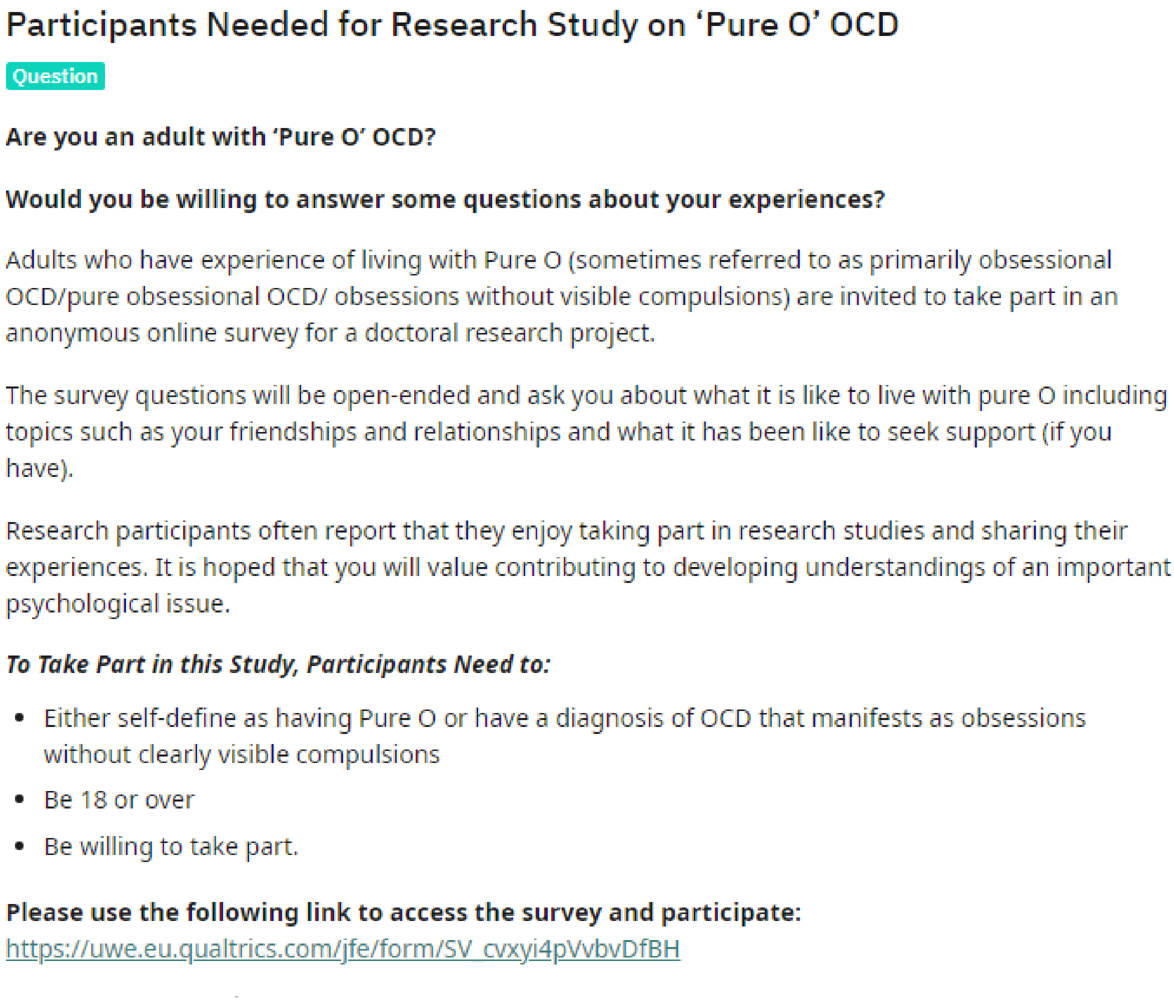
To Take Part in this Study, Participants Need to:

- Either self-define as having Pure O or have a diagnosis of OCD that manifests as obsessions without clearly visible compulsions
- Be 18 or over
- Be willing to take part.

Please use the following link to access the survey and participate:
https://uwe.eu.qualtrics.com/jfe/form/SV_cvxyi4pVvbvDfBH

UWE.EU.QUALTRICS.COM
An Exploration of the Lived Experience of Pure O (primarily obsessional OCD): A Qualitative Survey

Reddit Advert



Participants Needed for Research Study on ‘Pure O’ OCD

Question

Are you an adult with ‘Pure O’ OCD?

Would you be willing to answer some questions about your experiences?

Adults who have experience of living with Pure O (sometimes referred to as primarily obsessional OCD/pure obsessional OCD/ obsessions without visible compulsions) are invited to take part in an anonymous online survey for a doctoral research project.

The survey questions will be open-ended and ask you about what it is like to live with pure O including topics such as your friendships and relationships and what it has been like to seek support (if you have).

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To Take Part in this Study, Participants Need to:

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- Be 18 or over
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Please use the following link to access the survey and participate:
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Recruitment Poster – GP

Are you an adult with 'Pure O' OCD?

Would you be willing to answer some questions about your experiences?

Adults who have experience of living with Pure O (sometimes referred to as primarily obsessional OCD/pure obsessional OCD/ obsessions without visible compulsions) are invited to take part in an anonymous online survey for a doctoral research project.

The survey questions will be open-ended and ask you about what it is like to live with pure O including topics such as your friendships and relationships and what it has been like to seek support (if you have).

Research participants often report that they enjoy taking part in research studies and sharing their experiences. It is hoped that you will value contributing to developing understandings of an important psychological issue.

To Take Part in this Study, Participants Need to:

- Either self-define as having Pure O or have a diagnosis of OCD where you have obsessions without clearly visible compulsions.
- Be 18 or over
- Be willing to take part.

To take part in the survey, please scan the QR code or take a rip tab with the link to the survey from the bottom of the page.

If you would like any further information, please contact me via email: Virginia2.guy@live.uwe.ac.uk

'Pure O' OCD Anonymous Survey
tinyurl.com/pureosurvey

'Pure O' OCD Anonymous Survey
tinyurl.com/pureosurvey

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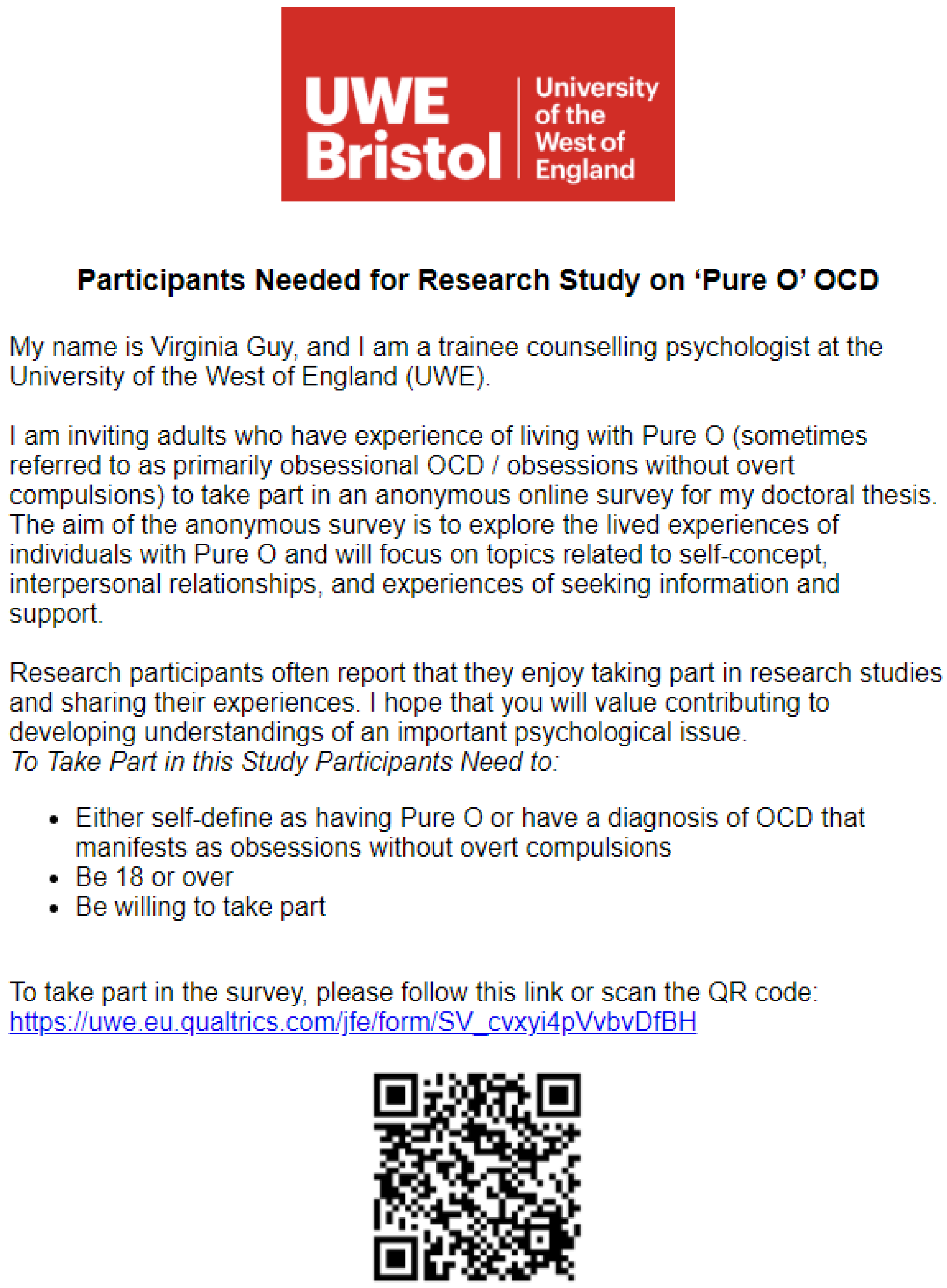
No Panic Newsletter Advert



UWE Bristol | University of the West of England

Participants Needed for Research Study on ‘Pure O’ OCD

My name is Virginia Guy, and I am a trainee counselling psychologist at the University of the West of England (UWE).

I am inviting adults who have experience of living with Pure O (sometimes referred to as primarily obsessional OCD / obsessions without overt compulsions) to take part in an anonymous online survey for my doctoral thesis. The aim of the anonymous survey is to explore the lived experiences of individuals with Pure O and will focus on topics related to self-concept, interpersonal relationships, and experiences of seeking information and support.

Research participants often report that they enjoy taking part in research studies and sharing their experiences. I hope that you will value contributing to developing understandings of an important psychological issue.
To Take Part in this Study Participants Need to:

- Either self-define as having Pure O or have a diagnosis of OCD that manifests as obsessions without overt compulsions
- Be 18 or over
- Be willing to take part

To take part in the survey, please follow this link or scan the QR code:
https://uwe.eu.qualtrics.com/jfe/form/SV_cvxyi4pVvbvDfBH

International OCD Foundation Website Advert

Are you an adult with ‘Pure O’ OCD?

Would you be willing to answer some questions about your experiences?

Adults who have experience of living with Pure O (sometimes referred to as primarily obsessional OCD/pure obsessional OCD/ obsessions without visible compulsions) are invited to take part in an anonymous online survey for a doctoral research project.

The survey questions will be open-ended and ask you about what it is like to live with pure O including topics such as your friendships and relationships and what it has been like to seek support (if you have).

Research participants often report that they enjoy taking part in research studies and sharing their experiences. It is hoped that you will value contributing to developing understandings of an important psychological issue.

To Take Part in this Study, Participants Need to:

- Either self-define as having Pure O or have a diagnosis of OCD where you have obsessions without clearly visible compulsions.
- Be 18 or over
- Be willing to take part.

To read the participant information sheet and take part in the survey, please click this link: www.tinyurl.com/pureosurvey

If you would like any further information, please contact me via email: Virginia2.guy@live.uwe.ac.uk

International OCD Foundation Newsletter Advert

Are you an adult with ‘Pure O’ OCD?

Would you be willing to answer some questions about your experiences?

Adults who have experience of living with Pure O (sometimes referred to as primarily obsessional OCD/pure obsessional OCD/ obsessions without visible compulsions) are invited to take part in an anonymous online survey for a doctoral research project.

The survey questions will be open-ended and ask you about what it is like to live with pure O including topics such as your friendships and relationships and what it has been like to seek support (if you have).

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If you would like any further information, please contact me via email: Virginia2.guy@live.uwe.ac.uk

Appendix H - Interview Schedule

Topic	Prompts
Broad experience of Pure O Only to be used if not answered in survey/if just doing interview.	➢ When did your intrusive thoughts first begin? ➢ Your experience of identifying as/ being diagnosed with Pure O? ➢ How it plays out in your day-to-day life? ➢ Do you feel Pure O has impacted your daily life? What areas of life do you feel it has the most impact upon? In what ways?
Perceptions of others	➢ How do you feel about telling others about your Pure O? What have been your experiences of this? How have others reacted? ➢ What is/was it like having pure O at school/university/work?
Relationships with friends and family- coping in family/family	➢ Disclosure - What was your experience of disclosing/not

dynamics/accommodation etc.	disclosing that you have pure O to friends/family? - Can you tell me about any experiences (if any) where your family may have helped you cope with Pure O? Or any ways that it has put strain on the family? - Has reassurance seeking been a factor in your experience? Who have you sought reassurance from? Has this had any effect on this/these relationships? - Intrusive thoughts about family? Any experiences of this affecting family relationships?
Current or past romantic relationship(s).	- Have you disclosed that you have pure O to present/past romantic partners? What has your experience been of disclosing/not disclosing?

	➢ Can you tell me about any ways (if any) you have received support with your Pure O form current/past partners? ➢ (If relevant) How do you feel about partner support? ➢ Could you describe any ways (if any) in which your partners support has influenced the dynamics of relationship? ➢ Can you describe any experiences (if any) of reassurance seeking in your relationships, and how this has been managed/not managed? ➢ (If intrusive thoughts about relationships) Can you describe experiences of Pure O single/in a relationship?

Self-concept/Identity	➢ Any ways Pure O has had an effect (if any) on the way you see yourself/your sense of who you are/your identity? ➢ Formative experiences – developing self-esteem? ➢ Conflicts with your role in family? (e.g., perceptions of the self as a parent). ➢ Relationship with diagnostic label? How do you feel about the label?

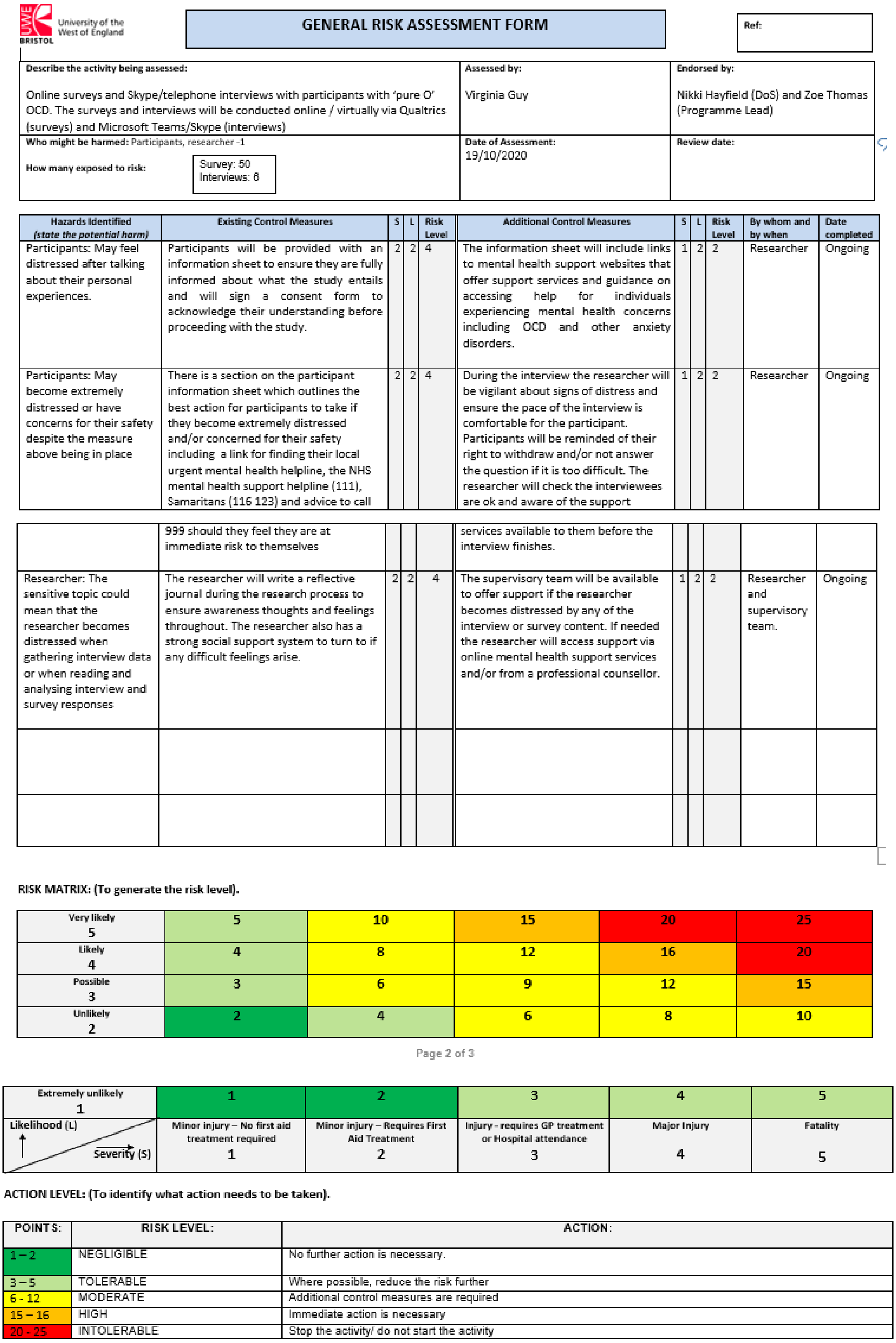
Sexuality and Gender	➢ Intrusive thoughts and sexual orientation. Experiences of questioning sexuality? ➢ Coping with intrusive sexual obsessions/separating sexual intrusive thoughts from actual sexual interests? ➢ Others understanding or sexual orientation thoughts? ➢ Sexual intrusive thoughts and societal stigma. ➢ Intrusive thoughts about gender identity. Questioning gender: What if I am trans/cis gender? Experience of this?
Moral, spiritual and/or religious values.	➢ Religious/spiritual rituals, teachings, rules, commandments? ➢ Sins, confessions/absolution. ➢ Anxieties around divine judgement/ criminal conviction?

	➢ Connection with early development of value system/parental influences?
Culture	➢ Cultural perceptions/beliefs about intrusive thoughts? ➢ Cultural factors and disclosure of condition.
Help Seeking Strategies	➢ Elaborate on how/why this was particularly helpful. ➢ Internet resources vs face to face therapy. Perceptions of face to face? ➢ How do you find hearing shared experiences of others with similar thoughts? ➢ Use of helping resources and potential conflicts with checking compulsions? ➢ What have you learnt about coping with your pure O that you would recommend to others?

	➢ Have other people tried to help? In what ways? Did you find it helpful? Was it also hindering at all?
Therapy experiences	➢ What were your expectations before engaging with therapy for Pure O? How did they match up with the experience? ➢ Helpful/ Unhelpful experiences? ➢ Therapeutic relationship factors- Can you describe the therapist qualities that you found most helpful/unhelpful in your therapy? ➢ Perceptions about disclosure in therapy? How was this for you? ➢ Expected/perceived reaction from therapist? ➢ Therapeutic modality/technique- what sort of therapy was it? Strengths/limitations? ➢ What was helpful/unhelpful? What did you take away from it?

	➢ In what ways (if any) would have liked your therapy to be different? Was there anything missing?
How could therapists improve?	➢ What might be helpful for therapists to know to better support individuals with Pure O? ➢ What might make you feel more/less comfortable talking to a therapist about pure O?
Is there anything further that you would like to share about your experience before we stop the recording today?	➢ Opportunity to add anything missed.

Appendix I - Risk Assessment Form



University of the West of England BRISTOL

GENERAL RISK ASSESSMENT FORM

Ref:

Describe the activity being assessed: Online surveys and Skype/telephone interviews with participants with 'pure O' OCD. The surveys and interviews will be conducted online / virtually via Qualtrics (surveys) and Microsoft Teams/Skype (interviews)	**Assessed by:** Virginia Guy	**Endorsed by:** Nikki Hayfield (DoS) and Zoe Thomas (Programme Lead)
Who might be harmed: Participants, researcher -1 **How many exposed to risk:** Survey: 50 Interviews: 8	**Date of Assessment:** 19/10/2020	**Review date:**

Hazards Identified *(state the potential harm)*	**Existing Control Measures**	**S**	**L**	**Risk Level**	**Additional Control Measures**	**S**	**L**	**Risk Level**	**By whom and by when**	**Date completed**
Participants: May feel distressed after talking about their personal experiences.	Participants will be provided with an information sheet to ensure they are fully informed about what the study entails and will sign a consent form to acknowledge their understanding before proceeding with the study.	2	2	4	The information sheet will include links to mental health support websites that offer support services and guidance on accessing help for individuals experiencing mental health concerns including OCD and other anxiety disorders.	1	2	2	Researcher	Ongoing
Participants: May become extremely distressed or have concerns for their safety despite the measure above being in place	There is a section on the participant information sheet which outlines the best action for participants to take if they become extremely distressed and/or concerned for their safety including a link for finding their local urgent mental health helpline, the NHS mental health support helpline (111), Samaritans (116 123) and advice to call 999 should they feel they are at immediate risk to themselves	2	2	4	During the interview the researcher will be vigilant about signs of distress and ensure the pace of the interview is comfortable for the participant. Participants will be reminded of their right to withdraw and/or not answer the question if it is too difficult. The researcher will check the interviewees are ok and aware of the support services available to them before the interview finishes.	1	2	2	Researcher	Ongoing
Researcher: The sensitive topic could mean that the researcher becomes distressed when gathering interview data or when reading and analysing interview and survey responses	The researcher will write a reflective journal during the research process to ensure awareness thoughts and feelings throughout. The researcher also has a strong social support system to turn to if any difficult feelings arise.	2	2	4	The supervisory team will be available to offer support if the researcher becomes distressed by any of the interview or survey content. If needed the researcher will access support via online mental health support services and/or from a professional counsellor.	1	2	2	Researcher and supervisory team.	Ongoing

RISK MATRIX: (To generate the risk level).

Very likely 5	5	10	15	20	25
Likely 4	4	8	12	16	20
Possible 3	3	6	9	12	15
Unlikely 2	2	4	6	8	10
Extremely unlikely 1	1	2	3	4	5
Likelihood (L) ↑ Severity (S) →	Minor injury – No first aid treatment required 1	Minor injury – Requires First Aid Treatment 2	Injury - requires GP treatment or Hospital attendance 3	Major Injury 4	Fatality 5

ACTION LEVEL: (To identify what action needs to be taken).

POINTS:	RISK LEVEL:	ACTION:
1 – 2	NEGLIGIBLE	No further action is necessary.
3 – 5	TOLERABLE	Where possible, reduce the risk further
6 - 12	MODERATE	Additional control measures are required
15 – 16	HIGH	Immediate action is necessary
20 - 25	INTOLERABLE	Stop the activity/ do not start the activity

Appendix J - Participant Demographics

Age		
Range	18 – 68	
Mean	32	
	%	***Count***
Gender		
Woman	63.29%	50
Man	16.46%	13
Trans	2.53%	2
Cis	11.39%	9
Agender	1.27%	1
Genderqueer/genderfluid/non-binary	3.80%	3
Questioning/unsure	1.27%	1
Other	0.00%	0
Student Status		
Yes, full time.	15.15%	10
Yes, part time.	7.58%	5
No	77.27%	51
Work Status (If in paid employment)		

Full Time	42.42%	28
Part Time	25.76%	17
No	31.82%	21
Work Status (If not in paid employment)		
Volunteer / Student unemployed Homemaker full time student; full time social work internship Unemployed but looking In between jobs. Entrepreneur about to start new venture Na unemployed/currently unpaid for creative work (writing) student Some kind of retired but might work someday (iâ€™m not english/american so i dont know the word) homemaker Homemaker - Mother		
Homemaker Employed, but off long term sick due to my mental health conditions.		

unemployed - Student Unemployed Unemployed

Sexuality	**_%_**	**_Count_**
Answer		
Heterosexual	66.67%	44
Asexual	1.52%	1
Bisexual	15.15%	10
Gay	0.00%	0
Lesbian	1.52%	1
Pansexual	10.61%	7
Queer	3.03%	2
Other	1.52%	1

Other - Text
Heterosexual with bisexual interest

Racial/Ethnic Background
Algerian/Arab
White
white
White

white
White
White
white
White
White
White
White
Very White - exclusively Northern European ancestry
white
Mexican
White
White
White
White
Asian. Indian to be precise.
White
White
White
White
White
White

White (Irish-American)
White
South Asian - Athiest
white
white
White
White
White
White
white
White
White British
White
white
White
White
White
Pacific Islander
European White
White
White Christian
white

White		
White Australian		
White		
White		
White / Christian		
White british/irish		
white		
White		
White		
Polish (born in Poland)		
Mestizo - Hispanic		
White and 1/4 thai		
White		
White		
Spiritual Agnostic		
White		
Hispanic		
White		
Social Class		
Answer	***%***	***Count***
Upper class	7.58%	5
Middle class	34.85%	23

A mixture of middle / working class	39.39%	26
Working class	13.64%	9
Lower class	3.03%	2
Other	1.52%	1
Disability		
Yes - If you are willing to share then please list your disabilities.	22.73%	15
No	77.27%	51
Disability Descriptions		
if OCD counts then yes		
Depression, ADHD, BPD, OCD, Fibromyalgia, chronic pain		
Yes, I cant hear from one year and I also have ADHD and discalculia.		
Chronic Migraine, IBS		
OCD		
Mental Health Conditions		
I consider my Pure OCD as a disability although Iâ€™ve never discussed it at work.		

Mental, Physical, Learning Disabilities, Autism + ADHD		
My OCD has caused me to use medical leave from work.		
Liver disease and OCD		
Relationship Status		
Answer	***%***	***Count***
Single	30.30%	20
With a partner (or partners)	40.91%	27
Married/Civil Partnership	24.24%	16
Separated	0.00%	0
Divorced/Civil Partnership Dissolved	3.03%	2
Other:	1.52%	1
Children		
Answer	***%***	***Count***
Yes	28.79%	19
No	71.21%	47
Childrens' Ages (if applicable)		
18 and 14		
19		

14 & 17		
1 and a half		
12		
2		
6		
41, 32, 28		
16, 11		
Not born yet		
21, 17, 12		
17		
4 and 5		
3, 5, 9		
2		
7 and 9		
17 and 15		
4.5yo & 7.5yo		
31, 29, 25		
OCD Diagnosis Status		
Answer	***%***	***Count***
Yes- from a mental health/medical professional	75.76%	50
Yes - Self diagnosed	18.18%	12
No	6.06%	4

Other Identified Mental Health Conditions		
Answer	***%***	***Count***
Yes- from a mental health/medical professional	75.76%	50
Yes - Self diagnosed	18.18%	12
No	6.06%	4

Descriptions of Other Identified Mental Health Conditions (if applicable)
Panic attacks/anxiety Generalized Anxiety Disorder anxiety and moderate depression Complex PTSD, severe social anxiety, generalized anxiety, depression, and maladaptive daydreaming Anxiety, PTSD depression and anxiety Anxiety and depression Depression, anxiety, adhd, bpd Anxiety, PTSD Anxiety and Depression Depression/dysthymia, social anxiety, ADHD Anxiety, PMDD, Agoraphobia, PTSD PTSD, anxiety, depression

Bpd traits, anxiety, disassociation.

Anxiety

PMDD

Depression, Anxiety and Social Anxiety + I have a huge Neuroticism.

GAD, MDD, SAD, and phobias (primarily agoraphobia)

depression, anxiety

Depression, anxiety, BDD

Depression, C-PTSD

Generalised Anxiety

Borderline(bpd) and ADD

panic disorder, generalized anxiety disorder, PMDD, PTSD (which I believe could be complex, but to an official DSM diagnosis in USA)

Bipolar 2 and Aspergerâ€™s

GAD, Depression

Generalized Anxiety Disorder

Anxiety. Apparently PTSD but I'm not sure if I agree with that

Depression

General anxiety disorder

EUPD and PTSD

Generalized anxiety, Avoidant Personality Disorder (both professionally dx), and suspected self-dx autism spectrum disorder
ADD - ADHD not yet diagnosed - self diagnosed
I was originally treated for depression and medicated for, although never officially diagnosed. As well as OCD
I was also diagnosed with GAD, however I believe this is just another aspect to OCD, not a mental health condition in itself.
BPD (and other PD traits), Schizoaffective Disorder (bipolar type), CPTSD, trich/derm, EDNOS, GAD, adhd, autism
GAD, Major Depressive Disorder

Appendix K- Interview Transcription Notation System

Transcription notation system based on the adapted notation system from Jefferson (2004) described by Braun and Clarke (2013).

Aspect of Audio Recording	**Transcription Notation**
Speaker's Identity	Name of the person speaking followed by colon. E.g., "Virginia:"
Laughing	((Laughs))
Inaudible speech	((inaudible))
Non-verbal utterances	Written phonetically e.g. "umm" "mm"
Overlapping Speech	((Overlap))
Unclear speech	If I was quiet sure I could identify the word but it was not completely clear I would put the word in brackets e.g. Laura: Whichever (comes up)
Abbreviation	wanna
Pause	Short pause: (.) Longer pause: ((Pause))
Punctuation	Punctuation was used to reflect the function of the speech such as using a question mark at the end of a question.
Identifiable information	*******

Appendix L -Example of Initial Coding

Data	**Codes**
I have had around 3 other 'serious' relationships since then and in all of them I have, after a short time of the relationship becoming official or serious in some way, been plagued by obsessive thoughts of a similar nature (not always exactly the same but after the second relationship I figured there was a pattern and it wasn't just to do with the relationship, which of course in the first one I thought 'I was just in the wrong relationship'). I have learnt over time that confessing or reassurance seeking does not help and makes things worse - this certainly really ruined my second and third relationships and unsurprisingly completely undermined any trust/confidence my partners had in the relationship. The second relationship I became consumed with thoughts about 'what if I still love my previous partner' - which has happened subsequently. The third relationship I was consumed with thoughts about physical flaws of my partner, as	Preyed on by OCD/intrusive thoughts. OCD as a bully Doubt about relationships Reassurance seeking impacting relationships. Strain on relationships. Doubt about relationships OCD infiltrating relationship.

well as being obsessed with the quality of our sexual life and constant thoughts about whether or not I might be gay (objectively I am definitely sexually attracted to men as well as women, but at the time I could not drop the thought that what if I was gay and that I wasn't being true to myself etc etc etc).	OCD impacting perceptions of sex/sexuality. Doubting sexuality

Appendix M- Examples of Initial Theme Ideas with Codes

Theme Idea	**Codes**
Social Support - Help of hinderance?	Acceptance/support from others is important. Communication is Key Family involvement Stain on Relationships (Risking) Becoming a burden Reassurance seeking impacting relationships
Widely Misunderstood	Others don't Understand /Believe You Education Needed Unhelpful therapy Misinterpretation by Others
Knowledge is Power- Knowing about OCD/Educating others	Self-Support Need to raise awareness Explaining/ Educating Others about OCD Knowledge is Power Needing to be educated
Shared Experience- If you've been there you get it.	Takes one to know one Useful when people have shared experience. Being seen
Hidden in Plain Sight	Hiding OCD from others Hidden nature of Pure O

Disclosure- Risky or necessary?	Relational fears/ difficulties due to OCD Fear of disclosure Selective Disclosure Positive experiences of disclosure. Risk of Hurting Partner Being open is better
Distance and Disconnection	Distance/dispute/ withdrawal from family Loneliness/Isolation Intrusive thoughts disrupting social interaction No Support Pure O as a barrier to relationships Avoiding Relationships Disruption to Intimacy Disconnection from others
Thanks, but no thanks – unhelpful responses/misinterpretation from others	Non-professional advice/unhelpful responses Stereotyping/not understanding Pure O Negative responses OCD? Me too! Stereotypical Views/Trivialisation of OCD
Divided Identities	Self-hatred Acceptance or rejection of OCD as part of self Negative perceptions of self

	Being good to ward off the badness Identity confusion/loss Preyed on by OCD/intrusive thoughts. OCD as a bully
Emerging Strengths	Positives as a result of Pure O Benefits of having OCD Living well with OCD

Appendix N- Summary of Results

Title: Exploring the Lived Experience of Individuals with Primarily Obsessional Obsessive-Compulsive Disorder (OCD): A Qualitative Study Focusing on Social Support and Help-Seeking

Short title: *Exploring the Lived Experience of Individuals with Primarily Obsessional Obsessive-Compulsive Disorder (OCD)*

Virginia Guy *[1], Dr Nikki Hayfield [2], and Dr Zoe Thomas[3]

[1] University of the West of England

Data availability statement:

The data that support the findings of this study are available from the corresponding author upon reasonable request.

Acknowledgements:

I would like to thank my supervisors Dr Nikki Hayfield and Dr Zoe Thomas for their invaluable support with this project. I would also like to thank my parents Richard Guy and Gilly Metherell and my partner Robert Jay for being a constant source of support throughout my research journey.

Abstract

Objectives

There has been little research focused specifically on primarily obsessional obsessive-compulsive disorder (OCD), particularly qualitative research. Primarily obsessional OCD is typically characterised by sexual, violent, or blasphemous intrusive thoughts with covert compulsions. The objective of the study was to gain a broad understanding of how individuals with primarily obsessional OCD experience help-seeking within the context of their lives.

Design: Online qualitative surveys and interviews were used to collect data from participants with primarily obsessional OCD.

Methods: Reflexive thematic analysis was used to analyse the survey responses and interview transcriptions.

Results: Two overarching themes are reported: “Hidden in Plain Sight: The Predicament of Disclosure” and “Perceived Misunderstanding and Misinterpretation of OCD in Personal and Professional Contexts” (with subthemes ‘Misunderstanding and Unhelpful Responses in Interpersonal Relationships’ and ‘Misunderstood and misbelieved by professionals’)

Conclusions: Individuals with primarily obsessional OCD may struggle to feel supported within their relationships and in therapy. Counselling psychologists and other mental health professionals need to consider educating themselves about the nuances of OCD to better support individuals' with primarily obsessional OCD and respect how they choose to define their experience.

Keywords: Primarily Obsessional OCD, qualitative study, counselling psychology.

Practitioner Points:

- Practitioners could further educate themselves in the nuances of OCD to better recognise primarily obsessional OCD.
- Individuals with primarily obsessional OCD may have been misbelieved by others and could benefit from practitioners validating their definition of their experience.
- Practitioners may need to clearly demonstrate their understanding of unacceptable intrusive thoughts to support clients to disclose.

Introduction

Background

Obsessive-Compulsive Disorder

The National Institute for Health and Care Excellence (NICE) (2005) report that between 1-2% of the population of the UK live with obsessive compulsive disorder (OCD). OCD is characterised by obsessions and compulsions (American Psychiatric Association, 2013). Obsessions are persistent unwanted thoughts, images, and urges such as thoughts of being contaminated or inappropriate sexual thoughts. Compulsions, which some with OCD feel compelled to perform in response to their obsessions, are described as repetitive behaviours or mental acts such as excessive cleaning, checking, or praying (APA, 2013). OCD is usually treated therapeutically with cognitive behavioural therapy (CBT), with exposure and response prevention (ERP) (NICE, 2005).

Researchers have attempted to categorise OCD symptoms into dimensions based upon the characteristics of obsessional thinking. In a recent meta-analysis, Bloch et al. (2008), created four symptom dimensions of OCD obsessions and associated compulsions: i) symmetry obsessions linked to compulsive counting, ordering, and repeating; ii) contamination obsessions linked to cleaning compulsions; iii) hoarding obsessions related to behavioural hoarding compulsions; and iv) a forbidden thoughts dimension related to sexual, aggressive, religious, and somatic obsessions linked to checking compulsions.

Forbidden/Unacceptable Thoughts and Primarily Obsessional OCD

OCD characterised by the presence of forbidden thoughts (with sexual, aggressive, or blasphemous themes) has also been defined as “unacceptable thoughts" and "taboo thoughts" (Abramowitz et al., 2003; Pinto et al. 2008). This terminology reflects the idea that the content of these thoughts can be experienced as shameful, and morally challenging. This form of OCD was historically labelled 'pure obsessional’ or “Pure O” because it was believed that it was not associated with compulsive behaviours, but rather only with obsessional thoughts (Baer, 1994; Bloch et al., 2008; Clark & Guyitt, 2007; Rachman, 1971). However, researchers have identified some associated covert compulsions such as mental rituals, reassurance seeking, checking and avoidance (Rachman, 2003; Williams et al. 2011). The term primarily obsessional OCD was used to refer to this form of OCD in the current study to concisely capture its largely covert nature. This form of OCD was the focus of the current study. Due to limited research focusing on primarily obsessional OCD specifically, the literature looking at OCD in general will be drawn upon to give a background to the present research.

Help-Seeking Challenges

Individuals with primarily obsessional OCD may find it particularly difficult to talk to others about their intrusive thoughts. Unacceptable thoughts are associated with shame and self-doubt, leading to negative self-perceptions of being "unsafe" to others or "on the verge of going crazy" (Rachman, 2003, p. 6;

Weingarden & Renshaw, 2015). Individuals can conceptualise a "feared self" that is deemed to be insane or immoral (Ferrier & Brewin, 2005). Individuals can therefore keep intrusive thoughts a secret to avoid revealing this feared identity to others (Rachman, 2003; Williams & Wetterneck, 2019). Moreover, Newth and Rachman (2001), suggest that individuals with OCD may conceal the content and frequency of obsessions to avoid shame, guilt or the loss of control.

Furthermore, individuals experiencing unacceptable thoughts are often deterred from seeking treatment due to shame, fearing judgement from others, and fearing hospitalisation (Glazier et al., 2015; Robinson et al., 2017). Moreover, considering that individuals with primarily obsessional OCD may be prone to shame and conceal their intrusive thoughts, it could be that individuals would find it difficult to describe their symptoms when therapy is sought (Rachman, 2003). These insights suggest that individuals with primarily obsessional OCD may struggle to seek professional support.

Interpersonal and Professional Stigma

Unfortunately, the fear of being judged negatively by others held by those experiencing unacceptable thoughts may not be unrealistic (Glazier et al., 2015; Robinson et al., 2017). The characteristics of primarily obsessional OCD may be associated with stigma from mental health professionals and the public (Cathey & Wetterneck, 2013; Glazier et al., 2013; McCarty et al., 2017). Vignette studies have suggested that members of the public would be more likely to socially reject a person with sexual obsessions than those with contamination obsessions and have a greater desire for social distance from individuals with taboo obsessions than other obsession types (Cathey & Wetterneck, 2013; McCarty et al., 2017). Research has also suggested that by comparison to contamination obsessions, taboo thoughts are less recognisable as OCD symptoms by mental health professionals (Glazier et al., 2013). Steinberg and Wetterneck (2017), found clinicians were more concerned about sexual, harming and contamination obsessions than religious obsessions. These studies indicate a lack of in-depth understanding of unacceptable thoughts in OCD which may negatively influence individuals' interpersonal and therapeutic experiences.

Rationale

Very few studies have explored dimension-specific experiences of OCD, hence the heterogeneity of differing presentations has been overlooked (Bhattacharya, & Singh, 2015; Brooks, 2011). Stigma associated with unacceptable thoughts and suggested lack of recognition by professionals indicates a need for further research to increase understanding of these symptoms (Cathey & Wetterneck, 2013; Glazier et al., 2013; McCarty et al., 2017; Steinberg & Wetterneck, 2017). There is also a dearth of subjective accounts of living with unacceptable thoughts and no known research to date has focused specifically on help-seeking experiences of individuals with primarily obsessional OCD. Much of the current knowledge is restricted to quantitative findings or case studies (Bhattacharya, & Singh, 2015; Ferris et al., 2012; Jacoby et al., 2016; Nelson et al., 2006; O'Connor, & Aardema, 2011; Purdon, 2004; Vorstenbosch et al., 2012). This means that there is limited qualitative research to provide a depth of understanding or research that listens to the voices of participants, an area that this project addresses (Fennell & Liberato, 2007; Keyes et al., 2018).

The Current Study

The current study used a qualitative survey and online interviews to explore the lived experiences of individuals with primarily obsessional OCD. The aim was to gain a broad understanding of how these individuals experience help-seeking in the context of their lives. The study set out to answer the following research questions: i) how do individuals with primarily obsessional OCD experience help-seeking outside of a therapeutic context and ii) how do individuals with primarily obsessional OCD experience help-seeking within a professional therapeutic context. It was hoped that the findings would generate knowledge that has the potential to be of use to counselling psychologists and other mental health professionals into the complexity of primarily obsessional OCD by prioritising the voices of those affected by the condition.

Methods

Design

A qualitative, exploratory approach was employed for the present study. Qualitive surveys and interviews were used to collect data. Survey data and interview transcripts were analysed using reflexive thematic analysis (RTA) (Braun & Clarke, 2021).

Theoretical Approach

The project was informed by a critical realist ontology and a contextualist epistemology. Both contextualism and critical realism are based on the notion that knowledge is always partial and inextricably situated within, and mediated by, a given context (Braun & Clarke, 2021; Jaeger & Rosnow, 1988; Madill et al., 2000).

Reflexivity

As a reflexive qualitative researcher, the contextual influences of my personal history and identity are embraced, rather than seen to be a limiting factor (Finlay, 2002; Gough, 2016; Gough, & Madill, 2012). Considering this, I identify myself as having primarily obsessional OCD. My personal experience motivated me to gain a deeper understanding of the topic and conduct research that has the potential to help others going through similar experiences.

Online Survey

An online qualitative survey was designed using Qualtrics online survey software with open-ended questions. The survey questions were based upon topics and issues identified within the broader OCD literature, and those specifically relevant to unacceptable thoughts. My areas of interest were also influenced by my own experience of primarily obsessional OCD. Aside from the demographic questions, 13 questions were used to collect data.

Interviews

Optional telephone or online interviews allowed for the opportunity to probe for further details beyond the responses provided in the survey. The interview questions were mainly determined by the survey responses. An interview schedule with possible prompts was created and adapted for the interview participants who had completed the survey. For the one participant who took part in the interview only, the survey questions were used as a basis for the interview schedule with the addition of prompting questions to encourage elaboration.

Recruitment

Participant Group Size

In total 70 participants completed the survey. I conducted a total of 4 interviews. While 3 of the interview participants were recruited via the survey, one was a through a contact known to me who was approached via WhatsApp.

Inclusion and Exclusion Criteria

The participants were required to be over the age of 18, have experience of unacceptable thoughts and either self-identify as having OCD or have a clinical diagnosis of OCD. Purposive sampling was used which involves selecting individuals with characteristics relevant to the topic and who hold information that should enable further understanding of that topic (Hennink et al., 2020; Patton, 2002).

Methods of Recruitment

Organisations and webpages offering support to individuals with anxiety disorders and/or OCD were approached for recruitment, and an advertisement poster was given to my local GP surgery. With permission from the organisations approached and the moderators of support pages, advertisements were posted in online forums and support groups, organisations' Facebook pages, information websites and charitable organisations' research webpages. Two of the organisations approached (No Panic and International OCD Foundation), also advertised the study in their newsletter.

Demographics

Of the participants that provided their demographic information (N=66 out of 71), participants' ages ranged from 18–68 years old (M= 32). The majority identified as female, were able-bodied, heterosexual, white and middle class, or middle/working class. Most participants were in relationships with a partner(s), married or in a civil partnership.

Piloting

To pilot the survey, data was gathered from 8 participants. The responses gathered largely indicated a good level of engagement with the survey questions.

Some questions that received less engagement or appeared to confuse participants were edited or removed.

Ethics and Procedure

Ethics were approved by the Faculty Research Ethics Committee (FREC) and a risk assessment was completed. Participants accessed the survey via a URL or QR code on the recruitment advert. The survey first displayed a participant information sheet (PIS) then a consent form. Sources of support were selected and provided at the beginning and end of the survey. The consent form detailed the right to withdraw at any point before data analysis. Participants were then taken to the survey. Those interested in participating in an interview provided their email address, were emailed an additional PIS, and asked to sign an interview consent form. Three interviews took place via Microsoft Teams, and one by telephone. The planned duration for each interview was 1.5 hours including interview time, a 15-minute description, opportunities for questions before and after and a debrief.

Analysis

The analysis followed the six-phase process of RTA (Braun & Clarke, 2006; 2013; 2021). The analysis was largely inductive focusing on identifying meaning conveyed through the participants' descriptions. However, my thinking was also informed by previous literature on the topic and how elements of the data resonated with previous findings. Textual data from the survey answers were collated and interviews recordings orthographically transcribed using the adapted notation system from Jefferson (2004), described by Braun and Clarke (2013). Both sets of data were anonymised and analysed together. Familiarisation involved immersion in the data by reading and re-reading the text whilst making initial notes (Braun & Clarke, 2006). During coding I went through the dataset twice with the research questions in mind, identifying interesting features and generating initial codes. Semantic codes were developed, capturing overt clearly identifiable aspects of the data, and latent codes capturing less obvious aspects of the data that convey implicit meaning (Braun & Clarke, 2021). Next, the codes and code labels were refined to ensure consistency (Braun & Clarke, 2021). Codes and data extracts were collated into initial candidate themes which were reviewed alongside the initial codes and the original data. The initial themes were refined and constructed into candidate themes which were later refined further and named during the process of developing the analytic narrative. Producing the written report was the final stage where interesting examples of the survey and interview data were presented.

Results

Theme 1 - Hidden in Plain Sight: The Predicament of Disclosure

This theme encapsulates the hidden features of primarily obsessional OCD, and the considerations and cautions around how much individuals' share with others about their experience. The accounts suggest that the absence of clear visible compulsions enables the individual to appear as if they are managing well from an outside perspective:

> *"Sometimes, I feel like they underestimate for what I'm going through, just because the majority of it is covert and also because I try to be as high functioning as possible […]." (Pam, 55)*

The idea that others see individuals as functioning "normally" conveys a sense of suffering in silence, as others are unaware to the full extent of their OCD. This suggests that individuals' distress may go unnoticed or unrecognised in their relationships if it is not explicitly disclosed. The distress associated with mental compulsions may also be overlooked by comparison to physical compulsions.

The accounts suggest a caution and a need for selectivity about both who they disclose to and the extent of their disclosure about their OCD:

> *"I haven't told anyone other than my therapists and current partners." (Sean, 25)*
>
> *"Only my doctor and psychiatrist really know what is going on." (Alice, 26)*

Furthermore, negative experience of disclosure may inhibit future disclosures:

> *"well, as I've got older I became much more cagey about what I disclose, for example, [….] told a couple of people [….] on my master's degree about it and they totally went around telling people that I was a psycho…" (Sam, 48)*

Sam's account coveys that disclosure is a risky business and suggests that individuals may feel it is necessary to conceal their OCD to avoid stigma.

Although the process of concealing rather than disclosing can be difficult or distressing, participants are in an uncomfortable no-win situation. Although they can hide their OCD, they can find that this is not good for them. When choosing to share they must be explicit, and this can be risky - with potentially detrimental effects. Some favour disclosure due to the effort and awkwardness of concealment or the sense that concealment feels like a deception:

> *"I don't want to hide it as it's exhausting and the more open and less awkward I am the less awkward others are about it and I can ask for help easily when needed." (April, 27)*
>
> *"I just feel like I'm always constantly lying to everyone around me because I keep having to mask the anxiety that's actively working to ruin my life." (Elijah, 21)*

For some concealment is perceived as a necessary exercise in the management of OCD, Sam infers a sense of partial disclosure and an internal debate about how much to open up:

> *"I haven't told her everything because you know, even with her I think… I just can't. You know, it's very, very difficult for me to disclose you know.. this part of me thinks well, do I have to? It's not like being secretive, it's*

> *just […] I don't feel like I need to say every little thing […] you know there is a part may face rejection and upsetting her, you know." (Sam, 48)*

Sam suggests a perception that no matter how understanding his partner may be, disclosing the full extent of his experience could risk rupturing his relationship. Similarly, individuals can feel that the understanding or acceptance from others is contingent upon moderating disclosure:

> *"she knows I have OCD and intrusive thoughts, and I have been able to tell her that I fear being a bad person but I have not been able to say those dreaded words ""I'm scared that I'm a paedophile"". Why? Because I'm afraid. I'm afraid of what she'll think, I'm afraid that she won't feel the same way about me […]" (Georgia, 31)*

There is a sense that participants are navigating whether to disclose, or not disclose, or somewhere in between. Rather than a binary of being out and open versus keeping it hidden there is a more complex ongoing process of contemplation conveyed in terms of how much they share with others. There is a process inferred of weighing up the extent of disclosure through exhaustive and constant internal negotiation. There is also a vulnerability communicated as if disclosure may leave individuals feeling exposed to negative interpersonal reactions.

Theme 2 – Perceived Misunderstanding and Misinterpretation of OCD in Personal and Professional Contexts

Misunderstanding and Unhelpful Responses in Interpersonal Relationships

This subtheme encapsulated experiences where participants have struggled to get support within their interpersonal relationships and felt that others did not understand when they have tried to explain their OCD. Participants convey both an expectation of being misunderstood and experiences of trying to explain OCD to others, but not being able to get the message across:

> *"Nobody knows because I feel almost no one would get it." (Edward, 24)*
>
> *"Most people dont know and dont understand the condition when explained." (Gemma, 32)*

Edward conveys that he has made up his mind that they will be misunderstood. This potentially leaves individuals in the state of being isolated within their relationships and others may not have the opportunity to try to understand their experience. Participants shared perceived misunderstanding and misrecognition from others both broadly and in relation to specific relationships.

> *"My best friends know about my OCD* […]. *They do not understand it at all, even my partner doesn't understand it, but they know." (Rosie, 29)*
>
> *"People don't see me as having OCD because they don't understand what OCD truly is, especially Pure O." (Jenna, 29)*
>
> *"I know my family wants to support me but I don't think they have the capability of understanding how intrusive thoughts work. They very seriously believe I should just try harder not to think about it. To my*

> *knowledge none of them know any more of the symptoms of OCD other than hand washing and some pickiness about how things are aligned or organized. It's a very ""television"" understanding of OCD." (Fran, 26)*

In some cases, perceived misunderstanding from others can leave individuals feeling unable to open-up about their OCD, or when they do, feeling unsupported and dismissed. Individuals may therefore have difficulty accessing social support. The data also suggests a lack of understanding societally about the different forms of OCD. This may leave individual's feeling marginalised, living with a "*lonely and isolating*" experience (*Denise, 51*).

What was also evident was some participants try to put right misunderstandings through attempting to educate others:

> *"I try to explain that it's not colloquial - it's a real, debilitating disorder. I share some of my symptoms and the consequences […] I think it's important for people with OCD to share their experiences with those who don't know much about it […] It will help remove stigma, as well as potentially educate people […]" (Julie, 34)*

> *"At first, I think she thought I was a lesbian. Until I told her my thought process and how it disturbed me and my daily life. It took a couple of days for her to fully get it, and I felt relieved that I told someone and they understood." (Oonagh, 19)*

Participants want others to understand their condition so they can feel understood and accepted. However, individuals convey that it is not an easy experience to explain. There is a sense that because primarily obsessional OCD predominantly involves internal experiences and covert compulsions rather objectively observable behaviours, this presents a challenge in educating others. Participants are tasked with verbalising an experience that can often not be seen objectively.

In addition, participants also shared experiences of receiving unhelpful, harmful, or stigmatising responses from others:

> *"When I was married it really did put a strain on our relationship. My husband would say...oh not this crap again...and then would go to the pub" (Ruth, 50)*

> *"Eventually I told my partner after 15 years and he thought I was making a mountain out of a molehill. He thinks I go looking for problems, which belittles my suffering. […]" (Sandra, 56)*

When explaining their OCD or seeking support, others may not always be supportive. The accounts convey that others may express frustration, have a difficulty empathising or see the individual to be at fault. Individuals may not only have difficulty explaining their condition to others but may receive responses that could increase distress or alienate them further.

In some cases, perceptions about stigma are shaped by how people talk generally about OCD. A shared feeling among participants was that others without OCD often trivialise, make light of, or joke about OCD characteristics:

> *"Wish it was on tv more. Everyone sees ocd as a joke or washing hands 20 times a day or just being obsessive in straightening things and stupid memes about bricks being wonky." (Alison, 36)*

Alison suggests that more representation of OCD may rectify misguided understandings of OCD. This also speaks to the shared perception in the data that others often have a stereotypical view of OCD. Many of the accounts that discuss experiences of others joking about OCD convey that this is an unhelpful, potentially hurtful response..

Several participants experienced others responding to the revelation of their OCD with claims about having OCD themselves:

> *"I have mentioned having ocd but 99% of the time am met with oh me too or I know just what you mean. At that point I say nothing more." (Alison, 36)*
>
> *"I've told my Mamas about it. She then proceeded to tell me that's she's OCD because she needs her keys to be in the same direction. I'll be talking to her about that because she's clearly not OCD truly. She's just throwing that word out." (Gloria, 30)*

The accounts infer that these experiences are perceived as barriers to communication and to feeling understood. These experiences also reflect responses that seem influenced by more widely recognisable presentations of OCD. It is inferred that these responses are perceived by participants as a communication of a narrow understanding of OCD that invalidates their experience.

Misunderstood and Misbelieved by Professionals

The notion of being misunderstood or misbelieved by others, also extended to experiences within therapy:

> *“My therapist still doesn't believe that I have it, which makes it really hard for me to open up to her about these thoughts or to get support from her for the OCD symptoms.” (Jenna,29)*
>
> *"The first psychologist I spoke to was just generally kind of useless, and did not understand OCD. When I said I thought I had OCD she said ""you don't have OCD; my patients with OCD are really messed up"" (Lisa, 23)*

Participants saw therapy as a route for support, but for some, there was a lack of acknowledgement or perceived understanding of their OCD from the therapist. Jenna’s experience infers that if therapists do not believe or acknowledge the client’s beliefs that they have OCD this may leave individuals unable to talk about their experiences in therapy or receive support. Lisa conveys that she has been treated appallingly by her therapist, not only by dismissing her experience, but so too by speaking in a derogatory manner about those with OCD. This potentially communicates to Lisa that if she does have OCD, this will be judged in a negative light. It is concerning that this can be individuals’ experience of therapy considering that it can be tough to seek help in the first place. It is concerning to think that for those who have braved seeking help, there may actually be a risk of making it worse through lack of belief, or at best lack of understanding.

Other accounts more specifically suggest that there is an absence of recognition of OCD presenting with the lack of visible compulsions:

> *"I spoke once again to the IAPT* [Improving Access to Psychological Therapies] *triage service who asked if I washed my hands all the time or liked everything to be neat and tidy. When I said I wash my hands the normal amount and don't really mind mess they told me I couldn't possibly have ocd and to get it out of my head […]" (April, 27)*

This dismaying experience suggests that professional assessment of OCD may not necessarily pick up primarily obsessional OCD and that individuals' experience can be dismissed. Worryingly, such accounts suggest that some support services are letting people with OCD down particularly for those with primarily obsessional OCD.

In multiple accounts participants share the perception that therapists need education about the different variations of OCD:

> *"I think all therapists should be aware of the idiosyncrasies of OCD in order to know when to refer people to someone who understands the condition." (Pam, 55)*
>
> *"Recognise the different forms of it! Do your research! Read the online communities and forums!" (Selena, 34)*

The accounts convey that for people with OCD to have the care and support they need; therapists need to be better educated on the nuances of OCD.

There were some accounts where therapists' beliefs about diagnosis left the participant feeling unsupported by the lack of acknowledgement:

> *"I don't talk about OCD* [to my counselling psychologist] *really at all…because when I have in the past when I […] tried explaining to her. I think I have OCD. […] Then she said to me.. […] "we don't believe in diagnosis"..* […] *…Another time she said to me like the DSM was created by like white middle-aged men, and it's constantly changing, so we can't rely on it um.. And she just negated the whole OCD experience. "(Laura, 26)*

Laura's account suggests that the counselling psychologist's perspective on OCD diagnosis not only invalidated her experience, but also prevented her from talking about it. This suggests that when individuals' beliefs about their distress is misaligned with the therapist's, this may present a barrier to support. Such accounts infer that some individuals are effectively being silenced when seeking professional help.

Discussion

Visibility and Invisibility: Deciding to Hide or Risk Disclosure

The results captured a sense of caution held by individuals about whether to disclose their OCD to others and the extent of that disclosure. This caution is consistent with previous literature looking at OCD in general (Fennell & Liberato, 2007; Yazdi-Ravandi et al., 2018). The current findings indicate that individuals carefully consider and monitor disclosure particularly regarding intrusive thoughts perceived as strongly taboo. What was clearly conveyed was a sense of risk and fear of how others might respond. Research has suggested that disclosure may indeed be risky. For instance, without prior education regarding paedophilia-related thoughts in OCD, others can believe such thoughts are an indication that the individual is a paedophile (Snethen & Warman, 2018). Furthermore, considering previous research on OCD and stigma, the expectation of stigma apparent in the data, sadly, does not seem to be unrealistic (Cathey & Wetterneck, 2013). This suggests that the highly taboo nature and the lack of wider social understanding of intrusive thoughts in primarily obsessional OCD may make it more difficult for individuals to feel safe to disclose to others. These findings indicate a need for mental health professionals to have an awareness of taboo intrusive thoughts and be prepared to demonstrate their understanding to support clients to discuss such thoughts.

Furthermore, in the current study, individuals could appear as if they do not have OCD because their compulsions are covert. However, individuals believed that this could lead others to underestimate their distress. Having an outwardly identifiable presentation of OCD may enable individuals to feel their condition is more recognisable. However, being able to conceal, albeit potentially distressing, allows individuals to keep their experience private. Though, this is double edged sword because individuals may appear well externally but carry the burden of suffering in silence.

Help-Seeking Issues

Previous qualitative studies have identified experiences where individuals' OCD was misunderstood or misinterpreted by others (Fennell & Liberato, 2007; Keyes et al., 2018). There are close similarities between aspects of the current study's results, and these previous studies, whereby participants reported experiences of being misunderstood by family, friends, and professionals and sometimes being met with negative reactions. There was also similarity in how some participants expected to be misunderstood, mirroring Fennell and Liberato's (2007) finding that individuals with OCD anticipate stigma from others.

Where the current project differs from extant literature, is that individuals reported experiences of others not recognising or validating their experience as OCD. There is a potential issue for those with primarily obsessional OCD, that mainstream media depicts dramatised representations of OCD which potentially impacts public perceptions (Martin, 2017). It has been noted that some individuals with OCD can find that narrow societal understanding of OCD deters them from talking about their experience (Werner, 2021). In the current study, participants reported that others attempt to understand OCD based upon stereotypical portrayals led them to feel frustrated and misunderstood because their experience does not match such representations. This suggests, in line with previous research, there is a risk that lack public awareness of different OCD presentations can make it challenging for individuals with primarily obsessional OCD to explain their experience to others and to feel understood (Werner, 2021). Media creators may play a valuable role in raising awareness among the public by improving media representation of those with primarily obsessional OCD.

Lack of Recognition

The multiple experiences of being misunderstood by professionals in the present study is consistent with the previous research indicating that professionals more frequently misinterpret taboo and sexually intrusive thoughts than other reported obsessions (Glazier et al., 2013; Steinberg & Wetterneck, 2017). It is concerning that individuals may be misunderstood when seeking professional help, particularly when expectation of misunderstanding is understood to be a barrier to help-seeking (Robinson et al., 2017). Participants' distress in not having their experience recognised as OCD opens a wider discussion about the use of diagnosis. More clients are entering therapy with an understanding of their distress informed by a self-identified, diagnostic information (Jutel & Nettleton, 2011). For some, diagnosis may serve the purpose of clarifying that they are not crazy and reducing shame around bewildering experiences (Giles & Newbold, 2011; Strong et al., 2015). Resistance from professionals to diagnosing OCD, could present a barrier to individuals with primarily obsessional OCD receiving support. Early recognition may also be crucial for preventing risk. OCD with unacceptable intrusive thoughts has been associated with increased risk of suicide (Albert et al., 2018; Albert et al., 2019; Angelakis et al., 2015). This along with mentions of suicide within the data highlights the importance of helping individuals to feel able to come forward and feel safe to discuss their experience. Disclosure can be challenging and attempts to do so with a professional can also be hindered by a lack of understanding and recognition. Improving professionals’ ability and preparedness to identify those with primarily obsessional OCD may help to avoid marginalisation and improve therapeutic support.

Considering that it was important to participants to have their experience recognised as OCD by professionals, it may be beneficial for counselling psychologists to take a pluralistic perspective to value the client’s sense making and subjective understanding of their experience (McAteer, 2010). Pluralism involves valuing multiple perspectives and working in ways that does not privilege one perspective over another, but rather focuses on collaboration and shared understanding with the client (Cooper & Dryden, 2016). So it may be that counselling psychologists can use the client’s chosen terminology to describe their experience, such as OCD, but also consider different perspectives alongside this, insofar as they are useful to the client.

Furthermore, it was apparent that participants felt therapists need to educate themselves about the different variations of OCD to better recognise and understand it. There may be a need for a greater emphasis on the heterogeneity of OCD during professional training. Participants also conveyed that therapists could learn from the perspectives individuals with OCD to better understand and support them. The integration of subjective accounts of different OCD manifestations into training programmes may help counselling psychologists and other therapists to have a better understanding of their clients.

Strengths and Limitations

A strength of the current study was my identities as a trainee counselling psychologist and insider researcher. Being an insider helped me construct survey and interview questions related to relevant issues. I also had experience of using online support sites and understood the type of language and keywords used within support groups which helped me search for participants (Bonner & Tolhurst, 2002). I was also able to resonate with participants' experiences but also recognise those that differed from my own. As a trainee counselling psychologist, I was also able to draw upon therapeutic skills to help participants feel comfortable to talk about their experience during interviews (Louw et al., 2011). However, there were also challenges related to my identity as a trainee counselling psychologist. When interviewing, I found it particularly difficult to hear the highly distressing experiences, without being able to help the individual therapeutically (Orb et al., 2001). It was therefore important to reflect on this during the research process through journalling and in supervision.

Another potential limitation was the decision to have the recruitment open to individuals who had not yet received a diagnosis of OCD. The intention of recruiting those who have self-identified as having OCD, was to access those who may not yet have or do not intend to seek help. This decision was also prompted by literature that associated shame with primarily obsessional OCD and help-seeking (Glazier et al., 2015). However, this brings into question whether the findings are transferable to clinical populations (Stenfors et al., 2020).

Future Research

Future researchers may wish to explore how mental health professionals and counselling psychologists learn about OCD and the influences that shape their understanding. It could also be interesting to further explore therapy experiences of those with primarily obsessional OCD and any aspects of therapy that helped individuals to feel understood and safe to discuss their intrusive thoughts. Finally, future researchers may wish to explore perspectives on diagnosis of those with OCD, counselling psychologists, and other mental health professionals to aid a more in-depth critical discussion about recognition and diagnosis.

Conclusion

The current study has built upon previous literature to add to our current understanding of primarily obsessional OCD. The study has offered insights into interpersonal issues which had not been previously investigated in such detail specifically in relation to primarily obsessional OCD. The study has also highlighted issues these individuals experience around receiving support both within and outside the therapy room. This study has also highlighted issues that can arise from therapeutic interactions that may hinder individuals access to appropriate support. It is hoped that the findings will have the potential to add further depth of understanding to counselling psychologists' perspectives on OCD and how to better support those presenting with primarily obsessional OCD.

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